VOICES FOR CHANGE

Empowering Change: Grassroots Advocacy Toolkit

CHRISTOPHER & DANA REEVE FOUNDATION
TODAY'S CARE TOMORROW'S CURE®

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WELCOME

On behalf of the Christopher & Dana Reeve Foundation, thank you for your interest in our grassroots advocacy toolkit.

We developed this resource to help drive changes benefiting the disability community. Whether you're new to advocacy or have been a voice for change for years, we're so glad you're here.

Advocacy is a powerful force for change. It can be as simple as a conversation with your neighbors or as involved as meeting with lawmakers. Every action, no matter the scale, contributes to improving the lives of people with disabilities. And this gets to the heart of what grassroots advocacy is about—***empowering people to take steps toward a shared goal.***

This toolkit is designed to help you get started or advance your advocacy efforts. Inside, you'll find:

- ***Insights into key policies** impacting caregiving, air travel, housing, and disability rights.*
- ***Personal stories** from advocates who have turned passion into progress.*
- ***Practical tools**, including scripts and guides to help you connect with policymakers.*
- ***Tips and guidance** to support grassroots advocates at every stage.*
- ***A directory of organizations** offering additional support for disability advocacy.*

Now more than ever, we need passionate voices calling for meaningful action. Although awareness around accessibility is growing, there are still gaps to fill. Grassroots advocates are uniquely positioned to bring attention to these issues and inspire real change. By advocating for improved policies and practices, we can create a future where accessibility is a right, not a challenge.

*Grassroots advocacy is impactful because it comes from people who care enough to make a difference—**people like you. Your voice matters!***

Let's get started. There's so much we can accomplish together!

Warmly,

Gerard Arnum

Grassroots Advocacy Manager

1 INTRODUCTION TO ADVOCACY

Whether you're a first-time advocate, or interested in expanding your advocacy experience, this toolkit will empower you with actionable information to create meaningful change for people whose lives are affected by disabilities.

What Does It Mean to Be an Advocate?

There are many ways to advocate. At the most basic level, being an advocate means speaking out for a cause that's important to you. In the world of paralysis and disability, advocacy is about using your voice, your experiences, and your passion to promote positive change, whether through policy, community support, or personal empowerment.

Why Advocacy Matters

The Christopher & Dana Reeve Foundation was born from advocacy at a time when scientists believed devising effective treatments for spinal cord injuries (SCI) was impossible. The Reeve Foundation's staunch refusal to accept that injuries could not be treated fueled an ambitious mission to redefine the future for people living with SCI—and today, the field is brimming with promise.

Organizations such as the Christopher & Dana Reeve Foundation lead powerful advocacy efforts to spotlight key issues for people with disabilities and all forms of paralysis. These advocates work tirelessly, urging Congress to make air travel more accessible, prevent workplace discrimination, and update safety net programs to better meet today's needs.

Advocacy is crucial because it brings attention to overlooked issues. It helps secure better policies, services, and research that can improve the lives of people living with disabilities. As an advocate, **you become a catalyst for change**, contributing to a more inclusive and supportive society.

Understanding Grassroots Advocacy

Now that you understand the concept of advocacy, let's do a deeper dive into its different forms, specifically grassroots advocacy. Understanding what advocacy looks like on the ground will help you identify how to make the greatest impact in the disability community.

General Advocacy: Connecting with Legislators

General advocacy includes a wide range of activities aimed at influencing policies, raising awareness, and securing support for a cause. This can happen at various levels from local communities to national and even international platforms.

General advocacy includes:

- **Educating:** Meeting with lawmakers or their staff to educate them about issues impacting the disability community.
- **Public Speaking:** Sharing your story and the importance of disability issues at events, conferences, and meetings.
- **Media Campaigns:** Using newspapers, TV, podcasts, and social media to spread your message and reach a wider audience.
- **Partnerships:** Collaborating with organizations, businesses, and stakeholders to strengthen your advocacy efforts.

Grassroots Advocacy: Cultivating Organic Growth

Grassroots advocacy begins with one person, and it's most effective when the messenger has a powerful personal story. This type of advocacy drives change from the ground up by mobilizing individuals, and eventually, entire communities. It's about people joining forces to support a common cause and amplifying their voices to create change. Grassroots advocacy involves:

- **Community Organizing:** Bringing people together to discuss disability issues, share experiences, and plan collective actions.
- **Email/Letter Writing:** Writing emails and letters to legislators and policy groups in support of a cause.
- **Local Events:** Organizing or participating in events such as walks, fundraisers, or informational sessions to raise awareness and build community.
- **Social Media:** Using platforms such as Facebook, Instagram, LinkedIn, YouTube, TikTok and X (formerly known as Twitter) to share your message, connect with others, and organize actions.

GRASSROOTS ADVOCACY SPOTLIGHT

HENRY STIFEL

In 1982, Henry Stifel was involved in a car accident that left the 17-year-old paralyzed from the neck down. Doctors said his injuries were untreatable—there was nothing they could do.

Henry's parents, Hank and Charlotte Stifel, refused to accept that their only son would never regain movement. They rallied family, friends, neighbors, and local political leaders to raise money—a grassroots approach—and then established a nonprofit dedicated to SCI research, which eventually became the Christopher & Dana Reeve Foundation.

At the time, the Stifels couldn't have known that the grassroots effort they'd started in Henry's bedroom would join forces with the American Paralysis Association (APA), and later with the already existing Christopher & Dana Reeve Foundation. They couldn't have known that these collaborations would evolve into a national movement that would make the impossible possible: That people living with SCI may, one day, regain movement.

Why Raising Awareness Matters

Raising awareness is crucial to effect policy change and educate the broader community about the challenges facing people with disabilities. The more people understand these concerns, the more likely they are to support policy changes and funding.

Every action, big or small, contributes to the larger goal of improving the lives of those impacted by disabilities. Whether you speak before Congress or chat with a neighbor, your advocacy efforts play a vital role in this mission. Let's continue to raise our voices, share our stories, and drive meaningful change.

What is the Regional Champions Program?

The Regional Champions Program is the cornerstone of advocacy efforts at the Christopher & Dana Reeve Foundation. Our champions are passionate volunteer advocates who bring the unique experiences of people living with disabilities into the halls of Congress.

Reeve's Regional Champions serve as legislative "first responders"—meeting with elected officials to alert them when important issues arise. Key components of the program include:

Regional Advocacy Training at LeGrand Coffee House in Woodbridge Township, New Jersey

- Learning about upcoming events and updates from Washington, D.C., through the Reeve Foundation's bi-monthly newsletters.
- Developing and maintaining relationships to educate legislators and key staff.
- Attending in-district legislative events, such as virtual town halls and briefings.
- Working with the Reeve Foundation to share Regional Champions' stories across our digital channels.
- Participating and attending Regional Champion Coffee Sessions.
- Recruiting other advocates to support our efforts.

As a Regional Champion, you will become part of a nationwide community of individuals who wish to speak up on behalf of the paralysis community.

If you would like to lend your voice to our initiatives, please sign up to become an online advocate for change at *https://www.votervoice.net/REEVE/Register*. You can make a real difference for people living with paralysis, as well as their families and caregivers.

Recruit a Regional Champion

The Reeve Foundation has a growing number of Regional Champions across the United States. Our goal is to recruit a diverse pool of Champions, including at least one champion in each of the 441 congressional districts. The larger our numbers, and the more Representatives and Senators we have the potential to reach, the better the outcome for our priorities.

If you know someone who has demonstrated engagement on issues impacting people with disabilities, or someone who has an existing relationship with elected officials or a willingness to forge these important relationships, ask if they're interested in joining the Regional Champions Program.

Interested in becoming a Regional Champion? Send an email to the Christopher & Dana Reeve Foundation's Public Policy and Advocacy Team at *Advocacy@Reeve.org*.

Getting Involved

Advocacy is a marathon, not a sprint, and it begins with a single thought, conversation, or motion. By taking part in advocacy efforts, you join a community dedicated to creating positive change for people living with disabilities. Together, we can achieve greater visibility for pressing issues, foster better understanding, and push for advancements that can change the trajectory of life for people in the disability community.

So, let's get started. Use this toolkit as your guide and remember: **your voice is powerful, your story is important, and your advocacy can transform lives.** **< Sign Up Here** *https://www.votervoice.net/mobile/REEVE/Register*

How to Be an Effective Advocate

Regardless of which type of advocacy activities you choose, certain qualities and actions can make you more effective:

- **Passion:** Being invested and displaying genuine care for the people and the cause.
- **Communication:** Whether you're telling your story, writing a letter, or speaking at an event, clear and compelling communication is key.
- **Persistence:** Advocacy is a long-term effort that requires you to stay the course, even when progress seems slow.
- **Collaboration:** The best advocates work with others in the community, including support groups, vested organizations, and thought leaders, to amplify their interests and promote change.

Stay informed about issues affecting the disability community. This includes keeping up to date with research and policies that help you relay information accurately, confidently, and in a way that inspires change.

Subscribe to the Reeve Foundation newsletter:

https://www.christopherreeve.org/newsletter

Actionable Steps to Get Started

At its core, effective advocacy is about educating people about a specific issue and moving them to action.

Elected officials need help understanding the challenges and costs associated with mobility issues and paralysis. They need information from you—**your personal story**—to make informed policy decisions that can improve the lives of those impacted by these challenges.

You don't need to be a Ph.D.-level scientist, researcher, economist, or paid lobbyist to advocate effectively. You just need to use your voice to make a difference. Here's how:

- **Share Your Story:** Begin by sharing your story with friends, family, and community members. Personal stories are powerful tools for raising awareness. If you are interested in sharing your story, see page 21 for how to do it effectively
- **Join a Group:** Connect with local or national advocacy groups. Many of these organizations have resources and information about how to best get involved.
- **Educate Yourself and Others:** Learn about the challenges facing people with disabilities and share that knowledge. Host a small informational meeting or use social media to educate your network.

> *You should never feel pressured to share your story to serve the "greater good." Personal stories are only one avenue for advocacy, and for some people in the disability community, constantly sharing their story depletes their energy.*

Remember, every voice counts, and every action matters. Whether you're engaging in grassroots advocacy or general advocacy, your efforts can help make a difference for those affected by disabilities. Let's harness our collective power to create change, one step at a time.

Opportunities for Advocacy

Advocacy can happen anytime and anywhere. In fact, some of the greatest efforts occur outside of Washington, D.C. If someone you know seems interested in hearing your story, or becoming an advocate themselves, share your experiences with them!

Exploring Advocacy Opportunities: Big and Small

There's an abundance of opportunities for advocacy within the world of disabilities. Let's explore some of the ways—both big and small—that you can contribute to the greater good.

REGIONAL CHAMPION JAMIE CLENDENING

Born with spina bifida and scoliosis, Jamie Clendening was miraculously mobile until a week before her 34th birthday when she walked into the hospital for a tethered cord release surgery on her spine and woke up paralyzed.

During her stay in rehab, she learned how to fall and get back up, how to wheel herself around, and even how to pick up her 1-year-old daughter. Yet, when she returned home, her house lacked essentials such as a ramp, a proper wheelchair, or an accessible bathroom.

Desperate for help, Clendening searched Google for resources and landed at the Christopher & Dana Reeve Foundation. An Information Specialist connected her to a Peer Mentor, and over time, Clendening decided she wanted to get more involved. She became a Peer Mentor, and then two years later, a Regional Champion for the Christopher & Dana Reeve Foundation.

As a Reeve Foundation Regional Champion, Jamie hosts a town hall meeting in her hometown of Shippensburg, Pennsylvania, writes letters to Congress, and hosts a local support group. "Helping others through tough times and improving quality of life for those with mobility challenges—that's what I'm here to do," she said.

Big Opportunities for Advocacy

The biggest opportunity for advocacy is pushing for legislative change. It's natural to feel intimidated when speaking with public officials and it's important to remember that elected officials work for the people. **That's YOU!**

Whether you're a powerful public speaker, or you communicate best in writing, there are plenty of opportunities to grab the attention of your elected officials and the larger community. See pages 18-19 for templates and suggestions about how to best communicate with elected officials.

Small Opportunities for Advocacy

Advocacy doesn't have to happen in Washington, D.C., or even within your local government. It can occur in your own backyard. Every day presents an opportunity to show up for people impacted by disabilities, share your story, and **ensure your voice is heard**.

Whether you share your story with friends and acquaintances, or broadcast your experiences through social media, your advocacy efforts play an important role in creating change for people with disabilities.

Here's how to be effective on a smaller scale:

Talk to People in Everyday Situations

Advocacy can happen in everyday interactions. Here are some tips for these casual yet impactful conversations:

- **Casual Interactions**: Wear T-shirts, buttons, or pins related to disability and if someone asks about your experience, take the opportunity to raise awareness. Share your story, mention an upcoming event, and provide information about how others can get involved in advocacy efforts.

- **Local Events:** Attend community events, such as parades and town hall meetings, and share information about disabilities. Hand out flyers or business cards with links to more information and ways to get involved.

Post on Social Media

Social media is a powerful way to raise awareness and mobilize support. Tips on how to use it effectively:

- **Start with Your Story:** Post about how a disability has impacted your life, highlighting challenges and triumphs.
- **Aim to Inform and Educate:** The best posts educate your audience with information about disabilities, including articles, statistics, and policy changes.
- **Use Hashtags:** To increase your reach, consider using relevant hashtags on your social media posts. Popular hashtags for the community include: #SpinalCordInjury, #SCIAdvocacy, #SCIStrong, #LifeAfterSCI, #AccessibleAirTravel #SSI #Disability #Advocacy, #DisabilityAwareness, #DisabledAndProud, #SCISupport, and #DisabilityAdvocate.
- **Engage with Others:** Comment on, like, and share posts from other advocates and organizations. Building a community online amplifies your message.

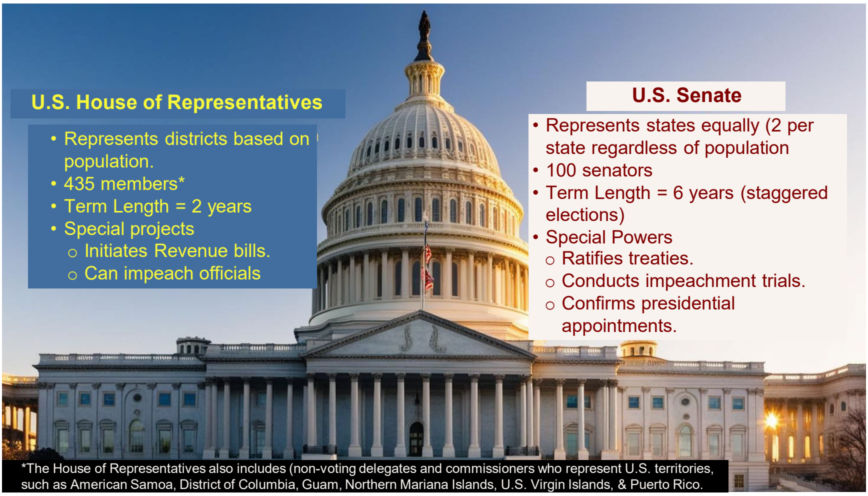
2 ENGAGING WITH THE UNITED STATES CONGRESS AND OTHER ELECTED OFFICIALS

One way to enact change as a grassroots advocate is by connecting with policymakers. Although they are busy, they value getting to know their constituents and what's important to them—including the experiences, perspectives, and priorities of people with disabilities.

About the U.S. Congress

Congress is the part of the Legislative Branch of government that makes and passes laws. Two chambers carry out this work:

1. **House of Representatives:** There are 435 representatives, each serving a two-year term. The number of representatives varies by state and is based on population.
2. **Senate:** There are 100 senators, each state, no matter how big or small, has two senators serving a six-year term.



U.S. House of Representatives

- Represents districts based on population.
- 435 members*
- Term Length = 2 years
- Special projects
  - Initiates Revenue bills.
  - Can impeach officials

U.S. Senate

- Represents states equally (2 per state regardless of population
- 100 senators
- Term Length = 6 years (staggered elections)
- Special Powers
  - Ratifies treaties.
  - Conducts impeachment trials.
  - Confirms presidential appointments.

*The House of Representatives also includes (non-voting delegates and commissioners who represent U.S. territories, such as American Samoa, District of Columbia, Guam, Northern Mariana Islands, U.S. Virgin Islands, & Puerto Rico.

DELEGATES AND COMMISSIONERS

Congress also includes (non-voting) delegates and commissioners who represent U.S. territories, such as:

- American Samoa
- District of Columbia
- Guam
- Northern Mariana Islands
- Puerto Rico
- U.S. Virgin Island

WHO ARE MY CONGRESS PEOPLE?

To find your Representative or Senator, go to:
https://www.congress.gov/members/find-your-member
and enter your zip code.

Getting in Touch with Congress and Policymakers

You don't have to be a policy expert or public speaker to be an effective advocate. Just reach out to your representatives. That's one key way elected officials learn what's important to their constituents.

These interactions enable you to:

- Educate and raise awareness of specific needs of people with disabilities.
- Share your experiences and challenges.
- Express support or opposition to proposed legislation.
- Foster change, which may include ideas for new legislation, research, or support.
- Safeguard your rights.

Congressional Staff

Even if you are not able to meet with your elected officials, it's still possible to feel heard. Representatives and senators have staff who help them carry out their work. Part of their role is learning about issues that are important to their constituents.

Staff most likely to be of assistance to a grassroots advocate include people who:

- Have health policy or healthcare in their portfolio.
- Specialize in disability rights.
- Are responsible for key grassroots advocacy issues, such as transportation, employment, and housing.

Speaking with one of these individuals is often as **impactful** as talking directly to a legislator. Staff are responsible for keeping congressmembers apprised of the subjects their constituents find important. Based on your input, they'll form actions and weave them into the agendas of upcoming meetings.

How to Engage with Lawmakers

There are many ways to get in touch with health and other congressional staffers:

- Phone calls
- Emails
- Social media
- Meetings (in-person or virtual)
- Local events, including town hall meetings

Outreach often starts by sharing a story highlighting your experiences living with a disability or as a caregiver to a person impacted by a disability. The communication should focus on the legislative priorities that matter to you and a request that helps enact change. Your request should be specific, measurable, and actionable.

Examples include:

- Modifying existing laws
- Additional funding for research or services that make your life easier
- Halting a policy proposal that could be harmful
- Requesting support for your rights related to items such as employment, travel, and housing
- Making it easier to access public services

Other Ways to Interact with Policymakers

There are many reasons you may wish to speak with legislators about policies affecting the disability community. Advocates frequently submit public comment about proposed rules to:

- Gain public support by speaking on behalf of your community.
- Highlight potential consequences, unintended impacts, or areas for improvement to guide the agency's decision-making.
- Foster decision-making that reflect the needs and concerns that matter to you.
- Advocate for stronger protections, such as additional reforms that may be necessary to strengthen an existing law.

This process is a cornerstone of participatory democracy, allowing people to directly engage with government policies that affect their lives.

Additional Ways to Connect with Representatives and Other Elected Officials

Speaking with your representatives gives lawmakers powerful information to influence change, but you can also make an impact by speaking with other elected officials as well.

No matter who you reach out to and which mode of communication you choose, the goal is two-fold:

1. To clearly communicate your message or request.
2. To build a long-term relationship with the representative or staff member.

Face-to-Face Meetings

When you call or email a representative or other elected official's office to coordinate a meeting, be sure to mention your advocacy focus and why it's important to you. During the meeting be kind, respectful, and concise. Building strong relationships translates to effective advocacy. Tips for conducting effective meetings include:

- Creating a list of talking points that includes specific requests so your goals are clear.
- Providing follow-up information as requested, including supportive documentation that they can review at their leisure.
- Being persistent, but flexible and respectful. Legislators are more likely to respond to people who are kind than to those who are rude and demanding.
- Focusing on relationship building. Be consistent about sharing information and updates with your elected officials.
- Requesting a virtual meeting. With today's technology, important meetings don't require travel to Washington D.C., ask your representative's office if they can meet via Skype, Zoom, Teams, or other virtual platforms.
- Attending or planning an in-district meeting. These meetings create opportunities for elected officials to meet face-to-face with the people they represent.

Letters and Emails

If you're writing a letter or email, begin with a brief introduction of your cause and why it's important to you. State the issue, your concerns, and what actions the elected official can take to improve the lives of people living with disabilities. Tips for crafting effective letters include:

- Addressing your letter to a person. If it's a legislator's office, address your correspondence to the staff member whose role aligns with the issue you'd like to highlight.
- Being brief. Limit your letter or email to three or four paragraphs, about 500 words.
- Include your personal story, if you feel comfortable sharing. It's okay to use a template as a starting point but personalizing your letter or email often has greater impact.
- Expressing appreciation for past or future support.
- Following up your letter or email with a phone call to confirm receipt.

SAMPLE LETTER OR EMAIL:

Dear <elected official's name>:

My name is <your name> and I am from <your city, state>. I live with <name of disability>. This condition brings many challenges, including <brief description of a challenge or two>. I would like to speak with a member of your staff about my experiences and how we can <choose one: change policy/create new laws/develop a better support system> to help make life a little easier for people living with <name of disability>.

I am eager to meet with a member of your staff <choose one: by phone/in person/via teleconference>. You can reach me at <your phone number or email address>.

Thank you for the opportunity to share more information about <name of disability>.

Sincerely,

<Your name>

PHONE CALLS

Making a phone call to your legislator or other elected official is the quickest and easiest way to be heard. It's especially effective in the weeks before an important vote, since staffers tally the number of calls they receive for or against an issue. Tips for effective phone calls include:

- Introducing yourself and including your name and address to ensure you're recognized as a constituent.
- Keeping your call brief, quickly share your story and clearly state what you are asking the Senator or Representative to do (supporting an amendment, educating about a bill, etc.). Hone in on a single issue, including two or three key points to support your position.
- Leaving a polite and concise message and request a call back if you are transferred to voicemail.
- Documenting the name and contact information of the staff member who answered your call, so you can ask for them by name the next time you reach out.
- Thanking the staff member and legislator for their time and following up with a thank you note or email.

PHONE CALL SCRIPT:

Hello, my name is <your name>.

I live with <name of disability>. I would like to speak with a member of your staff about my experiences and interest in <choose one: changing policy/creating new laws/developing a better support system>. Can you please direct me to the person whose portfolio includes this type of issue?

When you reach the appropriate staff member, tell them your story and end with an ask.

VOICEMAIL SCRIPT:

Hello, my name is <your name>.

I live with <name of disability> and I'm calling to share my experiences with <name of disability> and interest in <choose one: changing policy/creating new laws/developing a better support system>. I would like to <choose one: speak with you/meet via teleconference> at your earliest convenience. Please contact me at <phone number>. Thank you in advance for the opportunity.

Engaging with Congressional Lawmakers

Taking time out of your schedule to speak before Congress is a powerful way to shine a light on issues the disability community faces. Take a step-by-step approach to coordinating your visit:

- **Do your research:** Before you reach out to your representative, research the key issues and current legislation and be clear about your "ask." Which legislative changes will make the most impact for people living with disabilities?

- **Be brief:** Once you've identified your request, prepare a clear and succinct statement outlining your key points and personal story.
- **Make contact:** Reach out to your local representatives to express your interest in speaking. A simple online search will yield email addresses, phone numbers, and even website forms that allow you to schedule a meeting.
- **Speak clearly:** Prepare your speech in advance and rehearse it several times before you're scheduled to appear. When you speak, be clear, confident, and concise, and include specific actions legislators can take to improve the lives of people living with disabilities.

NEED HELP?

The Reeve Foundation
Advocacy and Public Policy Team is Here for You

We provide assistance with many facets of outreach. Our team can assist you in determining who to reach out to, determining which method is best for your preferences, help you craft your story, and formulate an ask.

Contact us at Advocacy@Reeve.org.

https://www.christopherreeve.org/get-involved/advocate-for-change/

Resources

Congress Connect: https://contactingcongress.org

Congress.gov—Search for Active Bills: https://www.congress.gov

GovTrack.us—Track Bills for Updates and Get Alerts: https://www.govtrack.us

Town Hall Project: https://townhallproject-86312.firebaseapp.com

USA.gov—Find and Contact Elected Officials: https://www.usa.gov/elected-officials

Reeve Advocacy Resources

Raise Your Voice: Succeeding Through Self-Advocacy: https://blog.christopherreeve.org/en/raise-your-voice-succeeding-through-self-advocacy

Advocacy & Disability Rights: https://www.christopherreeve.org/wp-content/uploads/2023/10/Advocacy-Disability-Rights-5-23-A.pdf

Become a Self-Advocate: https://www.christopherreeve.org/wp-content/uploads/2024/04/Self-Advocacy-Trifold-Accessible.pdf

3 SHARING YOUR STORY

Sharing your personal experience living with disabilities, or caring for someone who is impacted by them, is one of the most powerful tools in advocacy.

No one understands the reality of a disability better than those who live with them. By sharing your experiences with policymakers, thought leaders, and change-makers, you can play a critical role in educating others and inspiring change.

Whether you're speaking to a member of Congress, legislators, or the public, your story has the potential to make a significant impact. Let's dive into some practical tips and strategies to help you share your story effectively.

Why Sharing Your Story Matters

Sharing your personal story humanizes political and policy issues. When you share your experience with spinal cord injury, muscular dystrophy, or other types of disability, you provide a real-life perspective that facts and figures can't convey.

Legislators and policymakers are better equipped to understand and support your cause when they hear firsthand how these conditions impact daily life. Your story can evoke empathy, raise awareness, and motivate others to act. It can also empower and uplift others in the disability community, proving their voices matter.

How to Effectively Share Your Story

From the dawn of time, humans related to one another through storytelling. Personal stories create a profound emotional connection, allowing others to see beyond the statistics and understand the real-life impact of disability. They inspire and motivate change by putting a human face on key problems, making them more relatable and urgent.

Whether communicating with congressional offices, sharing your story in a local forum, or posting on social media, talking about your experience living with a disability has the potential to create lasting change.

Through storytelling, you can convey the obstacles, triumphs, and everyday life with a disability fostering empathy and understanding. Sharing your story puts a human face on the issues that are important to the disability community, and it helps legislators understand how their actions and votes impact their constituents.

Where do you begin?

Questions to Help Shape Your Story

It can be complicated, nerve-wracking, and intimidating to put words to your experiences with a disability. Remembering the reason you're sharing—to foster change in the disability community—may help the words flow more freely.

You should never feel obligated to share your story, but if *how* to tell your story is holding you back, we have tips. One way to break through a mental block: Think of your story as a movie, novel, or comic book. Who are the main characters? What obstacles do they face? How do they overcome them? Then, ask yourself the following questions and use your responses as the basis for story creation.

1. **How has a disability impacted your life?** Does disability impact you, or are you caring for a loved one who experiences mobility challenges? In either case, describe the extent of the condition, when and how it began, and how it affects your daily life.
2. **What challenges have you faced?** Highlight specific obstacles you've encountered, including physical, emotional, social, and environmental.
3. **How have you adapted and overcome these obstacles?** Share the changes you've had to make in your daily life to overcome challenges. Focus on resources that have helped you along the way and how they have been vital to your ability to cope.
4. **What do you want change-makers to understand about living with a disability?** Focus on key messages you want to convey.
5. **What changes or support do you need from policymakers?** Be clear about what you're advocating for, whether it's better healthcare, increased research funding, or improved accessibility.

Tips for Molding and Shaping Your Story

The following strategies will help you craft an effective and engaging story.

1. **Keep It Brief:** Congressional meetings are brief. A concise story—a few minutes or less—is easier to remember and more impactful.
2. **Be Relatable:** Aim for a conversational tone, as if you are sharing your story with a friend. Use simple, everyday language and avoid jargon and acronyms.

3. **Highlight Key Points:** Focus on a few key aspects of your experience to ensure your audience remembers the most important points.
4. **Include a Call to Action:** Wrap up your story with a **call to action** that spells out what you're requesting, and be sure to thank the person for their attention. This leaves a lasting impression and inspires your audience to act.
5. **Rehearse:** Write down your story and practice telling it to friends or family members. The more you practice, the more confident you'll feel sharing your experience with strangers.
6. **Use Visuals:** If appropriate, use photos or other visuals to complement your story. Visuals can make your story more engaging and memorable.
7. **Stay Authentic:** Be genuine and honest. Authenticity resonates with people and makes your story more powerful.
8. **Tailor Your Story:** Adjust your story to fit your audience. When speaking to policymakers, focus on how they can help make a difference through legislation or funding.

How to Share Your Story with Legislators

Sharing your story is a powerful tool for educating legislators and ultimately influencing policy decisions. Here's how to best share your story with policymakers:

1. **Schedule a Meeting:** Reach out to your local representatives to set up a meeting. Be clear about the purpose of your meeting and the issues you want to discuss.
2. **Focus on Clarity:** During the meeting, keep your story brief and to the point. Focus on how your experience relates to the policy changes or funding you're seeking.
3. **Bring Supporting Materials:** Provide written materials, such as a one-page summary of your story, statistics, and information about issues affecting people with disabilities.
4. **Follow Up:** Send a thank-you email after the meeting, reiterating your key points and offering to provide additional information.
5. **Share on Multiple Platforms:** In addition to in-person and virtual meetings, you can share what it's like to live with a disability through letters, emails, and social media. Telling your story through an array of channels helps shine a light on issues that are important to the disability community.

How to Use Social Media to Share Your Story

Social media is a powerful platform for raising awareness about issues that face the disability community. Sharing your personal story through a variety of social media channels allows you to reach a broad audience, connect with others, and advocate for change.

Here's a how-to-guide to help you navigate social media for advocacy:

Choose the Right Platforms

Different social media platforms attract different audiences—and the content you share on one channel may not be as effective on another.

The most popular platforms:

- **Facebook:** Use Facebook for sharing detailed stories, longer posts, photos, and videos. It's also great for building community and joining groups.
- **X *(formerly known as Twitter)*:** Tweets should be brief, impactful, and provide quick updates. Use hashtags to reach a broader audience and retweet posts that are meaningful.
- **Instagram:** Instagram tells stories visually, so it's best for sharing photos and short videos.
- **LinkedIn:** LinkedIn attracts a professional audience. It's an ideal platform for sharing research articles and professional achievements and connecting with policymakers and organizations.
- **TikTok:** Use TikTok to creatively share your story and raise awareness in a fun, engaging way.
- **YouTube:** YouTube can be a powerful vehicle for storytelling. Create videos that showcase your experience and educate viewers about the obstacles facing people who have disabilities.

Create Your Social Media Story

Use these five strategies for effective social media engagement:

1. **Be Authentic:** Authenticity builds trust and engages your audience.
2. **Keep It Tight:** Social media audiences have short attention spans.
3. **Use Visuals:** Photos and videos are more engaging than text alone.

4. **Include a Call to Action:** Encourage your audience to act, whether it's sharing your post, participating in an event to raise awareness, or contacting their local representatives.
5. **Use Hashtags:** Hashtags such as #SpinalCordInjury, #SCIAdvocacy, #ParalysisResearch, #DisabilityRights, #DisabledAndProud, and #DisabilityAwareness can help your posts reach a wider audience.

Decide What to Share

While you can share almost anything on social media, it's important to strike a balance between engaging your readership and burning them out. *Posts worth sharing include:*

1. **Personal Stories**: Share your journey, highlighting specific challenges and triumphs. Show how a disability has affected your life and what you've learned.
2. **Research and Advocacy**: Post about the latest research and advancements affecting people in the disability community. Highlight why funding and support are crucial.
3. **Community and Events**: Share information about community events, fundraisers, and support groups, and encourage others to get involved.
4. **Daily Life**: Show snippets of your daily life to humanize the experience and break down misconceptions about living with a disability.

Advocate Effectively

Effective social media advocacy isn't a once-and-done proposition. *Consider these tips to amplify your messages:*

1. **Engage with Your Audience**: Respond to comments, thank people for their support, and create a dialogue.
2. **Collaborate**: Partner with organizations, influencers, and other advocates to reach a broader audience.
3. **Monitor and Adapt**: If your goal is to enhance engagement and gain more followers, pay attention to which types of posts get the most engagement and adapt your strategy accordingly. Use analytics tools to track your performance.
4. **Stay Informed**: Keep up with the latest research, news, and advocacy efforts. Share relevant updates with your audience to keep them informed and engaged.

4 FUNDING CAREGIVING SOLUTIONS FOR THE DISABILITY COMMUNITY

Caregivers are the unsung heroes of the disability community. They work tirelessly to provide essential support to people who are impacted by paralysis or other disabilities. For the millions of individuals who have disabilities, caregiving is more than just a role—it's a lifeline. In this chapter, we'll explore the importance of caregivers, the challenges they face, and how we can advocate for the funding and resources they need.

The Importance of Caregivers in the Disability Community

Caregivers play a critical role in the lives of people with disabilities across the lifespan, offering physical, emotional, and practical support. They assist with activities of daily living (ADLs), manage medical care, and often serve as advocates. Without caregivers, many people with disabilities would struggle to maintain their independence and quality of life. Recognizing and supporting caregivers is not just an act of compassion—it's a necessary investment in the health and well-being of our communities.

Who Are Caregivers?

Caregivers can be family members, friends, or professional aides. No matter what their formal title, these individuals provide ongoing support to people with disabilities. Types of caregivers include:

1. **Professional Caregivers**: Trained to provide care as part of their profession, these caregivers or aides, work in private homes, assisted living facilities, and hospitals. They may be home health aides, nursing assistants, or personal care attendants (PCAs). They are in high demand due to workforce shortages.
2. **Family Caregivers**: The loved ones of people with disabilities shoulder most of the care. They are family members and relatives who provide typically unpaid support, often juggling caregiving with other responsibilities such as work and parenting.
3. **Informal Caregivers**: Friends, neighbors, community members, and volunteers may step in to offer help when needed. They might not see themselves as caregivers, but their support helps meet the needs of many people with disabilities.

What Makes You a Caregiver?

You're a caregiver if you provide assistance to someone who cannot fully care for themselves. This might include:

- Helping with daily activities such as bathing, dressing, or eating.
- Managing medications and medical appointments.
- Providing emotional support and companionship.
- Coordinating with healthcare providers and navigating complex medical systems.
- Advocating for the needs and rights of a person with a disability.

If you find yourself taking on these responsibilities, even occasionally, **you are a caregiver**. Recognizing this role is the first step in accessing the support and resources you deserve.

The Role of Family Caregivers

Family caregivers are the backbone of caregiving in the disability community. They often provide around-the-clock care, balancing this with work, family, and other commitments.

If compensated, this work would be valued at **$522 billion annually.** However, because this care is typically unpaid, families experience tremendous economic and emotional strain.

The Realities of Caregiver Burnout

Caregiving is incredibly rewarding, but it can also be incredibly taxing. Many caregivers experience burnout—emotional, physical, and mental exhaustion that results from the constant demands of caregiving.

This isn't just a personal issue; it's a public health crisis.

Why Caregiver Burnout Is a Policy Issue

Caregiver burnout affects the health of caregivers and the quality of care they can provide. When caregivers are overwhelmed, it can lead to increased stress, health problems, and even the inability to continue providing care. This, in turn, places a greater burden on healthcare systems and can lead to higher costs for both families and society.

Addressing caregiver burnout is essential, not just for the well-being of caregivers but for the sustainability of care within our communities. Caregiver burnout leads to high caregiver turnover and a lack of independence and autonomy for those relying on care. In some cases, caregiver burnout can lead to people who need care being forced into institutional settings, which is in direct contrast to policies created to support individuals who need care.

Resources for Caregivers

Caregiving is rarely a choice. Instead, it's a role caregivers take on in response to events and circumstances beyond their control. While caregiving is rewarding, it can also be draining. Caregivers experience higher rates of depression and anxiety than the general population, and they often struggle with feelings of isolation.

Without proper support, caregivers risk experiencing physical, emotional, and mental exhaustion, which not only affects their well-being but also impacts the quality of care they provide.

These five strategies can help ensure you're not only able to effectively support your loved one, but also create the time and space to maintain your own identity:

1. **Prioritize Self-Care.** When you prioritize your own physical, mental, and emotional needs, you'll be better equipped to care for your loved one. Follow a healthy lifestyle, schedule necessary medical and dental check-ups, and make time for activities that recharge your spirit, whether reading a book or meeting a friend for a walk.
2. **Connect with Other Caregivers:** Building a support network with other caregivers, whether through one-on-one mentoring or in support group settings, can alleviate feelings of isolation. National and regional nonprofit organizations, such as the Caregiver Action Network and the National Paralysis Resource Center (NPRC), can help you identify nearby programs and online support groups.
3. **Take Advantage of Respite Care Services:** These programs offer short-term care options, providing temporary relief to family caregivers. To

locate your state's respite care services, search the ARCH National Respite Network and National Respite Locator Service. Home & Community Based Services (HCBS) through Medicaid may help uncover other caregiving options and allow your loved one more independence.

4. **Counseling and Therapy:** Professional support can help caregivers manage stress and avoid burnout. Skilled therapists can help caregivers manage complicated feelings, including anger, frustration, guilt, and loss.

5. **Financial Assistance Programs:** A variety of public and private programs offer financial support to help offset the costs associated with caregiving. Whether you have private insurance, Medicaid, or Medicare, study the policy and statements of benefits to understand which services you qualify for. Services such as home health aides or Home & Community Based Services (HCBS) can allow you to have outside caregivers come in to lp the individual you're caring for.

THE REEVE FOUNDATION'S PEER & FAMILY SUPPORT PROGRAM (PFSP)

The Reeve Foundation recognizes the importance of providing caregivers with support. They also know that the best source of knowledge comes from people who have experience.

If you or a family member is living with a disability, learning to navigate the changing world for both of you can be overwhelming. The Christopher & Dana Reeve Foundation's Peer & Family Support Program connects people living with paralysis and their caregivers with peer mentors who can help them find a pathway forward.

Available across the country, our free peer-to-peer network helps everyone, from newly paralyzed individuals and their family members to people who have lived with paralysis for decades, by offering the personalized information and resources you need to live a fulfilling life. To learn more, and discover how you, too, can receive a Peer Mentor, please visit https://www.christopherreeve.org/todays-care/get-support/get-a-peer-mentor/pfsp-overview.

Legislation Supporting Caregivers

In recent years, there has been progress in recognizing and addressing the caregiver crisis. Some efforts include:

- **The RAISE Family Caregivers Act:** This law established the RAISE Family Caregiving Advisory Council, which developed a National Strategy to Support Family Caregivers (*https://acl.gov/programs/support-caregivers/raise-family-caregiving-advisory-council*). The council brings together stakeholders from across the country to identify and implement solutions that address the needs of caregivers.

- **The National Family Caregiver Support Program:** Provides funding to states to offer support services, including respite care, counseling, and training for family caregivers.
- **The Achieving a Better Life Experience (ABLE) Act:** A federal law that allows eligible people with disabilities to open tax-free savings accounts. Funds from the account may be used for disability-related expenses, such as education, housing, transportation and certain personal support services.

What Advocates Can Ask of Congress

Caregivers are essential to the disability community, providing vital support that allows individuals to live with dignity and independence. But caregivers also need support—both from their communities and policymakers.

Advocates play a crucial role in pushing for policies that support caregivers. Here are some actionable steps you can take:

1. **Prioritize and Adequately Fund Caregiver Solutions:** Advocate for increased funding for caregiver support programs, including respite care, mental health services, and financial assistance.
2. **Host a Town Hall:** Encourage your local representatives to host a town hall meeting focused on caregiving issues. This provides a platform for caregivers to share their experiences and advocate for change.
3. **Support Comprehensive Paid Family Leave:** Advocate for legislation that offers paid family leave, allowing caregivers to take time off work without financial hardship.
4. **Raise Awareness:** Use social media, community events, and other platforms to raise awareness about the caregiver crisis and the need for policy solutions.
5. **Collaborate with Organizations:** Partner with advocacy organizations such as the Christopher & Dana Reeve Foundation to amplify your voice and support legislative change.

By advocating for funding and resources, we can ensure that caregivers have the tools they need to continue their critical work. Together, we can build a society that values and supports its caregivers, recognizing their contributions, championing their successes, and alleviating their burdens so they can focus on what's important: building a life of meaning and purpose.

DANA REEVE: A CHAMPION FOR CAREGIVERS

Dana Reeve, wife of the late actor and advocate Christopher Reeve, was a powerful voice for caregivers. After her husband's spinal cord injury, Dana took on the role of primary caregiver, managing his complex medical needs while also raising a young family. She understood firsthand the challenges that caregivers face and used her platform to advocate for better support and resources.

Dana's work extended beyond her own experience. She became a leading voice in the fight for caregiver rights. Her legacy is a testament to the strength and resilience of caregivers—and a reminder of the importance of advocating for their needs.

"Being an effective caregiver means gaining some sense of control over the situation. One way this is done is through information, and by sharing experiences or solving problems with other caregivers. Please know that you are not alone, that you are extremely valuable, and that you and your family can lead active, fulfilling lives despite the challenges of paralysis."

– Dana Reeve (written in 2005)

Resources

AARP Care for America's Caregivers:
https://www.aarp.org/politics-society/advocacy/caregiving-advocacy
ACL 2022 National Strategy to Support Family Caregivers:
https://acl.gov/CaregiverStrategy
ARCH National Respite Network: *https://archrespite.org*
Caregiver Action Network: *https://www.caregiveraction.org*
Christopher & Dana Reeve Foundation Paralysis Resource Center:
https://www.christopherreeve.org/todays-care/paralysis-help-overview/about-the-paralysis-resource-center
Family Caregiver Alliance: *https://www.caregiver.org*
Lotsa Helping Hands (coordinating caregiver support):
https://lotsahelpinghands.com
Medicaid: *https://www.medicaid.gov/medicaid/home-community-based-services/index.html*
National Academy for State Health Policy: RAISE Act State Policy Roadmap for Family Caregivers:
https://nashp.org/raise-act-state-policy-roadmap-for-family-caregivers
Well Spouse Association (supporting spousal caregivers):
https://wellspouse.org

5 IMPROVING AIR TRAVEL FOR PASSENGERS WITH DISABILITIES

Air travel makes it possible to carry out important business, stay connected to loved ones, and enjoy grand adventures. But for the 25.5 million Americans with travel-limiting disabilities, navigating airports and airplanes often comes with challenges. In this chapter, we'll cover air travel barriers facing the disability community, policies that aim to improve accessibility, and how advocates can help enhance these efforts.

Barriers to Travel for People with Disabilities and Mobility Challenges

The compact layout of today's airplanes presents several barriers for the disability community, including:

- Injuries due to errors that occur when transferring from wheelchairs to assigned seats.
- Inability to safely access or use airplane bathrooms.
- Difficulty accessing medications, supplies, or food in luggage stowed in overhead bins.
- Discomfort from sitting in a standard airplane seat not attuned to one's specific physical support needs.

Some people experience problems before they even board the plane, such as:

- Large airports that require passengers to cover great distances to reach their gates.
- Challenges requesting accommodations in advance (such as seats with movable armrests), or airlines not being able to fulfill them.
- Security screenings that may require a physical pat-down, which can be uncomfortable and take longer than simply passing through a scanner.

Upon arriving at their destination, some people with disabilities must contend with additional issues, such as:

- Lost or broken wheelchairs or mobility aids.
- Missing mobility aid parts, such as wheelchair seat cushions.

- Delays with deplaning assistance that raise the risk of missing a connecting flight.
- Injuries experienced during transfer from wheelchairs to assigned seating and then back to wheelchairs from assigned seats.

These are not the travel experiences legislators intended. In fact, many policies are in place to protect the rights of the disability community when traveling by air—and additional policies are under consideration. Read on to learn more about them and how to use your experiences to push for improvements.

Regina's Story

No one is free from the challenges of flying with a disability. Not even the leader of a national advocacy organization for people with disabilities.

Regina Blye is the Chief Program and Policy Officer for the National Paralysis Resource Center (NPRC) at the Christopher & Dana Reeve Foundation. After sustaining a C6-C7 spinal cord injury at age 10, she has been living with paralysis and is a power wheelchair user.

Regina has endured several traumatic, painful, and undignified air travel experiences, prompting her to take up her concerns with the Department of Transportation (DOT). In 2024, she submitted a **public comment** (*https://publiccommentproject.org/how-it-works*) urging policymakers to take further measures to improve air travel for people with disabilities who use wheelchairs.

Regina has proposed the following measures supporting more inclusive and accessible air travel:

- Providing additional air carrier staff training to include techniques for safely lifting and assisting passengers with diverse body types, including those who experience spasticity.
- Prohibiting air carriers from requiring a passenger's companion to assist with transfers, lifting, or securing aisle chairs.
- Improving the deplaning process by ensuring prompt retrieval and return of mobility devices.
- Establishing clear legal pathways for passengers with disabilities to seek compensation for physical injuries and emotional distress.

Advocating for Better Accessibility in Airports and Airplanes

There are many policies dedicated to making it easier for people in the disability community to travel by air.

Current policies include:

Laws supporting equitable air travel for people with disabilities were first passed in 1986. Since then, lawmakers have created additional policies to expand the disability community's rights and protections.

Current policies include:

- **Air Carriers Access Act (ACAA)** guarantees all domestic and foreign airlines servicing the U.S. provide people with disabilities consistent and non-discriminatory treatment. It mandates the opportunity to preboard, availability of timely boarding and deplaning assistance, proper storage of assistive devices, and access to seating accommodations.
- **Airline Passengers with Disabilities Bill of Rights**, developed by the U.S. Department of Transportation, outlines fundamental rights created under ACAA, such as being treated with dignity and respect, receiving assistance, getting resolution of grievances, and more.
- **Federal Aviation Administration (FAA) Reauthorization Act of 2024** improves safety protocols and protections for people with disabilities who travel by air. Provisions include new training standards for airport personnel who provide assistance, better airplane evacuation procedures, safe transport of powered wheelchairs, and more efficient complaint-handling processes.

FAA Reauthorization takes place every five years. One topic under review for the next reauthorization (2029) is a pathway for determining whether passengers can safely remain in their wheelchairs during commercial flights.

Types of Assistance Available to People with Disabilities

Today's policies lay the foundation for more equitable air travel for people with disabilities by mandating:

Assistance at Airports

Airlines are required to provide assistance from the moment you arrive at the curbside area of the departing airport until you reach the outdoor passenger pick-up area of your destination. This includes ticket counters, concourses, terminals, boarding areas, and baggage claim.

Transportation for Service Animals

Airlines must transport service animals to, from, and within the U.S. Animals must be trained to perform specific tasks that aid people with disabilities. Passengers must carry documentation (attestation) verifying their animal meets health, behavior, and training requirements. It's important to note that airlines are only required to recognize dogs as service animals.

Seating Assignment Accommodations

Airlines should provide accommodations that ensure safe, accessible travel, including:

- Movable armrests for aisle seats
- Bulkhead seat assignments, when needed
- An adjoining seat for caregivers and personal care attendants
- Other accommodations that provide adequate personal space.

Transport of Assistive Devices

Devices include wheelchairs, walkers, hearing aids, portable oxygen concentrators, and more. Certain aids can be stowed in the cabin for easy access during your flight. Airlines are responsible for safely transporting larger devices in the aircraft's cargo area and returning them to you promptly upon arrival.

Passenger Feedback on Current Policies

Air Carrier Access Act (ACAA) and other policies have significantly improved air travel experiences for the disability community. However, research shows room for improvement.

A survey (*https://pva.org/wp-content/uploads/2022/09/2022-ACAA-Survey-Results-FINAL.pdf*) of more than 1,200 individuals conducted by the Paralyzed Veterans of America between October 4 and December 6, 2021, revealed that the disability community is still experiencing significant air travel challenges. Respondents were living with some type of mobility challenge. However, some questions did not apply to all respondents.

Survey highlights include:

- **92 percent** of people need accommodations but have difficulty submitting their requests when booking online.
- **67 percent** of passengers wait 15 minutes or more for help upon arrival at their destination, which may increase the likelihood of missing a connecting flight.
- **32 percent** of passengers needing assistance navigating an airport regularly encounter resistance.

- **70 percent** of those who travel with a wheelchair or scooter reported damage to the device.
- **37 percent** of individuals who use service animals experience challenges with new attestation forms.

Proposed Policies

Proposed policies are strengthening protections for air travelers with disabilities by:

- Making airplanes more accessible.
- Ensuring the safety of people with disabilities and mobility issues.
- Minimizing damage to wheelchairs and other mobility aids.
- Holding airlines accountable for achieving accessibility standards.
- Giving the disability community a voice as it relates to air travel accommodations.

How to Share Your Air Travel Story with Congress

It's important to inform lawmakers about your experiences so they can determine whether regulations are working as intended. When they're not, being able to cite examples from your personal experiences helps lawmakers prioritize and implement changes to existing policies.

A few ways you can share your air travel story:

Face-to-Face Meetings

Telling your story to a congressmember or their staff helps them understand how air travel policies impact the disability community. You may wish to have an in-person or virtual meeting to share your experience and make a specific ask. Whether it's support or opposition of a current bill, or input on proposed changes, representatives from Congress want to hear from the people they represent.

Phone Calls or Emails

These are some of the easiest ways to share stories about air travel in the disability community. The most effective communications are brief, actionable, and express appreciation for past or future support. Chapter 2 provides templates to help you get started.

Want to learn more about sharing your story?

Chapter 3 provides prompts, tips, and everything you need to know about effectively telling your story to legislators, on social media, and in everyday life.

Need Help?
The Christopher & Dana ReeveFoundation Advocacy and Public Policy Team Is Here for You

We provide assistance with many facets of advocacy outreach. Our team can assist you in determining who to reach out to, which method is best for your preferences, help you craft your story, and formulate an ask. Contact us at Advocacy@Reeve.org.

Social Media

Use whichever platform you are comfortable with—Facebook, Instagram, X (formerly known as Twitter), TikTok, YouTube, or LinkedIn. In addition to written stories, sharing images and videos with members of Congress can help shed light on real-life experiences with air travel policies. Don't forget to use hashtags such as #AccessibleAirTravel, #Flightmares, #WheelchairTravel, and #FlyInclusive.

Watch Air Travel Advocacy in Action

Learn more about how people's air travel experiences have paved the way toward new legislation and the need to continue pushing for reforms that make travel easier for the disability community. Visit www.MDA.org/AirTravel.

Tips for Navigating Air Travel with a Disability or Mobility Issue

Are you planning to travel by air? These tips can help you have a smoother, safer, and more comfortable experience:

- **Get help:** Talk to a travel agent or disability advocate for information about your destination, getting there, and how best to navigate the airports you'll travel through.
- **Speak up:** Although airline personnel may have received training providing the type of assistance you need, if a task needs to be performed in a specific way, let them know. Provide as much guidance as you feel is necessary to assure your safety.

- **Streamline security:** TSA Cares provides information to help passengers with disabilities prepare for the security screening process. You can also request on-site assistance at airport security checkpoints. Contact TSA Cares by calling 855-787-2227 or visiting *https://www.tsa.gov/contact-center/form/cares/*.
- **Take essential mobility aid parts on board:** Remove controls, cushions, headrests, power cords, and other detachable parts of your wheelchair or scooter before they are put in the cargo hold.
- **Escalate a concern:** If an issue occurs while you are in transit and on-site staff cannot assist you, contact the airline's Complaint Resolution Official. They are experts on disability-related airline travel matters and every airline has one.

If you feel the airline did not resolve the issue to your satisfaction, you may want to file a complaint with the U.S. Department of Transportation (DOT).

*The DOT has a hotline you can call Monday-Friday from 9 am – 5 pm ET at **1-800-778-4838**. Grievances can also be made online at https://secure.dot.gov/air-travel-complaint.*

Resources

MDA Advocacy Institute—FAA Reauthorization Passes (YouTube video): *https://www.youtube.com/watch?v=nVhF_QDSN70*

MDA Quest Media—FAA Reauthorization is Law: Major Victory for Accessible Air Travel: *https://mdaquest.org/faa-reauthorization-is-law-major-victory-for-accessible-air-travel/*

Navigating the Friendly Skies: A Guide to Air Travel with a Disability: *https://unitedspinal.org/pdf/NavigatingTheSkies.pdf*

Overview of ACAA Survey Results Regarding the Air Travel Experience of Passengers with Disabilities: https://blog.christopherreeve.org/hubfs/reeve-assets-production/2022-ACAA-Survey-Results-FINAL.pdf?hsLang=en

Public Comment Project—How Public Comment Works: https://publiccommentproject.org/how-it-works

Transportation Security Administration (TSA)—Disabilities and Medical Conditions: https://www.tsa.gov/travel/tsa-cares/disabilities-and-medical-conditions

U.S. Department of Transportation—Aviation Consumer Protection—What to Do If You Have a Problem: https://www.transportation.gov/individuals/aviation-consumer-protection/what-do-if-you-have-problem

U.S. Department of Transportation Air Passengers with Disabilities Bill of Rights: https://www.transportation.gov/sites/dot.gov/files/2022-07/508_Airline_Passengers_with_Disabilities_Bill_of_Rights_07132022_ADA.pdf

Reeve Air Travel Resources

Webcast: Air Travel for Wheelchair Users: https://www.christopherreeve.org/todays-care/living-with-paralysis/lifestyle/accessible-air-travel/

Paralysis Resource Center Fact Sheet-Travel: https://www.christopherreeve.org/wp-content/uploads/2023/10/Travel-QA-7-22-A.pdf

Top Travel Tips: https://www.christopherreeve.org/todays-care/living-with-paralysis/lifestyle/top-14-travel-tips/

6 KNOWING YOUR RIGHTS

If you're living with a disability, empowering yourself with information about the rights and protections available to you not only helps safeguard your independence, but it also enables you to advocate for change.

This chapter covers key laws and programs designed to help members of the disability community. We'll break them down into easy-to-understand terms and provide actionable steps so you can make the most of the resources available to you.

The Americans with Disabilities Act (ADA)

Why It Matters

Enacted in 1990, the ADA is a landmark civil rights law that protects the rights of people with disabilities across all areas of public life. The ADA ensures people with mobility challenges have the same rights and opportunities as everyone else, including:

- **Access to Public Services:** Sidewalks, parks, buildings, and public transportation services must be accessible to everyone, regardless of their level of mobility.
- **Workplace Protections:** Employers must provide reasonable accommodations, assuming they're able to meet them without "undue burden," including wheelchair access, flexible hours, and comfortable workspaces, to all qualified applicants and employees.
    - For the appropriate Equal Employment Opportunity Commission field office in your geographic area, contact: 800-669-4000 (voice), 800-669-6820 (TTY), 844-234-5122 (VP), or *www.eeoc.gov*.
- **Equal Access:** All businesses, including restaurants, theaters, shopping malls, and grocery stores, must be accessible to people with disabilities. Some businesses, such as historical buildings and landmarks, may not be subject to the same requirements.

The ADA also prohibits any person or entity from coercing, threatening, or retaliating against people with disabilities who are asserting their ADA-given rights.

Examples of ADA violations include:

- Inaccessible restrooms.
- Lack of handrails.
- Walkways that cannot accommodate wheelchairs.
- Insufficient accessible parking.
- Inoperable elevator and escalator systems.
- Workplace discrimination.

*It's important to note spaces must meet specific guidelines to comply with ADA regulations, but that doesn't mean they must be accessible to everyone. A restroom, for example, may not be accessible based on your specific needs, but still be ADA compliant.

What to Do

- **Request Accommodations:** Don't be afraid to speak up if you need accommodations at school or work. Submit a request to the organization's disability office (or the diversity, equity and inclusion administrator) outlining your needs, including detailed solutions. Depending on the organization, you may simply communicate your requests to your direct supervisor.
- **Note Barriers:** If you come across inaccessible public spaces, take note of the specifics, including date, time, and location.
- **Express Your Concerns:** Talk with the business owner about the noted barrier and how it can be resolved.
- **Report Violations:** If you encounter an entity or business that is violating ADA regulations, file a complaint with the U.S. Department of Justice at *www.civilrights.justice.gov/report* or by phone at 800-514-0301.

Section 504 of the Rehabilitation Act

Why It Matters

Passed in 1973, Section 504 protects individuals with disabilities from being excluded from or denied the benefits of any program or activity that receives federal funding. If you rely on federally funded programs and activities, Section 504 ensures you have equal opportunity and access to the following services:

- **Education:** Schools, colleges, and universities that receive government funds must make programs accessible to students with disabilities.
- **Health and Nutrition Services:** Providers of health insurance, nutrition assistance, and home-based care and support must ensure programming is accessible to the disability community.
- **Public Programs:** Public housing, libraries, and transportation systems must ensure seamless access to people with disabilities.

What to Do

- **Request Accommodations:** If you come across a government-funded program that does not provide equal access to services, you can request necessary adjustments under this law.
- **Partner with Advocates:** If you're a student, work with your school's disability services to ensure you receive appropriate accommodations. A growing number of schools have student disability organizations on campus, which can be a great resource for the student disability community.

Social Security Disability Insurance (SSDI)

Why It Matters

If a disability or mobility issue prevents you from working, SSDI provides a safety net, but only if you've already paid into the system.

- **Eligibility:** To qualify for SSDI, you must have a documented disability and sufficient funds paid into Social Security through your employment history.
- **Benefits:** Once you're approved for SSDI benefits, you'll receive monthly financial assistance. After two years on SSDI, you automatically qualify for Medicare.

What to Do

- **Start Early:** It can take a long time to get approved for SSDI, so it's important to apply for benefits as soon as you know you become eligible.
- **Start Record-Keeping:** Keep detailed medical records that document your disability. You'll need easy access to this information when you apply for benefits.

Supplemental Security Income (SSI)

Why It Matters

SSI provides supplemental monthly income to people with disabilities who have limited income and resources, even if they have not worked or paid into Social Security as part of their work history.

- **Eligibility:** SSI is based on financial need, not prior work history. It's designed to cover the basics, including food, housing, and transportation. Efforts to reform and modernize eligibility requirements for programs such as SSI are a key focus on the advocacy agendas of many disability organizations.
- **Health Coverage:** Most people who qualify for SSI are also eligible to receive Medicaid, which covers approved medical expenses.

What to Do

- **Check Eligibility:** If you have limited resources, check with your local Social Security office to see if you qualify for benefits (each state has different eligibility criteria).
- **Gather Information:** Collect the necessary financial documents and medical records to apply for SSI.

You may apply for SSDI or SSI at any Social Security office. If you have one or more children with a disability, you may also apply for SSI on their behalf. For more information, visit *https://www.ssa.gov/benefits/disability/qualify.html*.

Medicare and Medicaid

Why It Matters

Healthcare considerations are priority number one for many people who have disabilities. Both Medicare and Medicaid provide essential healthcare coverage.

- **Medicare:** Medicare may be best known for providing healthcare coverage to people who are 65 and older, but it also covers younger people who qualify through SSDI. Benefits include coverage for hospital stays, certain types of medical equipment, prescription medications, and outpatient care.
- **Medicaid:** Medicaid is a joint federal and state program that provides medical care to people who have limited income and disabilities. The program covers an array of services, including long-term care, home health services, certain types of medical equipment, and rehabilitative therapies. In certain cases, Medicaid waivers can help individuals with disabilities access additional services. Check with your local Medicaid office to see if you qualify.

What to Do

- **Check Your Status:** Apply for SSDI as soon as you become eligible. After two years in the program, make sure to enroll in Medicare.
- **Apply for Coverage:** If you have limited income, apply for Medicaid to help with medical costs not covered by other insurance. You should automatically qualify if you're on SSI.

Veterans Affairs Assistance for Veterans with Disabilities

Why It Matters

If you're a veteran with a service-related disability, the VA provides a variety of services designed to support you, including:

- **VA Disability Compensation:** A tax-free payment made to veterans with at least a 10% disability rating due to military service.
- **Veteran Readiness and Employment (VR&E):** This program offers training, education, and career counseling to veterans with disabilities. Veterans may also get help with starting their own businesses or accessing services for independent living if they are unable to work

traditional jobs.

- **VA Health Care:** Veterans with disabilities qualify for comprehensive healthcare, including mental health services, rehabilitative therapies, long-term care, and prosthetics.

What to Do

- **Reach Out for Help:** Contact your local VA office to better understand your benefits and protections.
- **Take Advantage of Available Resources:** Apply for VA Disability Compensation, access VA healthcare services for specialized care, rehabilitative therapies, support, and reach out for employment-related assistance.
- **Report a Violation:** If a business or entity is violating your rights as a veteran or service member, reach out to your local VA for assistance. You can also contact the U.S. Department of Justice (*https://www.justice.gov/servicemembers/how-we-can-help*) if you don't receive a resolution.

Christopher & Dana Reeve Foundation's Military & Veterans Program

The Reeve Foundation's Military & Veterans Program (MVP) supports the unique needs of all military service members—regardless of when you served or how your injury was obtained. With a wide array of information and expertise, MVP specialists can help devise a personalized plan to get you back into your community and a place of well-being. We're here to help you connect to the information and resources you need. Please contact us today at military@ChristopherReeve.org or 1-866-962-8387.

https://ChristopherReeve.org/MVP

Affordable Care Act (ACA) *https://www.healthcare.gov*

Why It Matters

Passed into law in 2010, ACA expanded healthcare access for millions of Americans, including people with disabilities and mobility issues. Key provisions include:

- **Pre-Existing Conditions:** Health insurance companies cannot deny coverage, or charge you more, because of a pre-existing condition, such as spinal cord injury or muscular dystrophy.

- **Essential Health Benefits:** The ACA mandates coverage for critical healthcare benefits, including rehabilitation, mental health services, prescription drugs, chronic disease management, and preventive care without annual or lifetime coverage limits.
- **Expanded Coverage for Young Adults:** Young adults can remain on their parents' insurance plan until age 26, which benefits young people with disabilities transitioning to independence.

What to Do

- **Explore Available Policies:** If you're not covered under SSDI or Medicaid, contact a social worker or other support professional to determine whether you qualify for other programs. Consider reaching out to your local Aging and Disability Resource Center (ADRC) or Center for Independent Living (CIL). Disability advocacy groups may also be able to direct you to relevant resources.
- **Check Your Benefits:** Monitor what your selected plan covers, and make sure that you are receiving your allotted benefits. If you receive a bill, call the provider or your health insurer to verify accuracy, and ensure you're not being charged for services that should be covered.
- **Take Action:** If you discover that your health plan has limited or denied coverage for a covered service, submit an appeal to your insurance provider. You may also file grievances for general concerns, such as excessive wait times for a scheduled appointment.
- **Escalate Your Concern:** If your health plan does not provide timely resolution of a grievance or appeal, you still have options. Contact your state Department of Health or local legislator.

If you want to learn more about available programs and benefits near you, please reach out to our team of highly trained Information Specialists who are available to answer your questions in 170 languages. They will ensure you have access to the correct resources and information.

Christopher & Dana Reeve Foundation Information Specialists:

Toll-free 1-800-539-7309
https://www.ChristopherReeve.org/Ask
infospecialist@ChristopherReeve.org

Why Knowing Your Rights Matters

Knowing which services and programs are available—and how to access them—can empower you to advocate for yourself and others who face mobility issues and other disabilities. Whether you're navigating healthcare, seeking employment, or needing accessible public services, these laws exist to protect you.

How to Advocate for Yourself

- **Speak Up:** If you encounter barriers—physical access, discrimination, or lack of needed services—you have the right and responsibility to advocate for yourself and others in the disability community.
- **Get Connected:** Many organizations, including the Christopher & Dana Reeve Foundation, are dedicated to helping people with disabilities advocate for themselves. Working with these organizations can help maximize your impact.
- **Stay Informed:** Laws and policies change over time, so stay informed about your rights by subscribing to advocacy newsletters and following legal aid organizations, and government resources.

SHERI DENKENSOHN-TROTT, JD

CO-FOUNDER, HAPPY ON WHEELS, LLC

When Sheri Denkensohn-Trott was 16 years old, a car accident left her paralyzed. As the youngest—and only female—patient at Burke Rehab Center in White Plains, New York, Sheri quickly noticed the lack of support for women in her situation.

The men in the unit went to 'life class,' where they learned about relationships, social skills, and more, but there was no support for her. This gap in resources fueled Sheri's passion for advocacy. A lawyer and fierce advocate, she identifies one of the biggest challenges for the disability community: access to qualified caregivers.

With the push for people with disabilities to enter the workforce, fewer will qualify for Medicaid. That means paying out of pocket for care, which isn't sustainable for most people with disability.

Sheri is on the frontlines advocating for policies that impact the lives of people with disabilities. From ensuring women with disabilities have access to mammograms and high-quality medical care to encouraging friends and family members to report ADA violations, her efforts are creating lasting change for people with disabilities.

"With advocacy, it takes a village," she said. Her dedication proves the power of the collective can make a difference.

By knowing your rights and taking action, you become not just an advocate for yourself, but a voice for others in the disability community. Together, we can ensure these laws continue to evolve and improve, providing the support we all deserve.

Need Help?

The Reeve Foundation Advocacy and Public Policy Team provides assistance with understanding your rights and advocating for yourself. We can assist you in determining who to reach out to, which method will best achieve your objective, and how to get results. Contact us at Advocacy@Reeve.org.

https://www.christopherreeve.org/get-involved/advocate-for-change/

Resources

HealthCare.gov—The Affordable Care Act:
https://www.healthcare.gov/glossary/affordable-care-act

Medicare.gov—Medicaid:
https://www.medicare.gov/basics/costs/help/medicaid

Medicare.gov—Medicare:
https://www.medicare.gov

Social Security Administration Medicare.gov—Social Security Disability Insurance (SSDI):
https://www.ssa.gov/disability

Supplemental Security Income (SSI):
https://www.ssa.gov/ssi

U.S. Department of Health & Human Services—Section 504 of the Rehabilitation Act:
https://www.hhs.gov/sites/default/files/ocr/civilrights/resources/factsheets/504.pdf

U.S. Department of Justice—Americans with Disabilities Act (ADA):
https://www.ada.gov
U.S. Department of Justice—How to Report a Violation:
www.civilrights.justice.gov/report

U.S. Department of Labor—Resources for Veterans:
https://www.dol.gov/agencies/ofccp/veterans/resources

Reeve Resources

Accessible Medical Healthcare: https://www.christopherreeve.org/get-involved/advocate-for-change/advocacy-issue-civil-rights/accessible-medical-healthcare

Medicare, Medicaid and Other Insurance: https://www.christopherreeve.org/wp-content/uploads/2024/01/Medicare-Medicaid-and-Insurance-1-24-A.pdf

Insurance Appeals: https://www.christopherreeve.org/wp-content/uploads/2024/01/Insurance-Appeals-1-24-A.pdf

7 IMPROVING AFFORDABLE, ACCESSIBLE HOUSING FOR THE DISABILITY COMMUNITY

Everyone deserves safe and affordable housing, but for people with disabilities, finding and retaining a suitable place to live can be a challenge. This chapter explores those challenges and highlights the steps advocates are taking to make housing more accessible and affordable. You'll also learn how to get involved and help drive change.

Current State of Affordable Housing for the Disability Community

If you are living with a disability, securing long-term affordable housing isn't always easy. Financial constraints, homes lacking accessible accommodations, even outright discrimination can create major roadblocks. Add policy shortcomings and lack of oversight to the mix, and safe, comfortable housing remains out of reach for many people.

Why Affordable and Accessible Housing Matters

Affordable, accessible housing provides more than just a roof over your head. For people with disabilities, housing security fosters positive changes that lead to a better quality of life.

Long-term housing security:

- **Promotes dignity:** You may be able to cook, bathe, and move about without assistance. This frees up precious energy for the relationships and activities that matter most to you.
- **Supports autonomy:** Affordable housing helps reduce the need for shared living arrangements and institutional settings. It also helps you integrate into your community, gives you a sense of belonging, and

improves your sense of well-being.

- **Reduces reliance on caregivers:** When your home is accessible, there is sometimes less need for caregivers or family assistance. If your living space is set up to meet your needs, you may be able to safely carry out daily tasks with minimal assistance.
- **Improves wellness:** A safe living environment reduces the risk of accidents and injuries that can worsen health issues. An affordable home also reduces stress, which improves your mental health.
- **Promotes financial independence:** In some cases, affordable, accessible housing makes it possible for you to return to or stay in the workforce. This is especially true when housing is close to job opportunities and public transportation.

Current Housing Challenges for the Disability Community

Although there are policies in place to improve housing affordability and accessibility for the disability community, many people still experience challenges. Barriers include:

Lack of accessible design

Accessible design creates a home environment that facilitates daily tasks. It requires home modifications, big and small, in nearly every area of the home. Yet these modifications are often costly and can be difficult to implement. Challenges include finding contractors experienced in accessible design. Sometimes special permitting and inspection requirements cause significant delays.

Housing discrimination

Even if you find affordable, accessible housing, you may face discrimination. In some cases, people with disabilities are turned away—even though this practice is illegal. You might also encounter steering tactics, where landlords attempt to convince you to choose a less desirable unit under the premise of accessibility.

Limited financial resources

Accessible housing units tend to cost more, yet the people who need them are typically on fixed incomes and sometimes unable to work. Individuals often qualify for housing assistance. But even with this benefit, you may still find it challenging to cover your monthly expenses.

Limited housing options

People who are eligible for assistance that makes housing more affordable aren't always able to take advantage of it. For example, some landlords are reluctant to accept housing vouchers. Also, there are often more people eligible for assistance than available units. Sometimes, what's available is not accessible, creating a potentially unfit living environment.

Policy and Legislative Framework

The Americans with Disabilities Act (ADA) lays the foundation for disability rights. However, it applies to public spaces such as sidewalks, stores, restaurants, schools, and public transportation. Separate federal laws protect the housing rights of people in the disability community.

Existing policies

- **Section 504 of the Rehabilitation Act of 1973** prohibits discrimination against individuals with disabilities who are part of any federally funded program, including housing services. A certain percentage of units must comply with accessibility standards.
- **Fair Housing Act (also known as Title VIII of the Civil Rights Act of 1968)** protects people against discrimination when buying, renting, or financing a home. It also mandates that multi-family housing units have certain accommodations for people with disabilities.
- **Fair Housing Amendments Act (FHAA) of 1988** amends the FHA to include protections for people with disabilities. FHAA establishes accessibility standards for specific types of dwellings, including multi-family buildings and public housing projects.

About the National Paralysis Resource Center

We connect individuals who have disabilities with housing resources through a variety of support programs. Our relationships with Centers for Independent Living and other organizations help many people access local housing assistance and other services that optimize their independence. For details, go to: https://www.christopherreeve.org/todays-care/paralysis-help-overview/about-the-paralysis-resource-center.

Accessibility Standards and Design

Accessible design creates an environment that makes it easier for you to navigate and optimize your living space. From garages to kitchens, bedrooms, and bathrooms, every corner of your home can be enhanced to help you live independently and comfortably.

It's natural to want to feel welcome in other people's homes, even if they are not part of the disability community. Universal design aims to do just that. Defined as "the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design." Universal design aims to accommodate everyone's needs regardless of their abilities.

What are accessible and universal design standards?

There are many types of standards. What they all have in common is that they improve your ability to live in, use, and enjoy your home. Examples include:

- **Doorways** with level entrances free of steps and raised thresholds as well as ramps when necessary.
- **Living rooms** with open floor plans, motorized window blinds, and electrical switches that are easy to reach.
- **Kitchens** with sinks and counters that have open spaces underneath and pull-out drawers.

- **Bathrooms** with no-slip flooring, roll-in showers, and toilet seats that are raised or lowered for easy access.
- **Bedrooms** with extra floor space around beds and storage areas closer to the ground.

Are accessible design standards mandatory?

Depending on where you live, dwellings may or may not be required to adhere to accessibility standards:

- **Federally funded housing units** must adhere to many accessibility laws and regulations.
- **Multi-family dwellings** with four or more units must adhere to certain standards.
- **Private, single-family homes** are typically not bound to these laws and regulations.
- **Landlords of private residences** who rent to the disability community must make reasonable accommodations.

How Advocates Can Make an Impact

There are many steps you can take to improve affordable, accessible housing for people with disabilities:

- You can push for legislative reform and new policies by sharing your experiences with lawmakers. Explain how current policies may be falling short and propose steps that can be taken to address these issues. If affordability is an issue, ask for support in expanding rent and mortgage assistance programs.
- Identify legislators who express an interest in accessible housing initiatives. Ask for their commitment to enacting specific changes that are important to you. Check in with them periodically to ensure follow-through with proposed action steps.
- Collaborate with developers of housing websites and platforms to create accessibility filters. You could suggest filters for wheelchair accessibility, proximity to public transportation, and zero-step entryways.
- Organize public awareness campaigns about the importance of accessible housing. Reach out to local disability advocacy groups, housing authorities, and nonprofits to gather support. You may wish to lead workshops, panel discussions, or town hall meetings where stakeholders can discuss issues and potential solutions.

- Post on social media to raise awareness, using hashtags such as #AccessibleHousingNow or #HousingForAll. Launch a campaign during National Fair Housing Month (in April) to draw attention to accessibility gaps in housing. Partnering with influencers or community leaders may increase the visibility of your efforts.

Resources

Administration for Community Living: Housing and Services Resource Center: Accessible, Affordable Housing: https://acl.gov/HousingAndServices/Accessible-Housing

NCIL: Home Modifications Fact Sheet for Centers for Independent Living: https://ncil.org/wp-content/uploads/2022/01/1-4-22-Home-Mods-Fact-Sheet.pdf

Paralysis Resource Guide: Home Modification & Universal Design: https://www.christopherreeve.org/wp-content/uploads/2024/05/PRG-6th-Ed.-English-online-A.pdf

United Spinal Association: Understanding the Fair Housing Amendments Act: https://www.unitedspinal.org/pdf/fair_housing_amendment.pdf

U.S. Department of Housing and Urban Development: Information for Persons with Disabilities: https://www.hud.gov/topics/information_for_disabled_persons

U.S. Department of Justice Civil Rights Division: The Fair Housing Act: https://www.justice.gov/crt/fair-housing-act-1

Reeve Housing Resources

Housing for People with Disabilities: https://www.christopherreeve.org/wp-content/uploads/2024/02/Housing-1-24-A.pdf

Reasonable Accommodations and Modifications in Housing Settings. https://www.christopherreeve.org/wp-content/uploads/2024/02/Housing-Reasonable-Accommodations-and-Modifications-QA-1-24-A.pdf

Paralysis Resource Center Fact Sheet: Home Modification: https://www.christopherreeve.org/wp-content/uploads/2023/10/Home-Modification-QA-5-22-Apdf

Notes

Notes

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