

ADVOCACY IN ACTION: A TOOLKIT FOR THE ROLLING REVOLUTION



**United Spinal
Association**

INTRODUCTION

Advocacy plays a key role in our system of democracy by giving everyone a voice.

"I want to make sure Congress understands what life is like from a wheelchair user's point of view before voting on an issue important to those of us in the disabled community."

- Andrew Davis, GA, United Spinal Advocate

United Spinal Association wants to make it easy for you to get involved and use your voice for change. Every advocate plays an important role in communicating what members of the spinal cord injury and paralysis community need to be successful. Across the country, people are sharing their stories and working to educate their lawmakers about the issues that affect them most. Your life experience and a passion for change can make a difference.

This guide will give you tips and tools to help understand what advocacy is and how to become an effective advocate in your community. Being an advocate is an important step to ensuring that you and those around you have equal access and opportunity.

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WHO ARE WE?

United Spinal Association is the largest nonprofit organization, founded by paralyzed veterans, dedicated to enhancing the quality of life of all people living with spinal cord injuries and disorders (SCI/D), including veterans, and providing support and information to loved ones, care providers and professionals.

United Spinal has over 70 years of experience educating and empowering 2.5 million individuals with SCI/D to achieve and maintain the highest levels of independence, health and personal fulfillment. United Spinal has over 52,000 members, 54 chapters, close to 200 support groups and more than 100 rehabilitation facility and hospital partners nationwide, including 10 distinguished Spinal Cord Injury Model System Centers that support innovative projects and research in the field of SCI/D. United Spinal Association is a VA-accredited veterans service organization (VSO) serving veterans with disabilities of all kinds.



ABOUT US: UNITED SPINAL ASSOCIATION



“CHANGE IS DIFFICULT. THE OPPONENT IS THE STATUS QUO. WE MUST EDUCATE, EMPOWER, AND MOTIVATE THOSE SEEKING JUSTICE AND EQUALITY TO HELP US HELP THEM.”

JAMES WEISMAN
UNITED SPINAL PRESIDENT & CEO

OUR IMPACT

We believe no person should be excluded from opportunity based on their disability. Our goal is to provide people living with SCI/D programs and services that maximize their independence and enable them to remain active in their communities.

United Spinal transforms the lives of people with SCI/D by:

Advocating for greater access to healthcare, mobility equipment, public transportation, rehabilitation, community services and supports, and the built environment

Empowering our members with resources, one-on-one assistance, and peer support

Promoting independence through employment opportunities and community integration

United Spinal is actively committed to advocating for greater civil rights and independence for people with disabilities, including expanding education and employment, improving enforcement of the Americans with Disabilities Act (ADA), ensuring adequate access to public transportation and taxi services, and amending Medicare rules that restrict many individuals to their homes and nursing facilities.



VETSFIRST

Leads the way in advocating for veterans living with disabilities and ensuring they achieve the highest level of independence and quality of life.

VetsFirst is a program of United Spinal Association with 70 years of expertise in helping America's veterans with disabilities, their spouses, dependents, survivors and other eligible family members receive health care, disability compensation, rehabilitation and other benefits offered by the U.S. Department of Veterans Affairs. We supply direct representation, proactive legislative and regulatory advocacy, individual support and counseling services, guidance on education and employment, news and information and valuable self-help guides.



Founded by World War II veterans, United Spinal saw great impact expansion early on under the 32 year leadership of by veteran James J. Peters. To Jim Peters, 'life in a wheelchair' meant a life devoted to demanding recognition and respect for veterans with disabilities. His advocacy furthered healthcare, research, education, transportation, housing and related legislation. Peters' strategy was straightforward—he simply refused to accept no for an answer.

ROLL ON CAPITOL HILL

United Spinal's annual legislative event brings together member advocates from across the nation to roll and walk Capitol Hill as an allied community. Event participants meet with and educate Congressional leaders about the policy issues that impact the health, independence, and quality of life of individuals living with spinal cord injuries and disorders, including disabled veterans.

"I've met so many amazing individuals with spinal cord injuries and disorders from across the country. We unite to impact change and fight for disability rights. That's what makes Roll on Capitol Hill so rewarding." -- Richard Bagby, VA, United Spinal Advocate



DEFINING ADVOCACY



"WHEN I SEE SOMETHING AND SAY, 'SOMEONE OUGHT TO DO SOMETHING ABOUT THAT,' I CAN ACTUALLY BE THAT PERSON. I HAVE THE TOOLS AND RESOURCES TO BRING ABOUT CHANGE."

LAUREN DEBRUICKER, PA
UNITED SPINAL ADVOCATE

WHAT IS ADVOCACY?

Acts of public support or recommendation of a particular cause or policy. To advocate (advocare) means, in Latin, to call in as counsel. A modern translation of 'to advocate' is to call for, to speak out, to voice. This makes active advocacy simple, we just need to speak up and make our voices heard.



WHY IS IT IMPORTANT?

Through advocacy, communities like ours are able to raise awareness, break down barriers and help further the causes we care about most. Effective advocacy shapes the public debate on social issues and ensures that communities have a voice in the policies that impact their lives. Advocacy allows us the power to influence and advance change.

GRASSROOTS ADVOCACY VS. LOBBYING

While direct lobbying is often conducted on behalf of organizations or associations and exercised by registered lobbyists...

Grassroots advocates are members of the community who are personally affected by an issue. Grassroots advocacy is awareness building that relies on people to use their own voice and stories to reach local, state, or federal decision-makers regarding the issues that affect them directly. As a grassroots advocate, each of us has an opportunity to 'plant seeds' of concern and nurture the kind of awareness that helps a movement grow, like grass.

As a grassroots advocate you have the power to:

- Be heard by decision-makers
- Educate policymakers
- Defend and safeguard your rights
- Share your SCI/D story and experiences
- Show support for or against legislation
- Build influential relationships
- Advise and be considered in life-affecting decisions
- Be part of positive change

ADVOCATES IN ACTION: GROWING GRASSROOTS



KELLEY SIMONEAUX, VA UNITED SPINAL ADVOCATE

In 2018, Kelley faced discrimination when an app based ridesharing driver refused to transport her wheelchair. Rightfully feeling wronged, Mrs. Simoneaux sought out all avenues available to voice her grievances and to bring attention to this issue.

In doing so, she filed a complaint with the ridesharing company via their app, called out the company and experience on social media, contacted news networks and shared her story with press, and filed a human rights violation in the county where the incident occurred.

As she shared her story, she began hearing from other wheelchair users about their own negative experiences using ridesharing. For many, the stories were similar, but for those who are unable to transfer into a car, the option of ridesharing commonly wasn't an option at all.

With further awareness of the current gaps in service, regulation and recourse, Kelley was driven to keep pushing. She worked for months to get a sit-down with corporate leadership from Uber, but left the meeting feeling demystified with the lack of enthusiasm the company showed in making accessibility improvement changes internally.

With that, Ms. Simoneaux made a commitment, "If they're not going to do it on their own, what I can do is help shape policy that will make them change how they operate." In the time since, she has done just that, working with legislators to fight for the changes needed to make ridesharing accessible for all.

KNOW YOUR RIGHTS: A SIMPLE GUIDE TO KEY DISABILITY LEGISLATION



"KNOWING MY RIGHTS EMPOWERS ME AND
STRENGTHENS MY CONFIDENCE TO ASK FOR THE
CHANGES I SEEK."

IAN RUDER, OR
UNITED SPINAL EMPLOYEE AND ADVOCATE

THE AMERICANS WITH DISABILITIES ACT (ADA)

Since 1990, the ADA has prohibited discrimination on the basis of disability. In 2008, the Americans with Disabilities Amendments Act (ADAAA) reframed the ADA's definition of disability and broadened the scope of coverage. As it stands, the ADA defines a person with a disability as an individual with physical or mental impairment that substantially limits one or more major life activity. The ADA is divided into 5 titles:

- **Employment (Title I).** Requires employers to provide reasonable accommodations to people with disabilities who are applicants or employees. It also prohibits discrimination on the basis of disability in all aspect of employment.
- **Public Services (Title II).** States that public services, like public transportation, cannot deny service or participation to a person with a disability.
- **Public Accommodations (Title III).** States that all newly constructed and modified facilities, such as restaurants, grocery stores, commercial stores, and hotels, must be accessible to people with disabilities.
- **Telecommunications (Title IV).** Requires telecommunications companies offering services to the general public to provide telephone relay services to people who use telecommunication devices.
- **Miscellaneous (Title V).** Prohibits coercing, threatening, or retaliating against people with disabilities asserting their rights under the ADA.

ADDRESSING ADA VIOLATIONS

Examples of ADA violations

Failure to install a wheelchair ramp where necessary, inadequate restroom accommodations, lack of handrails, walkways that are too narrow or steep, problematic elevator or escalator systems, insufficient accessible parking, employment discrimination, websites that do not meet the needs of those with disabilities, inaccessible public spaces and transportation etc.

What to do/where to go for help

If you believe that you or another person has been discriminated against by an entity covered by the ADA, you may file a complaint with the Disability Rights Section (DRS) in the Department of Justice.

Additional Resources

www.ada.gov/complaint



AFFORDABLE CARE ACT (ACA)

Since being signed into law by President Barack Obama on March 23, 2010, the ACA (in full, known as The Patient Protection and Affordable Care Act (PPACA) together with the Health Care and Education Reconciliation Act of 2010 amendment, represents the U.S. healthcare system's most significant regulatory overhaul and expansion of coverage since the passage of Medicare and Medicaid in 1965. Regulations include:

- Insurers cannot deny coverage to individuals due to pre-existing conditions;
- Premiums must be the same for everyone of a given age, regardless of pre-existing conditions;
- Essential Health Benefits (EHB) must include: ambulatory patient services; emergency services; hospitalization; maternity and newborn care; mental health and substance use disorder services, including behavioral health treatment; prescription drugs; rehabilitative and habilitative services and devices; laboratory services; preventive and wellness services and chronic disease management; and pediatric services, including oral and vision care.
- Annual and lifetime coverage limits on EHB prohibited.
- Additional preventive care and screening for women;
- Creation of health insurance exchanges in all fifty states. The exchanges are regulated, largely online marketplaces, administered by either federal or state government, where individuals and small businesses can purchase private insurance plans

ADDRESSING ACA VIOLATIONS

Examples of ACA violations

As with all things, you must monitor what your plan covers. Read and familiarize yourself with your plan's benefits very closely and speak out if you are receiving discriminatory services or inappropriate benefits such as:

- fewer therapy visits than listed in your plan
- specialists in your network that do not align with your needs
- denying your enrollment into a plan
- denying savings based on your income level

What to do/where to go for help

- you can submit an appeal to your plan
- contact your state Health Department ombudsperson/ administrative personnel or leadership (varies between states)
- contact your local, state or Federal legislators

Additional Resources

ACA plans and benefits:

www.healthcare.gov

Private insurance options:

www.healthcare.org

Want to contact your local, state, or federal legislators?

www.unitedspinal.org/advocacy-action/resources

AIR CARRIER ACCESS ACT (ACAA)

Since 1986, the ACAA has prohibited commercial airlines from discriminating against passengers with disabilities. Some of your rights under the ACAA include:

- All domestic and foreign American air carriers are required to have accessible websites and kiosks.
- You have a right to timely enplaning, deplaning, and connection assistance. You also have a right to be provided equipment (e.g., wheelchairs and aisle chairs) and personnel (e.g., individuals to propel wheelchairs and aisle chairs and individuals to assist in carrying and stowing their baggage).
- Airlines must allow passengers to safely stow their wheelchairs or parts of wheelchairs in the overhead bins or under seats.
- Airlines must ensure there is a space for at least one passenger with a disability to stow a folding wheelchair in the cabin of the airplane if the aircraft has 100 or more seats on board.
- Service animals must be allowed to accompany passengers with disabilities and to sit in close proximity to the passenger as long as they do not block the aisle.
- Those providing wheelchair service while traveling may not charge for service or ask for a tip for their service.

Potential ACAA violations include:

Wheelchair damage, bodily harm, excessive wait times, inaccessible ticketing site, service animal denial, etc.

In 2018, Roll on Capitol Hill advocates lobbied for support of further ACAA reform, namely the Air Carrier Access Amendments Act, assisting in the passage of the **Federal Aviation Administration Reauthorization Act** requiring:

- Increased civil penalties for bodily harm to passengers, equipment, or mobility aids
- Review and revise regulations to ensure passengers receive dignified, timely and effective assistance
- Creation of Advisory Committee on the Air Travel Needs of Passengers with Disabilities
- Development of Airline Passengers with Disabilities Bill of Rights

ADDRESSING ACAA VIOLATIONS

What to do/where to go for help

- Contact the airline with which you are traveling. Many employ designated disability customer service agents. When possible, speak with someone at the airport
- Speak with a Complaint Resolution Officers (CRO) who will have disability related procedure and resolution training and are available in all US airports in person or by phone 24/7
- Follow-up any ACAA violation by filing an incident report with the Department of Transportation
- www.transportation.gov/airconsumer/file-consumer-complaint
- <https://www.transportation.gov/civil-rights/civil-rights-awareness-enforcement/people-disabilities>
- https://www.faa.gov/about/office_org/headquarters_offices/acr/com_civ_support/disab_act/

ADVOCATES IN ACTION: SKY-HIGH STANDARDS

KENNY SALVINI, WA UNITED SPINAL ADVOCATE AND CHAPTER LEADER 2019 FINN BULLERS CO-ADVOCATE OF THE YEAR AWARD

After facing not only one, but two, heavily damaged wheelchairs caused by airline mishandling during his travels to Roll on Capitol Hill's 2016 and 2017 events, Kenny ran chair first into an advocacy discussion he could not ignore.

"This is just the beginning of a larger conversation about accessible travel that must be had. Because I'm paralyzed from the neck down, these chairs are more than just my legs, they are also my arms and extensions of my brain; they are how I control my telephone, access my home and run my business. In short, they are my life, and that should not be put at risk every time I want to travel and do life," said Salvini.

In 2018, Kenny and other attendees spent several days advocating for increased air travel rights and protections included in the Air Carrier Access Amendments Act (ACAA). Fueled with education and an empowered voice, Kenny spoke out. After sharing his story on social media, he wrote a poignant piece on the subject for New Mobility magazine, winning honorable mention in the Ruderman Awards for Excellence in Reporting on Disability. Beyond his pen, Kenny continues to use his voice as an advocate and advisor, working with Alaska Airlines to share his story and facilitate improved equipment handling.



FAIR HOUSING AMENDMENTS ACT

Since 1988, the FHA Amendments Act (FHAA) has extended Title VIII of the Civil Rights Act of 1968, which prohibits discrimination on the basis of race, color, religion, sex or national origin in housing sales, rentals or financing to include protection to persons with a disability.

FHAA requires two types of reasonable accommodations to make existing housing more accessible to persons with disabilities. These accommodations consist of structural modifications and policy changes:

Structural modifications: Housing providers must permit reasonable modifications of existing premises if such modifications are necessary for a person with a disability to be able to live in and use the premises. The cost of the modification is to be paid by the resident with a disability.

Policy changes: FHAA requires that the housing provider make reasonable modifications in rules, policies, practices or services necessary to give persons with disabilities equal opportunity to use and enjoy the dwelling.



ADDRESSING FHAA VIOLATIONS

Examples of FHAA violations

Landlord denial based on disability, race, religion, or familial status, failure to provide reasonable accommodation to a dwelling, unfair mortgage practices, exclusionary advertising, etc.

What to do/where to go for help

The Office of Fair Housing and Equal Opportunity is the agency responsible for administering and enforcing federal fair housing laws. If you feel you have faced an FHAA violation, you can contact FHEO to file a complaint or visit your local Housing and Urban Development office.

Additional resources

www.unitedspinal.org/pdf/fair_housing_amendment.pdf

www.hud.gov/program_offices/fair_housing_equal_opp/online-complaint



THE REHABILITATION ACT

In 1973, the Rehabilitation act replaced the Vocational Rehabilitation Act with reforms including:

- Expansion and revision of grants to states for vocational rehabilitation services, with special emphasis on services to individuals with the most severe disabilities
- Broaden federal responsibilities and research and training programs with respect to individuals with disabilities
- Provide linkage between state vocational rehabilitation programs and workforce investment activities carried out under title I of the Workforce Investment Act of 1998
- Establishing special responsibilities for the Secretary of Education for coordination of all activities with respect to individuals with disabilities within and across programs administered by the federal government

Potential Rehabilitation Act violations

Unfair hiring practices, discrimination, unmet employment assistance needs, refusal to provide adaptive technology, etc.

Where to go for help/file a complaint

Complaints can be filed with the US Equal Employment Opportunity Commission or with state Fair Employment Practice Agencies can be used for claims that inform locally specific worker protection laws. For additional guidance: <https://www.eeoc.gov/laws/types/disability.cfm>

VIETNAM ERA VETERAN'S READJUSTMENT ASSISTANCE ACT

Since 2003, the VEVRAA has required that businesses with a federal contract or subcontract in the amount of \$100,000 or more entered into on or after December 1, 2003, take affirmative action to employ and advance qualified protected veterans.

Veterans covered by VEVRAA are those who receive VA disability compensation, were recently separated from active duty, served on active duty during a war or in a campaign or expedition for which a campaign badge was authorized, and those who an armed forces service medal was awarded.

Where to go for help/file a claim

VEVRAA is enforced by the Office of Federal Contract Complaints Programs and impacts employers with federal contracts or subcontracts of \$100,000 or more. For further information visit: www.eeoc.gov/eeoc/publications/ada_veterans.cfm



UNIFORMED SERVICES EMPLOYMENT AND REEMPLOYMENT RIGHTS ACT (USERRA)

Since 1994, passage of USERRA established rights and responsibilities for uniformed service members and their civilian employers. Including:

- Reemployment rights
- The right to be free from discrimination and retaliation
- Health insurance protection
- Enforcement guidelines

Where to go for help/file a claim

The US Department of Labor, Veterans Employment and Training Service (VETS) is authorized to investigate and resolve USERRA violation complaints. Call 1-866-4-USA-DOL or visit:
<https://www.dol.gov/vets/programs/userra>



UNDERSTANDING THE LEGISLATIVE PROCESS



"WE THOUGHT JUST SHOWING UP IN HEARINGS WAS HOW IT'S DONE. REALLY, IT'S OFFICE VISITS WITH KEY LEGISLATORS, FOLLOWING UP ON THAT, AND CRAFTING YOUR MESSAGE THE RIGHT WAY."

ROB WUDLICK, MN
UNITED SPINAL REGIONAL ADVOCACY COORDINATOR
2019 FINN BULLERS CO-ADVOCATE OF THE YEAR

LEGISLATION VS REGULATION

Despite being often used interchangeably, these words refer to different things

Laws are passed by either Congress or state legislatures. The legislature creates bills that become law once passed by a vote. Laws establish the general framework of principles in which a government will act.

Regulations are standards and rules that govern how laws will be enforced. They are often issued by the administrative agencies responsible for enacting the laws. Regulations are also codified and published, like laws.



FROM CITY COUNCIL TO SENATORS

Federal, state, and local governments all make laws, but each level has different legislative responsibilities. It's important for advocates to understand the role of their elected representatives and what they can do for you:

FEDERAL REPRESENTATIVES

Your representatives at the Federal level are in Congress—the House and Senate. Your members of Congress are responsible for passing legislation that impacts the entire country (e.g. amendments to the ADA or federal health care policy).

STATE REPRESENTATIVES

State government mirrors federal government in that there are legislative, judicial, and executive branches of government. The State legislature has both an upper and a lower house with State Senators and State House or Assembly members. These representatives enact laws for their state.

LOCAL REPRESENTATIVES

Local representatives handle administration of towns, cities, municipalities, counties, and districts. Local government runs things that impact our daily lives, like utilities, libraries, emergency services, and law enforcement.

HOW THE U.S. CONGRESS WORKS

Congress, the bicameral legislature of the Federal Government has 535 voting members and consists of two chambers chosen through direct election. The House of Representatives and Senate are equal partners, with all legislation requiring the consent of both chambers before any action.

The House of Representatives: 435 voting members, and six nonvoting members representing Puerto Rico, American Samoa, Guam, Northern Mariana Islands, US Virgin Islands, and the District of Columbia. Members serve two-year terms representing the people of a single constituency, known as a district. Congressional districts are apportioned to states by population using the U.S. Census results

Unique powers of the House: Initiation of impeachment cases and revenue raising bills

The Senate: 100 voting senators are elected at-large in their state for a six-year term. All states, regardless of population or size, have two senators and terms are staggered so that every two years approximately 1/3 of the Senate is up for reelection.

Unique powers of the Senate: treaty ratification, approval of presidential appointments, impeachment decisions

Once any legislation has passed both through the House and Senate, it is then put in front of the President of the United States to be signed into law or vetoed.

HOW A BILL BECOMES A LAW



Step 1: Bill Introduced Any member of Congress, either a Senator or Representative, may introduce a bill. It is then assigned a bill number and sent to the committee with jurisdiction over the area affected.

Step 2: Committee Action The committee as a whole may consider the bill or be referred to a subcommittee. Public hearings are usually held to hear various viewpoints on the bill. The committee can vote to report (approve) the bill, with or without amendment, or to kill it.

Step 3: House Floor Consideration If the committee votes to report the bill, it is sent to the floor of the full House. Members may debate the bill and offer amendments. The House then votes on final passage. A bill that is defeated will go no further in the process. A bill that is passed will then go to the other House of Congress.

Step 4: Second House In the second House of Congress, a bill usually goes through the same steps as outlined above. This House may vote to pass the bill, with or without amendments, or to defeat it.

Step 5: Resolving Differences If the two houses pass a different bill, a conference committee will usually be appointed with both House and Senate members. This committee attempts to work out the differences between the House and Senate versions of the bill. If the committee reaches agreement, a revised bill is sent back to both houses for a vote. The House and the Senate must approve it.

Step 6: Presidential Action – Final Approval After both the House and the Senate have passed a bill in identical form, it is sent to the President. The President may sign the bill into law or allow the bill to become law by letting it sit for 10 days while Congress is in session. If the President disagrees with a bill, he may veto it and send it back to Congress. If the bill receives 2/3 vote or greater, in both Houses, the bill becomes law.

REASONS TO GET INVOLVED WITH FEDERAL POLITICS

There are ample reasons why someone might want to get involved in Federal advocacy and/or public policy. Federalism refers to a mixed mode of government, combining central or 'federal' government with regional governments (state, territorial or other subunit governments) in a single political system.

What is public policy?

Public assistance programs, legislation such as the Affordable Care Act, environmental laws, etc. A public policy is not simply a passed law or regulation. Instead, it includes the beliefs and attitudes that result in the passage of a law or regulation.

Getting involved at the Federal Level means engaging with Congress and with the various agencies that make up the Federal Government, such as the Department of Transportation, the Department of Justice, the Department of Health and Human Services.

One individual can make a big impact at the Federal level. You can:

1. Call attention to issues of importance;

In response, a Senator or Representative may address your issue on the floor, talk to their colleagues, talk to the press, attend one of your events
In addition, the head of a Department, may make some administrative changes within their department due to hearing from advocates

2. Ask a Senator, Representative or Department head to introduce a piece of legislation or regulation to fix an issue

DID YOU KNOW?

Senators and Representatives are elected and expected to represent the wants and needs of their constituents. Members of the legislature are not the only ones with the power to create new laws. Anyone can propose an idea for a bill in your state and get involved with the political process.



Above, United Spinal member advocates encourage Arizona legislators to write a bill that requires a minimum number of wheelchair accessible bathrooms in apartment buildings during their Roll on Arizona event.

“We want to ensure that the accessibility issues that affect the health and safety of people with disabilities, including entering and exiting buildings quickly and having access to bathroom facilities, are addressed.” - Gina Schuh, AZ, United Spinal Advocate

HOW STATE LEGISLATURES WORK

Each state, except Nebraska, uses a bicameral legislature structured similarly to the federal legislator, utilizing two separate legislative chambers or houses. One, called the Senate, that is also known as the “upper house.” In 41 states, the larger chamber is called the House of Representatives, but a number of states use the term “Assembly” or the “House of Delegates.” In Nebraska, they use a one-chamber legislator called the Senate.

The Senate: Generally, but not always, has the exclusive power to confirm appointments made by the governor and to try articles of impeachment. In most cases, this smaller chamber represents more citizens and serves longer terms. Often, 4 years.

The House of Representatives/Assembly/House of Delegates: Customarily has the exclusive power to initiate taxing legislation and articles of impeachment. This larger chamber usually serves terms of 2 years.

In the majority of states, once any legislation has passed through both the upper and lower chambers, it is then put in front of the Governor be signed into law or vetoed.

Each state has a different legislative session, to find out when your state is in session visit:

www.statescape.com/resources/legislative/session-schedules.aspx

REASONS TO GET INVOLVED WITH STATE POLITICS

Think globally, act locally.

1. Lawmakers are more accessible. State and local legislators have more time to speak with you over the phone or meet in person.

2. There is a lot to learn at the state level. At the state level, policy teams are innovative idea creators, tackling issues deeply from a variety of angles.

3. Ideas move quickly in the states. Legislative attention and progress in one state, can quickly spread and be adopted by other states.

4. You can get ahead. Federal work can be reactive, while the work being done at the state level is often proactive.

5. States have more freedom. Unlike the federal government, states are less dictated by pressures and mandates that restricts change. States are often where the action is.



FINDING YOUR PLACE AT THE POLITICAL TABLE

Create change locally by being directly involved in the political process

Go to Meetings

A great way to get to know your local political leaders and new candidates, is to attend and participate in your town and county political committee meetings. These meetings are usually open to anyone and provide a great opportunity for you to not only get to know other active constituents, but also to learn about issues facing your community.

Join an Advisory Board, Task Force, or Apply for Commissionership

By committing to a public service committee or council, you can work with other community members and share your unique perspectives on issues and how they affect your life. You can contribute by doing research, taking public testimony, reviewing reports, and creating recommendations for local problems.

Run for Office

The pinnacle of involvement in local party politics is running for office yourself. Think about running for party offices, as well as, civic offices, such as judge of elections, school board, or town council.

ADVOCATES IN ACTION: GETTING POLITICAL



NICK LIBASSI VICE PRESIDENT OF PARTNERSHIP EXPANSION FOR UNITED SPINAL

Elected to Rochelle Park, New Jersey, Township committee in 2018. Nick shares,

"I decided to run for office because it is not enough to sit on the sidelines. You have to be willing to work towards making things better, whether it is accessibility, disability or issues that have nothing to do with either it was important to me to be active and try to make the changes that I feel are needed."



JOSE HERNANDEZ UNITED SPINAL EMPLOYEE AND ADVOCATE

Appointed New York City Commissioner of Civic Engagement in 2019. Jose shares,

"Living with a disability, I have always recognized the importance of advocating. However, it wasn't until I attended Roll on Capitol Hill that I understood how much our voices as individuals with disabilities resonate when we come together. As a commissioner, I use my experience and passion for advocacy to encourage others with disabilities to get involved in their communities too."



POLITICAL ENGAGEMENT



"IT IS REWARDING TO EXPERIENCE PEOPLE SHARING THEIR COMPELLING PERSONAL STORIES ABOUT HOW PUBLIC POLICIES AFFECT THEIR LIVES AND HOW REPRESENTATIVES VALUE THE EXPERIENCES TOO."

KENT KEYSER, VA
UNITED SPINAL PUBLIC POLICY FELLOW

COMMUNICATING WITH ELECTED OFFICIALS

Effective advocacy starts with clear communication

It is important to be as informed and prepared as possible before contacting your legislator.

Be persistent about your engagement with your elected officials. Make sure they know you are invested in these issues and are not going away. The following pages will outline the best ways to effectively and efficiently engage elected officials.



IN PERSON VISITS

Build a long-term relationship

Elected officials want to get to know their constituents.

Building a professional relationship will pay long-term benefits to both you and them.

Find common ground. Look more broadly than the few issues on your current legislative agenda. Find that “golden nugget” that makes an elected official or senior staff person tick and, if you can, support their priorities. Introduce them to as many like-minded family and friends as you can by inviting them to events, meetings and showing support for them on social media.

Think and act long term. If the member supports your issues, always let them know of your appreciation and express it through social media. If the member doesn't yet support your issues, their support may come in the future. Patience is a virtue and knowing of your support on issues, may very well keep your member from actively opposing your issues. Keep them updated.

Staff make a difference. Legislators depend on the advice of their staff, so building relationships with them will be an advantage. An aide may be more knowledgeable about a particular issue and may have more time to talk with you. Legislators have offices in their home states and districts, and most make themselves available through public venues to meet with constituents. State and district staff work hand in hand with Washington staff. They can open many doors for you. Also, do not forget the expertise of committee staff. Committee staff are specialists by nature, whereas staff in members' offices tend to be generalists. Keep a dialogue open with as many staff as you can.

IN PERSON VISITS CONTINUED

Information is power

Sharing reliable information is a powerful tool in establishing trust with members of Congress and their staff. Trust is the strongest foundation on which you can build a solid relationship.

Tell your story. Your personal story about how an issue affects your life is central in making your case for a change in public policy. A personal story can help explain the technical parts of a complex issue. Let members and staff know you hope they will share your story with their colleagues.

Know the lay of the land. Know both the upsides of your issue and any potential downsides. Sharing a general overview of all sides of an issue will help speed decisions on your issues and will be appreciated by staff and members who deal with overwhelming workloads and time constraints.

Bring it home. Members and staff want district or state-specific information, so connect the impact of your issues to their constituents. Statistics matter but so do individuals and organizations back home that support your position. Put it in writing so they will be able to use it later.



IN PERSON VISITS CONTINUED

Be yourself and always be at your best

The way you approach, interact and follow up with members and staff is as important as the message you want to deliver. Being at your best will quickly build lasting relationships.

Your mom was right. Little courtesies pay big dividends. Leading with a smile or a kind word and a thank you for their valuable time sets a proper tone for face to face meetings, as well as, for emails and other forms of communications. Be brief in your presentation and considerate of their time.

Be honest. Facts and figures are important but so are passion and determination, so speak from your head in your own words, but by all means also speak from your heart. Don't worry, if you don't know an answer to a question, just assure them you will try to find the best answer you can.

Always follow through by following up. Send a thank you note (email) immediately after your meeting or when you receive a reply. But, give offices some reasonable time to get back with you before you contact them on the same issue again. When you do follow up, begin with another note of thanks for their valuable time. Please always ask before you share their reply in any public venue.



TELEPHONE CALLS

Telephone calls are usually taken by a staff member, not the member of Congress. Be sure to ask to speak with the aide who handles the issue that you are calling about.

- Identify yourself to the aide.
- Let the aide know if you are a constituent (someone who resides in the elected official's district).
- Tell the aide you would like to leave a brief message, such as: "Please tell Senator/Representative (Name) that I support/oppose "S.____/H.R.____)." You should also state reasons for your support or opposition.
- Personal stories can be very persuasive. If possible, share how the legislation would affect (positively or negatively) your life if passed/not passed.
- If unknown, ask for your Senators' or Representative's position on the bill.
- You may also request a written response to your telephone call.



E-MAILING CONGRESS

Generally, the same guidelines apply as with writing letters to Congress. E-mailing is a good method of communication with a Congressional office.

- Your purpose for writing should be stated in the first paragraph of the e-mail.
- If your e-mail pertains to a specific piece of legislation, identify it accordingly, e.g., House bill: H. R. _____, Senate bill: S._____.
- Be courteous, to the point, and include key information, using examples to support your position on the legislation/issue.
- Address only one issue/topic in each email; and, if possible, keep the letter short.
- These days, written letters are sent via email.

ADDRESSING WRITTEN CORRESPONDENCE

- An appropriate greeting is "Dear Representative" or "Dear Senator" or "Dear "Congressional Staffer's Name""
- When writing to the Chair of a Committee or the Speaker of the House, they must be addressed as "Dear Mr. Chairman or Madam Chairwoman:" or "Dear Madam Speaker or Mr. Speaker:"

TOWN HALL MEETINGS

Connect with legislators and your local community

Representatives often hold town hall meetings and keep their websites updated with dates and locations of upcoming meetings. Town hall meetings are a great way to engage in person with your elected officials. If you're concerned about the accessibility of the meeting venue, make sure to call your elected official's office to inquire about accessibility beforehand.



SPEAKING UP AT TOWN HALL MEETINGS

Making your mic-time count

- Prepare any questions you want to ask and research your elected official's positions before the meeting.
- Representatives hold town halls to hear first-hand experiences from constituents, so share your personal stories when discussing existing or proposed legislation.
- Talk to the elected officials' staffers at the meeting and ask for their business cards. This is an opportunity to build that relationship with staff in the office.
- Be respectful. Town halls can get heated when attendees feel strongly about issues, but it's important to remain professional.



SOCIAL MEDIA

The internet is a powerful advocacy tool

Consistent contact with your elected officials through social media, such as Twitter, Facebook, or even Instagram, can be an effective way of engaging with your legislators and sharing your personal story. You can also reach more advocates and allies on social media who can help elevate your message. Following your elected official's social media accounts can also help you keep track of their activities, events, and policy positions. The following tips will help ensure your use of social media is most effective:

- Be courteous and to the point. Staffers will often remove comments seen as offensive or harassing toward the representative.
- If possible, share how the legislation would affect (positively or negatively) your life if passed/not passed.
- Be consistent. According to the Congressional Management Foundation, as few as 10 social media posts to a member of Congress is enough to catch that office's attention.



ADVOCATES IN ACTION: RALLYING ONLINE

GINA SCHUH, AZ WESTERN REGION ADVOCACY COORDINATOR

For both business and pleasure, Gina Schuh loves to travel. Over the years, her frustration has grown over the large variance she faces in the height of hotel beds. When a bed is too tall, it makes transferring from a wheelchair impossible or unsafe. After hearing consistent complaints from other wheelchair users, it hit home that this was a community-wide problem that needed her help. Gina explains, *"In the grand scheme, this seems like a small issue, but it has enormous impacts on people with disabilities being able to travel with ease. Currently, this appears to be the result of a lack of education and awareness by policymakers and those in the hotel industry."*

After raising this issue at the National Council for Disability meeting, Gina checked with the United States Access Board about any hotel bed height guidelines. Upon learning they were nonexistent, Schuh engaged other wheelchair users and got to work on a resolution that reflected the community's needs. Armed with a plan, Gina started a petition on change.org by summarizing the issue and asking those in her network to read, sign-on, and share. Noting, *"It was a simple process, but once it was out there, it spread like wildfire. Seeing the huge amount of sharing and support clearly shows what an important issue this is and that our community needs hotel bed height regulation."*

Today, the petition has 44,000 signatures, but Gina is looking to increase that to 100,000 signatures. With this clear demand, Gina will start talking to legislators and bring this data to the U.S. Access Board along with individual experiences and stories to hotel brands and chains to help realize this important need.



EFFECTIVE PERSONAL STORYTELLING



"ROCH HAS GIVEN ME SKILLS TO GO TO ANY STATE AND SIT WITH AN OFFICIAL, NOT ONLY TO SHARE MY PERSPECTIVE, BUT TO BUILD A SOLUTION THROUGH POSITIVE DIALOGUE."

ANDREA DALZELL, NY
UNITED SPINAL ADVOCATE

SHARING YOUR STORY

Storytelling is one of the most powerful tools for affecting change in our society. By relating your own personal experiences, your audience can more easily relate and empathize. The stories we share are unique and have the power to motivate others to support a cause.

"At home I had felt alone, at ROCH 2012, I realized that my wife and I mattered, that my issues were real, and that I could possibly be the first person Capitol Hill had ever seen using a wheelchair that can stand me up with a voice communicator that responds to my eyes."

- Earle Powdrell, TX, 2018 Finn Bullers Co-Advocate of the Year



STORY DEVELOPMENT QUESTIONS

Tailoring your story to your audience

- What is the purpose of this conversation? Who is my audience?
- What is my core message for this conversation?
- What do I want my audience to take away from this conversation? How do I want them to think about the issue?
- How will my story help someone more deeply understand this issue or policy?
- What parts of my story specifically relate to this societal issue or policy?
- How does my story connect to someone else's experience? How does it connect to a broader context?
- How can my story create change? How can it help someone see a new perspective?



MESSAGES THAT INSPIRE ACTION



ENGAGE YOUR AUDIENCE

In a sentence or two, make a statement about your experience that will grab your audience's attention.

PRESENT THE PROBLEM

Describe what the issue is, who it is affecting, and the impact on your life. If you have data, this is a good time to present it.

SHARE A STORY

Share an experience that helps the legislator empathize and understand how the problem effects your community as citizens.

CONNECT VALUES

Take the time to research what issues your audience cares about and frame your story with that in mind to help make an impact.

STICK TO THE HIGHLIGHTS

You want to make your point, but leave them wanting to know more. When they ask questions, you've caught their attention.

SHARE A SOLUTION

If you have an idea of how to help, speak up, showing a policymaker a path to change may allow them to serve you better.

MAKE YOUR REQUEST

Legislators expect requests. Let them know what would help and ask for their support. If they say "yes," you have a supporter.

INITIATIVE CREATION



"ADVOCACY IS IMPORTANT TO ME BECAUSE I WANT TO HELP PEOPLE WHO ARE VULNERABLE, LIKE THOSE WHO STOOD UP FOR ME WHEN I WAS AT MY WEAKEST."

KAREN ROY, LA
UNITED SPINAL ADVOCATE

WHAT IS AN INITIATIVE?

Is there is an issue affecting your community that needs immediate action? An organized plan to address the issue is called an initiative. Initiatives create a shared goal for groups of like-minded citizens. Having a defined initiative makes it easier to rally support and ask policymakers for the change needed. Throughout our nation's history, citizens have called upon our elected officials to take action on issues as an important means of progress.



STRATEGIZING AN INITIATIVE

Several ingredients make for a successful advocacy initiative

- The rightness of the cause
- The power of the advocates (larger numbers are helpful)
- The thoroughness of your research of issues, opposition and the climate of opinion about the issue to the community
- The skill with which you use the advocacy tools available
- The selection of the right strategies and tactics

It's important that you thoroughly understand your chosen issue

- Where is the problem?
- Who is the problem affecting?
- What are the impacts of this problem?
- What needs to happen to change this problem?
- What is happening to change this issue currently?
- How can I work with others to change this issue?

The best time to start planning for an advocacy initiative campaign is when your direct experience and research shows you cannot achieve your goals in any other way and you're sure you have the capacity to carry it through due to enthusiasm and energy.



INITIATIVE DEVELOPMENT STEPS

Having clear goals and an action plan is key

Step 1- Set the right goal. What you want to accomplish? Consider your time and energy commitment and define a goal that will impact your community with the resources you have.

Step 2- Set objectives. Determine the milestones that will help you achieve your goal. Use SMART goals that are specific, measurable, achievable, realistic, and timely.

Step 3- Determine your tactics. How do you want to get your message out? What activities will inspire the support you need to move your initiative forward. Tactics are your action steps. The icing on the cake and the part that shows. They can cover a wide range of activities, from writing letters, speaking up at City Council meetings, filing complaints, setting up negotiations, boycotts, demonstrations and carrying out surveys.

Make sure your tactics:

- Carry out your strategy and are appropriate for your goals
- Fit your style
- Are doable and cost-effective, within your resources and funds
- Make your group feel good about themselves and the action

Step 4- Create your plan. Keeping a detailed record of what needs to be accomplished, by whom, and by what date will help keep you on track. What is the scope of the action? Who will carry it out? When will it happen and for how long? Are the resources available to accomplish this? Which allies and constituents should be involved? Who might oppose the action or resist?

Step 5- Take action. Once you have an initiative plan, it is time to get out there and create the change you need.

CRAFTING AN ISSUE SUMMARY

An issue brief is a short one-page written document that explains:

Your issue

State the issue for consideration. Briefly explain its importance to you and your community in the current context and issue relevance to your intended audience.

Recommendation

State the action you seek in connection with the above-stated issue. The recommendation may indicate the continuation, elimination, or amending of the issue.

Current law

List any current law or regulatory framework that authorizes or supports the issue.

Background

Provide supporting information relevant to the issue and recommendation.

Use any additional available space to:

List organizational policy that supports this issue

List actions or activities used to demonstrate the importance of the issue to you.

List current evidence that supports your actions, activities, or suggestions.

Below is an example of a easily digestible issue summary brief:

www.unitedspinal.org/pdf_advocacy/Save_Access_to_Manual_Wheelchairs.pdf

ASSEMBLING A COALITION



“ADVOCATING HAS GIVEN ME A DIFFERENT PERSPECTIVE ON THE POLITICAL PROCESS. I GET TO SHARE WHAT I LEARN WITH MY LOCAL CHAPTER TO DEVELOP A STRONGER VOICE.”

RICK HAYDEN, CA
UNITED SPINAL ADVOCATE AND BOARD MEMBER

UTILIZING COALITIONS

Teaming up to drive change together

A coalition is an alliance of individuals and/or organizations working together to achieve a common purpose. Together coalition members address the needs and concerns of their particular community. Often, coalitions are organized around a single initiative or event. By collaborating with other advocates and organizations who have similar goals, it's easier to reap the benefits of partnership and maximize effectiveness in your efforts.



ORGANIZING A COALITION

There is power in numbers when it comes to like-minded individuals. This can simply mean working with other people with disabilities on an advocacy issue. For a larger coalition, it's good to have groups of allies with different roles who see eye to eye on the same issue. For example:

On any health issue, you'll want to include: consumers, nurses, physicians and case managers

On a transportation issue, you'll want to include: fixed route operators (trains and buses), ridesharing entities, automobile manufacturers and related partners in order to better show them the importance of the necessity for people with disabilities as customers

Who holds authority in your local area? Choosing people who have built-in credibility and community respect is important. Think about inviting members of the media, elected officials, and other advocacy groups

Consider whether you want this to be a fully fledged formal correlation or loose alliance of allies? Make sure interests align and you can work together.



ADVOCATES IN ACTION: COMMUNITY ROLLERS



RAFFERTY LAREDO, TX UNITED SPINAL ADVOCATE AND CHAPTER LEADER

As a standout Houston spinal cord injury ally, Rafferty has supported his local chapter's advocacy in a myriad of ways. Notably, by fighting alongside and connecting individuals with opportunities to be heard. Laredo encourages,

"Many voices can shout down the walls, because together we are one."



KIM HARRISON, GA UNITED SPINAL CHAPTER ADVOCACY REPRESENTATIVE

Active participant in city town hall advisory and planning meetings and GA statehouse advocate

"It's about speaking for others that can't, both locally and nationally. We get to make important legislative relationships at major events like ROCH, but we have to build on those relationships with representatives on a local level to show them more of our lives and stories. When I visit legislators on a national level, it's nice to mention that person's counterparts name at the local level. When I visit local offices, I can mention their counterpart at a national level."




PLANNING A "ROLL" ADVOCACY EVENT



"I HAVE FOUND THAT THE GREATEST IMPACT WE MAKE IS WHEN A GROUP OF INDIVIDUALS ATTEND A PUBLIC MEETING TO SPEAK UP ABOUT THE CHANGE WE WANT."

BRUCE BLOWER, NY
UNITED SPINAL ADVOCATE

"ROLL" EVENT PLANNING BASICS



Understand Your Issue(s). Clearly define your group's issue and your plan to educate attendees as an important initial step. Everyone attending your advocacy day should have a clear understanding of the issue they will be discussing and why.

Create a Budget and Fundraise. Early on, your planning team must lay out a budget for expenses that will incur for your event. Will you be providing food? Transportation? Include printing costs, room or space rental, promotion costs etc.

Schedule Visits. Once you have identified elected officials you would like to meet with, it's time to schedule visits. This can be done by calling the elected official's office or contacting the staffer in charge of scheduling. Once you have a date set for your event, start scheduling appointments as soon as possible.

Develop Talking Points. Make notes that explain your issues simply and make your position on the issue clear. Each advocate should be prepared to talk about why the issue is important to them and your group collectively. It's critical that everyone involved understands your "ask" and what you are requesting from your legislator.

Prepare Materials for Your Visit. Develop a one-page "Issue Paper" (see page 42 for template) and a simple handout explaining a bit about your chapter and the reason for your visit. Include at least one business card or document with contact info for your group.

Attend and Share Your Story. With your confidently prepared advocacy team by your side, speak up to share your experiences and the reason for your visit with the staffer or elected official. Make sure everyone is introduced and consider designating roles for individuals to lead. Before leaving, sum up the issue and make your ask. Designate a notetaker to write down meeting developments.

Follow-up. A thank you note and any information you agreed to provide should be sent soon after your visit. This provides an opportunity to follow-up with your ask directly and in writing. It's a nice gesture to send a thank you letter or email to the scheduler and the office staff expressing your appreciation.

ADVOCATES IN ACTION: ROLLING TOGETHER



IOWA CHAPTER OF UNITED SPINAL ADVOCATES

While the Iowa Chapter of United Spinal Association has been around for 15 years, their advocacy committee began its work in January 2019. Since then, they have worked hard to rally members to join the voices of others in Iowa to create positive policy change.

This March, members met and rolled together at their Des Moines statehouse to urge legislatures to make changes in the Medicaid benefits that help Iowans with spinal cord injuries and other disabilities live in the community. In 2016, Iowa switched to private management of Medicaid, a decision that has forced some wheelchair using Iowans into long-term care facilities and made finding care more difficult for many others looking to stay in their homes.

Jenn Wolff, Iowa's Chapter Advocacy Leader, said in the arranged press conference, "I think it's time legislators see people with disabilities not as a sick person, not as a person who is home-bound or wheelchair-bound, not somebody who is a drain on the system, but as people who want to give back to the state of Iowa."

The event allowed individuals with disabilities to better understand the importance of their own voice in the legislative process, while increasing awareness for a change their community needs. The Iowa Chapter of United Spinal Association's advocacy committee would like to encourage each legislator to, "Look past their personal and partisan biases and see these issues as they are in our daily reality. To sit at the same table [as people with disabilities] and work together to create a sustainable Medicaid program in Iowa that we all can be proud of."

ADDITIONAL RESOURCES



"ONE OF THE MOST IMPORTANT STEPS OF ADVOCACY IS FOLLOWING UP, IT IS BEING PROACTIVE ABOUT THE CHANGES WE NEED MOST, EVEN WHEN IT'S DIFFICULT."

BROOK MCCALL, OR
UNITED SPINAL GRASSROOTS ADVOCACY MANAGER

ADDITIONAL RESOURCES

For additional resources and information, you can contact United Spinal Association at:

Address:

United Spinal Association
120-34 Queens Blvd. #320
Kew Gardens, NY 11415
United States

Phone: 718-803-3782
Fax: 718-803-0414

Resource Center: <http://www.unitedspinal.org/ask-us/>

We are grateful to United Spinal Association's Corporate Members who have invested in our mission, programs, and advocacy to improve the quality of life for all people with spinal cord injury and disease. Learn more here: <https://www.unitedspinal.org/corporate-members>

