



*United Spinal
Association*

Taking Action

A Step by Step Guide
to Becoming a Self-Advocate
& Making a Difference

Mission Statement

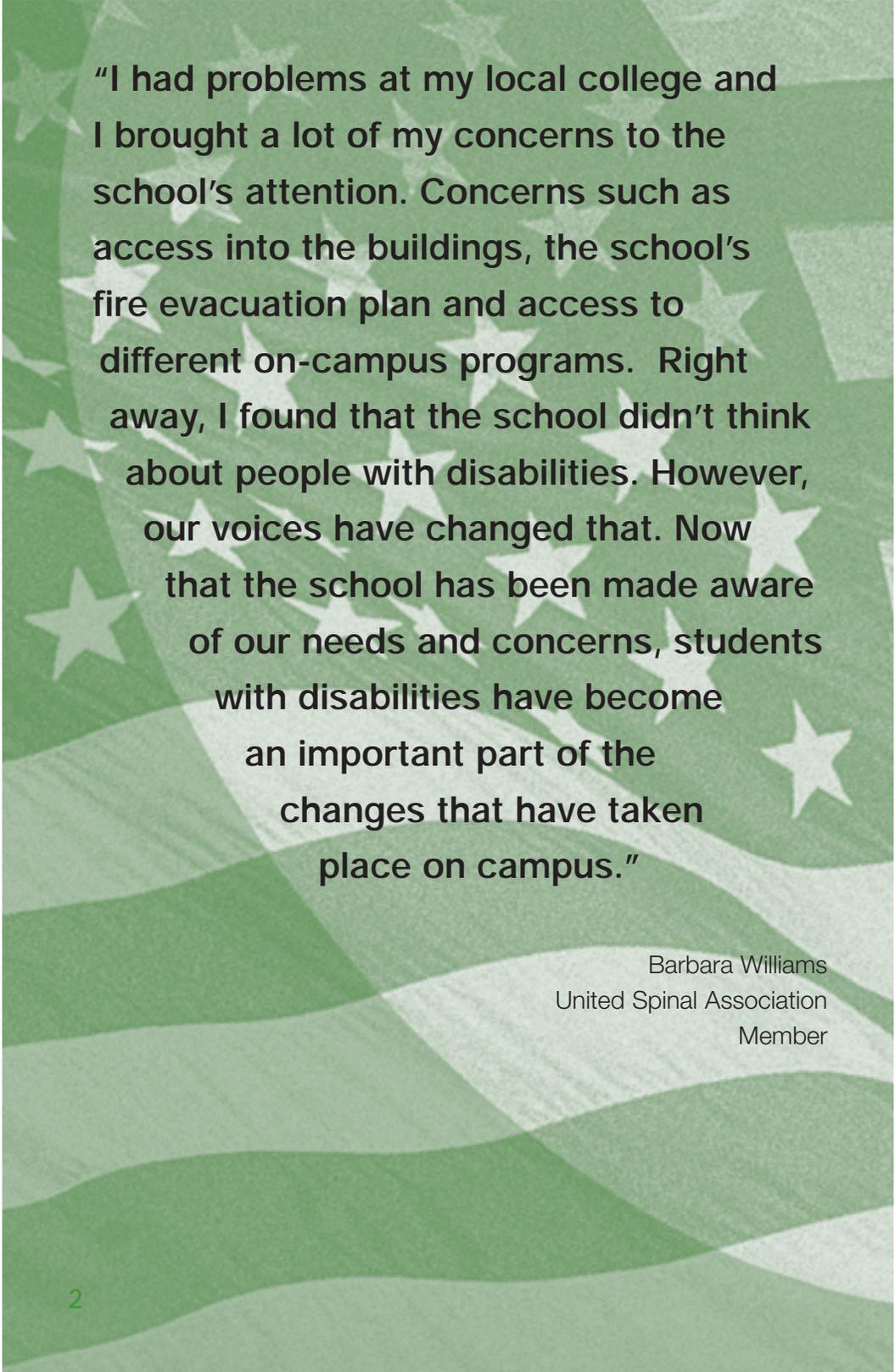
United Spinal Association is dedicated to enhancing the lives of individuals with spinal cord injury or disease by ensuring quality health care, promoting research, advocating for civil rights and independence, educating the public about these issues, and enlisting its help to achieve these fundamental goals.

About Us

United Spinal Association was founded in 1946 as Eastern Paralyzed Veterans Association to help enable members, as well as others with disabilities, to lead full and productive lives. We participated in drafting the Americans with Disabilities Act and other civil rights laws, and continue to promote their enforcement. Our advocacy, sports and recreation, and medical research programs, and our accessibility services are supported by your donations.

Contents

Introduction3
Five Steps of Self-Advocacy5
Self-Advocacy List of Do's and Don'ts7
Complaints & Applicable Laws9
Is Access Required?12
Sample Letters19
What if Nothing Happens?28
The Legislative Process30
Helpful Tips for Communicating With your Legislators33
Helpful Web Sites41
Final Thoughts42
United Spinal Association Contact Information43



"I had problems at my local college and I brought a lot of my concerns to the school's attention. Concerns such as access into the buildings, the school's fire evacuation plan and access to different on-campus programs. Right away, I found that the school didn't think about people with disabilities. However, our voices have changed that. Now that the school has been made aware of our needs and concerns, students with disabilities have become an important part of the changes that have taken place on campus."

Barbara Williams
United Spinal Association
Member

Introduction

The information contained in this pamphlet is designed to enable you to become an effective self-advocate. A self-advocate is someone that does exactly what the quote from Peter McWilliams states: someone who is *actively involved in getting* what they want. As advocates for organizations can attest, advocacy is a process. This process involves research, outreach, follow-up, and most importantly, dedication. The end result of your advocacy efforts may not always turn out as you had planned, but the process of educating your audience, meeting with them, writing letters, and using informative materials to make your point, will invariably make a change for the better.

United Spinal Association recognizes that to become involved in issues of importance to you, the first step is to become informed about the topic or subject matter. The information contained in this pamphlet is designed to guide you through the process of self-advocacy. Included you will find:

- Quotes from individuals on self-advocacy (provided throughout booklet)
- Five steps of self-advocacy
- Self-advocacy do's & don'ts
- Complaints & applicable laws
- A sampling of access related complaints & scenarios
- Sample letters
- What happens if nothing happens—tips on moving forward
- Helpful Web sites

It is our hope that you will use this information to advocate for yourself. Everyone has the ability to be an effective advocate. Using your voice and relaying personal experiences is certainly the most effective advocacy tool. Please take some time to review the enclosed information and think about your day-to-day life. If you think of something that you would like to change . . . go ahead and try. If you need additional help with your advocacy efforts, don't hesitate to contact a staff member at United Spinal Association.

"If you're not actively involved in getting what you want, you don't really want it."
Peter McWilliams, Author



Five Steps of Self-Advocacy

Self-advocacy is an excellent tool to encourage change in your community and/or workplace. Self-advocacy is a process and includes the following **Five** steps:

1. Know the Law

- Federal laws such as the Americans with Disabilities Act (ADA) and the Fair Housing Amendments Act (FHAA)
- State laws
- Local laws and ordinances

2. Develop/Use Your Resources

- Government/elected officials
- Local code enforcement officers
- Advocacy organizations—local & national

3. Assert Yourself

- Make contact with your resources via letters, telephone, e-mail, etc.

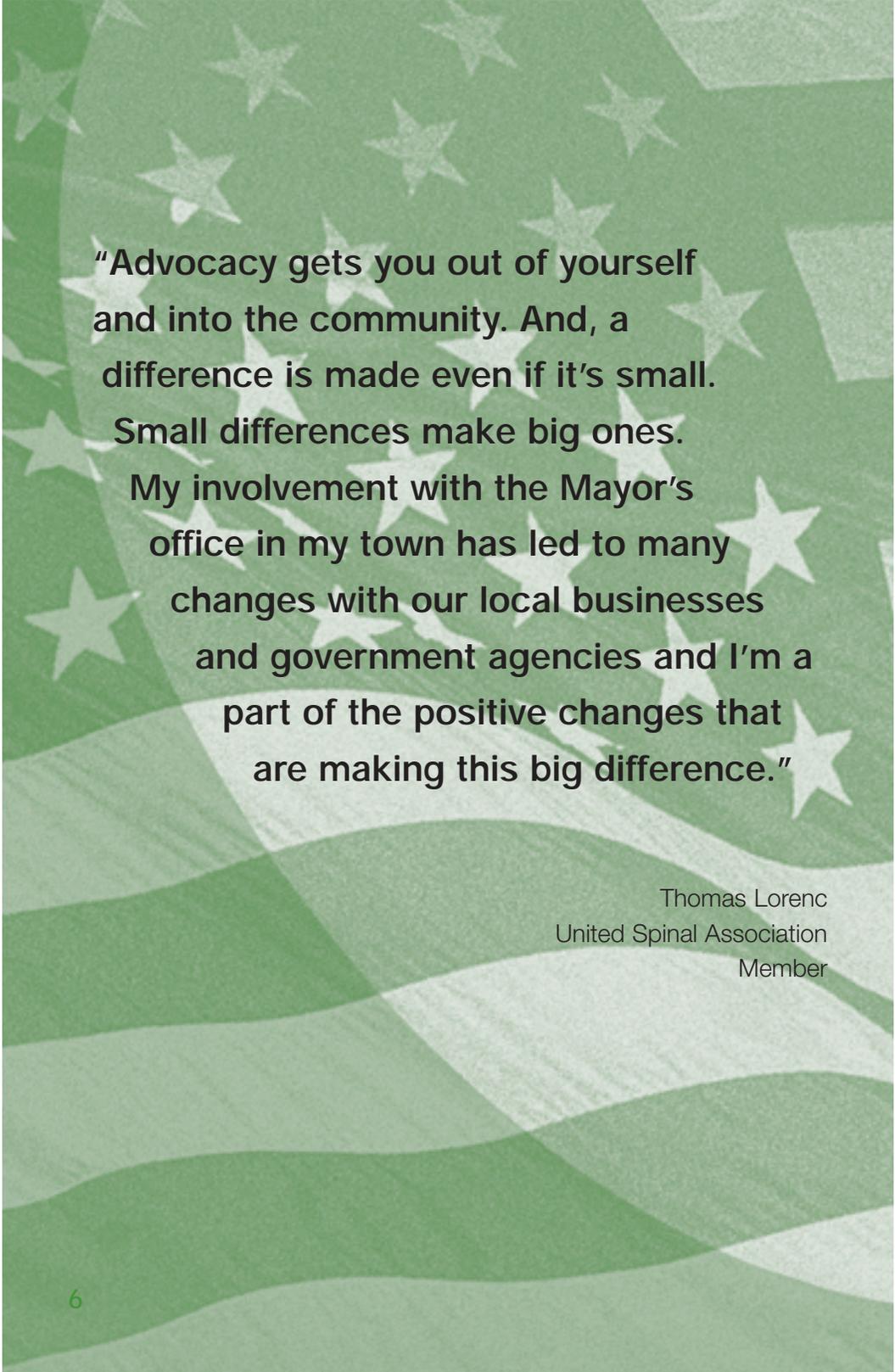
4. Ask for Change

- Write letters
- Arrange meetings
- Make **specific** requests
- Get others to join your efforts

5. Follow-up

- Always follow-up. It can be in writing and/or by a phone call.

Read on for more helpful tips and information that will assist you in your self-advocacy efforts.

The background of the page is a green-tinted American flag. The stars are a light green color, and the stripes are various shades of green, creating a wavy, layered effect.

**"Advocacy gets you out of yourself
and into the community. And, a
difference is made even if it's small.
Small differences make big ones.
My involvement with the Mayor's
office in my town has led to many
changes with our local businesses
and government agencies and I'm a
part of the positive changes that
are making this big difference."**

Thomas Lorenc
United Spinal Association
Member

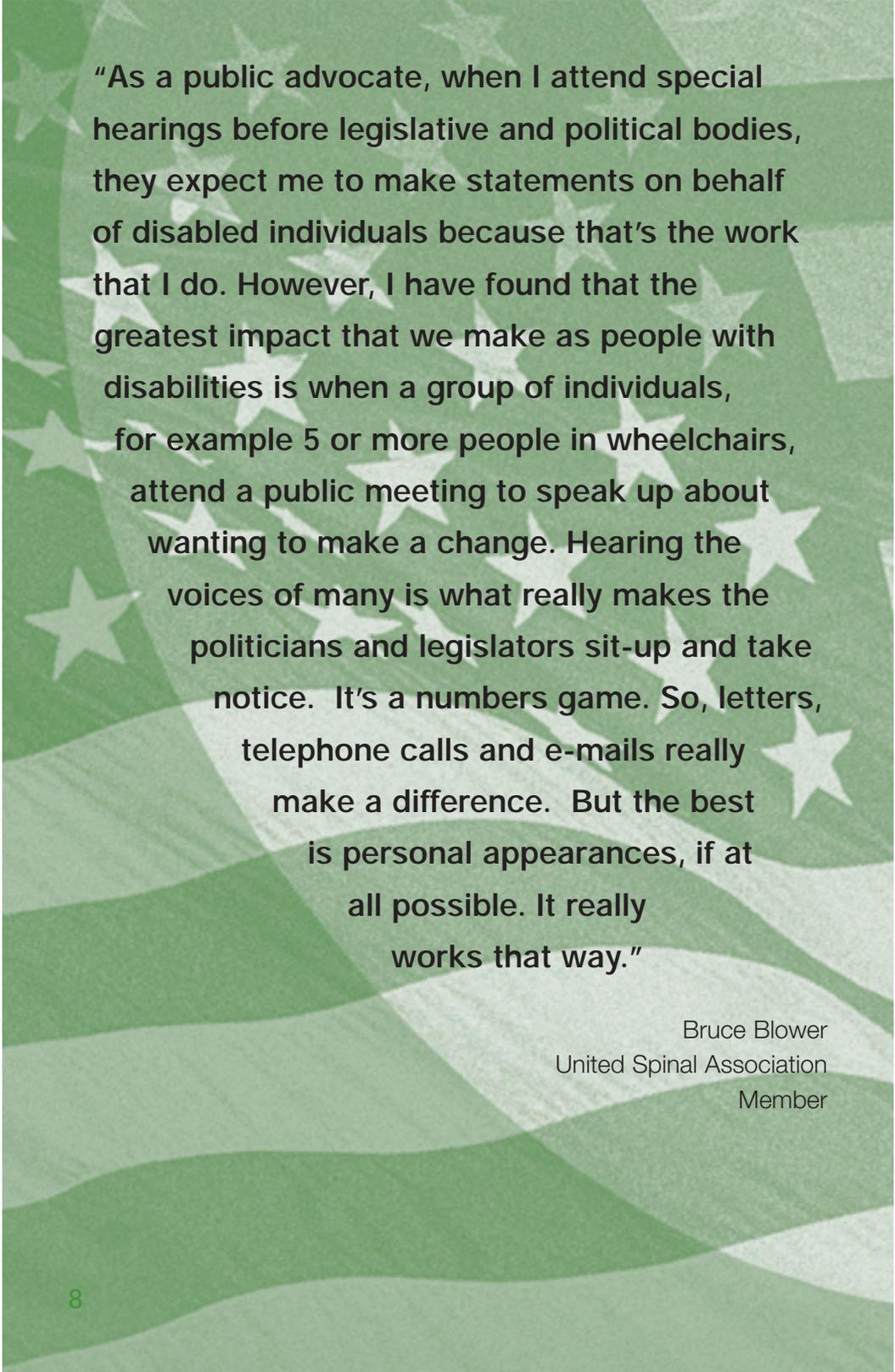
Self-Advocacy List of Do's and Don'ts

Do . . .

- Remember to state the reason and purpose for your action/complaint. Remember to give your name and be specific.
- Start at the top. Get the name, telephone number, and address of a person in charge (*e.g., manager, general manager, owner, supervisor, mayor, town administrator*). By getting the name of someone in charge you will avoid explaining your problem to individuals who are in no position to help or change a situation.
- For a housing complaint, speak to a supervisor at your management company or a supervisor at your town or city housing authority.
- Put complaints in writing when possible (*see Sample Letters on pg. 18*). If your matter becomes a legal issue, you will need written documentation of your actions and activity. Follow any conversations, even unfavorable ones, with a letter confirming your discussion.
- Keep a file or record of **any** and all correspondence. Remember to keep track of any conversations, including the date and name of the person that you spoke to.
- Be courteous, yet direct. Remember, the ultimate goal is to improve accessibility.
- Offer assistance and guidance.

Don't . . .

- Make personal insults or accusations. They won't get you anywhere.
- Get into arguments or make threats of lawsuits. Again, your initial contact should be one to advise and assist in making a positive change.
- Let too much time elapse between each of your calls or letters.
- Be afraid to take your complaint or issue to the next level if you get negative feedback from the business or public official. Remember, there are laws in place that protect the rights of individuals with disabilities.



“As a public advocate, when I attend special hearings before legislative and political bodies, they expect me to make statements on behalf of disabled individuals because that’s the work that I do. However, I have found that the greatest impact that we make as people with disabilities is when a group of individuals, for example 5 or more people in wheelchairs, attend a public meeting to speak up about wanting to make a change. Hearing the voices of many is what really makes the politicians and legislators sit-up and take notice. It’s a numbers game. So, letters, telephone calls and e-mails really make a difference. But the best is personal appearances, if at all possible. It really works that way.”

Bruce Blower
United Spinal Association
Member

Complaint & Applicable Laws

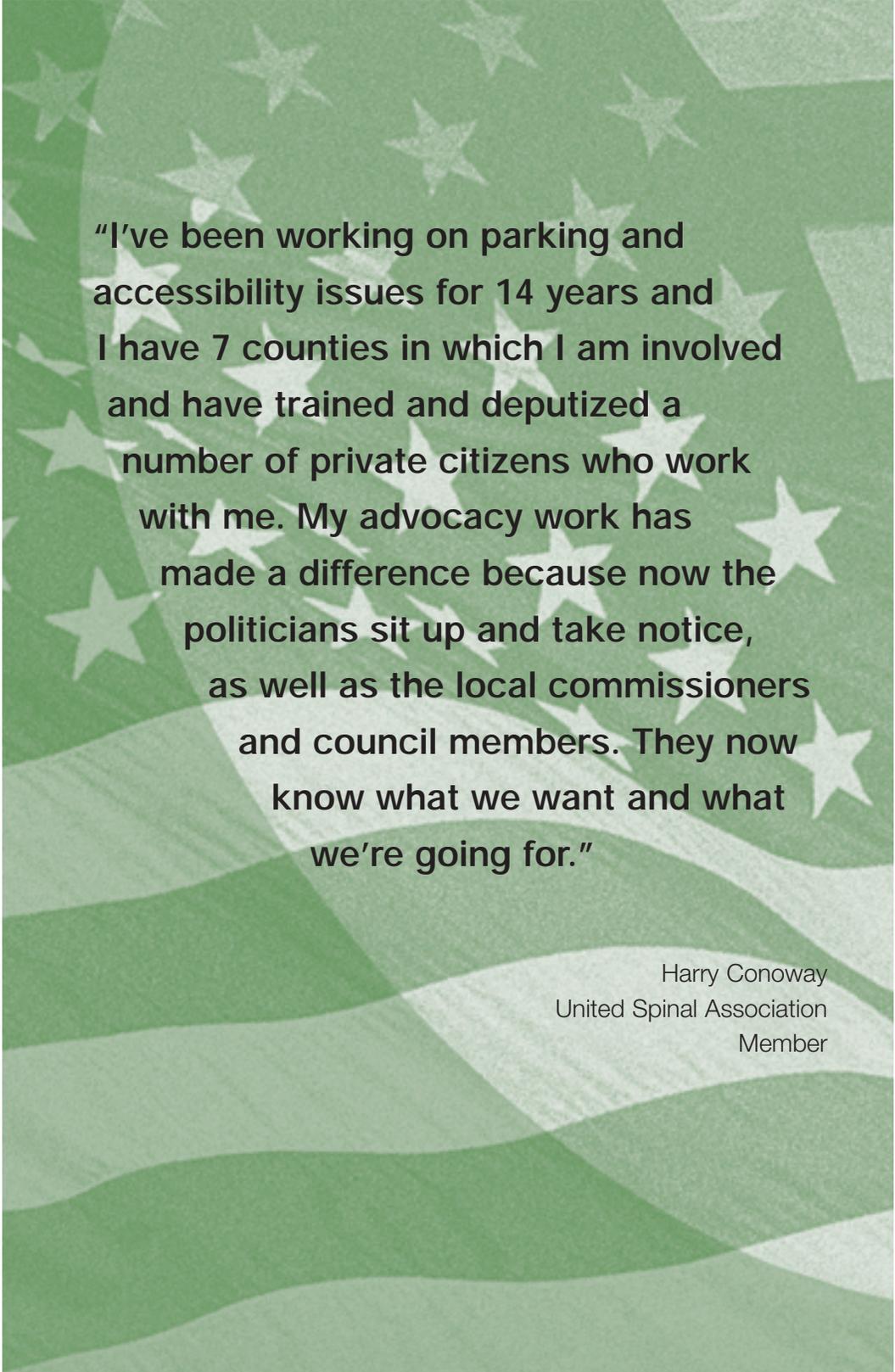
The following is a list of typical accessibility complaints and the federal laws that address them. The first column details the problems, while the second column identifies the federal laws that apply to every specific problem. Please use this list as a starting point to identify typical complaints from people with disabilities. If one of these complaints mirrors a problem that you or someone you know experienced, you may want to look up the corresponding law in some of United Spinal Association's literature. Knowing specific laws helps you to be a successful advocate.

Complaint	Law
The local city council meetings are held in a building that isn't accessible to wheelchair users.	Americans with Disabilities Act (ADA), Title II
My boss said that if I can't perform even a minor function of my job description, due to my disability, I will be fired.	ADA, Title I
My favorite airline suddenly stopped being my favorite when they said people with disabilities had to travel with a companion.	Air Carrier Access Act (ACAA)
I want to picnic in a state park, but I am afraid there is no path that will accommodate my wheelchair.	ADA, Title II
I cannot get my wheelchair out of my apartment because I cannot navigate the step leading to the door.	Fair Housing Amendments Act (FHAA)
I want to take my date to a new restaurant, but there is no way for me to get my wheelchair in the door.	ADA, Title III
My voice relay service isn't available after midnight.	ADA, Title IV

Complaint & Applicable Laws

(cont'd)

Complaint	Law
My disability causes me to become fatigued later in the day and my work schedule was recently changed to the graveyard shift.	ADA, Title I
My gym says I cannot use the pool because people with disabilities can injure themselves.	ADA, Title III
The public transportation in my town doesn't provide service for people who cannot walk onto the buses.	ADA, Title II
I looked at newly constructed condos with 3 steps to all ground floor units.	FHAA

The background of the entire page is a green-tinted American flag. The stars are a light green color, and the stripes are various shades of green, creating a wavy, layered effect.

"I've been working on parking and accessibility issues for 14 years and I have 7 counties in which I am involved and have trained and deputized a number of private citizens who work with me. My advocacy work has made a difference because now the politicians sit up and take notice, as well as the local commissioners and council members. They now know what we want and what we're going for."

Harry Conoway
United Spinal Association
Member

Is Access Required?

As you become more familiar with the process of effective advocacy, you'll discover that not all situations are the same nor are the answers as clear-cut as you might assume. The following are just a few examples of accessibility complaints that you or someone you know might encounter. Keep in mind, however, that as you read these scenarios, the answers, while they may appear to be quite obvious, may indeed surprise you.

1. A former tailor shop has been converted to a pizza parlor. The pizza parlor offers delivery, take-out, and dining space for up to 50 people. Bill noticed that an accessible entrance has not been provided and decides to contact the owner. The owner tells Bill that since the pizza parlor delivers, there is no obligation to provide accessibility.

Is access required?

Title III of the Americans with Disabilities Act (ADA) requires that alterations to buildings comply with the ADA Accessibility Guidelines. In this case, since an alteration was made to the "primary function area" of the business, there is an obligation to spend additional funds making the entrance, restrooms, telephones, and drinking fountains accessible. It may be that the entrance should have been made accessible with these additional funds.

Also, many building codes require an accessible entrance to a building that has undergone a change of occupancy. In this case, the building changed from a mercantile (tailor shop) to assembly (restaurant) occupancy, and such codes will require an accessible entrance, regardless of the cost.

2. A town hall constructed in 1949 has two stories and no elevator. The town completed a Transition Plan and as a result installed a ramp to provide an accessible entrance to the 1st floor. The 1st floor offices include the supervisor, town clerk and tax assessor. The 2nd floor offices include the building department, town attorney, and recreation office. Sandy needs a building permit in order to make renovations to her home and visits the town hall to obtain one. Since Sandy uses a wheelchair, she is unable to get to the second floor building department office. The

"As you become more familiar with the process of effective advocacy, you'll discover that not all situations are the same nor are the answers as clear-cut as you might assume."



receptionist calls upstairs and arranges for a clerk to meet with Sandy in a 1st floor office to take care of business. Sandy feels that all parts of the building should be accessible and she writes a letter to the town supervisor. The supervisor responds to her letter by informing her that the town has met its obligation under the ADA by arranging for her business to be taken care of on an accessible level of the building.

Is the Supervisor correct?

The municipality has met its obligation in this case. Title II of the ADA requires a municipality to ensure programs, services, and activities are available to qualified individuals. However, compliance can be achieved via methods such as program relocation or reassignment of services to accessible locations. In other words, the town's solution to Sandy's issue is allowed and legal under the ADA.

3. Mark is a freshman at a local community college. Mark is interested in joining the college radio station, however, the station is located in a sub-basement not served by an accessible route. Mark is a communications major and was hoping to gain experience at the radio station. Mark brings his concern to his student advisor and is told that the college cannot afford to provide a lift and therefore Mark should consider an alternate activity such as the school newspaper.

What laws apply here?

A community college is subject to the requirements of Title II of the ADA and Section 504 of the Rehabilitation Act of 1973. Therefore the concept of "program accessibility" is applicable in this case. Programs of the college are required to be accessible. This can be achieved by providing an accessible route to the space or relocating the program to an accessible space. A Title II entity is not required to take any action that would result in a fundamental alteration of a program or would impose an undue financial or administrative burden. If making the program accessible would not result in an undue burden, then the college is obligated to provide access. Section 504 is applicable because the college receives federal funding in the form of student loans or assistance in the form of grants. Therefore, by receiving federal funding from the

government, the college must ensure that the disabled student has access and/or opportunity to the same programs and activities afforded non-disabled students.

4. Sadie has a concern regarding accessible parking at her neighborhood grocery store. Accessible parking spaces are provided, however, there are no adjacent access aisles. Sadie speaks with the store manager and explains why access aisles are important because they give her space to transfer from her car into her wheelchair. The manager suggests that she shop later in the evening or early in the morning so her car does not get “blocked in.” He then tells her he will “look into the matter.” Sadie has not received a response and 3½ weeks have passed since her conversation with the store manager.

Is his advice correct?

Title III of the ADA requires a public accommodation to remove architectural barriers where such removal is readily achievable, in other words, easily accomplishable without much difficulty or expense. In this instance, the provision of accessible parking is probably achievable, in which case access aisles would be required.

5. Bev and Charlie recently married and they found an apartment they would like to rent. The apartment is located on the ground floor of a 4-unit building. The building was constructed in 1960 and is privately owned. Bev uses a wheelchair and wants to make some modifications to the apartment. Bev and Charlie meet with the landlord and explain that they would like to install grab-bars for the bathtub and near the toilet. They would also like to remove the base cabinet under the kitchen sink. They inform the landlord that they will pay for the modifications and will return the apartment to its original condition when they move out. The landlord denies their request and tells them to look for “special” housing for people with disabilities.

Does the landlord have the right to do this?

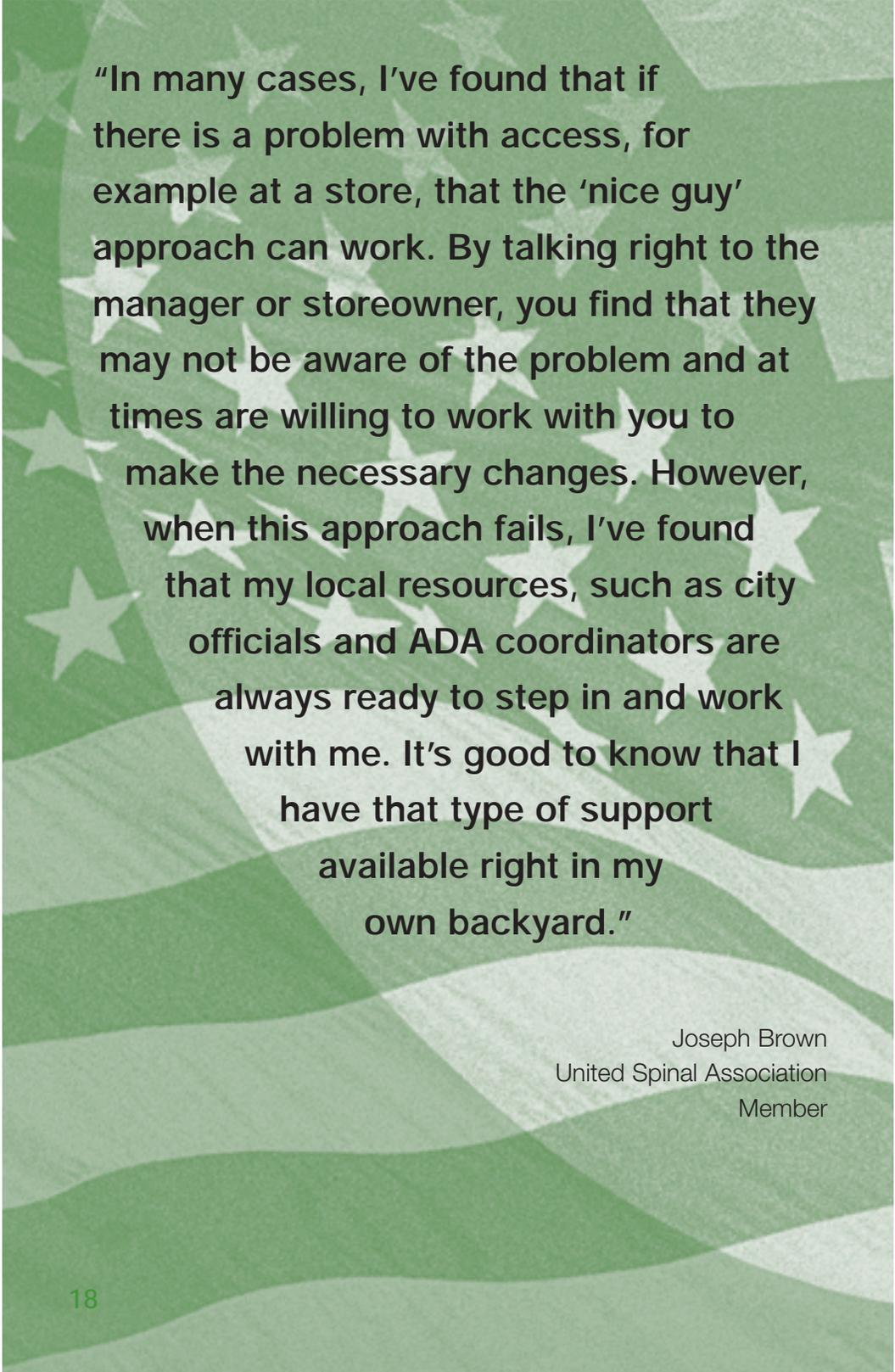
The Fair Housing Amendments Act (FHAA) requires that housing providers permit reasonable modifications of existing premises if the modifications

are necessary to permit a person with a disability to live in and use the premises. In this case, the landlord must permit the installation of grab-bars and the removal of the base cabinet beneath the sink. The tenants (Bev and Charlie) are responsible for the cost of the modification and must return the premises to the condition prior to the modification when they vacate the premises. The tenants should also know that the landlord may require that they establish an interest bearing escrow account to cover the costs of restoring the dwelling unit to its original condition once they leave.

6. A coffee shop owner has received a complaint regarding accessibility. The shop has existed and been in business since 1972. There have been no alterations to the building. The owner was told he is violating the ADA because the shop does not have an accessible entrance due to the 4-inch threshold at the door. There is also a complaint that the bathrooms are not accessible. The owner is willing to modify the entrance but is afraid that if he does he will have to make the restrooms accessible and he cannot afford to do so.

What is the owner required to do?

In this instance, the coffee shop owner may be required to provide an accessible entrance to comply with Title III of the ADA if the modification is readily achievable. However, the restrooms would not have to be modified at this time if a determination has been made that it is **not** readily achievable. Keep in mind, however, that the business owner has an ongoing obligation to remove barriers. If the building is renovated in the future, modification to the restrooms may be required.



“In many cases, I’ve found that if there is a problem with access, for example at a store, that the ‘nice guy’ approach can work. By talking right to the manager or storeowner, you find that they may not be aware of the problem and at times are willing to work with you to make the necessary changes. However, when this approach fails, I’ve found that my local resources, such as city officials and ADA coordinators are always ready to step in and work with me. It’s good to know that I have that type of support available right in my own backyard.”

Joseph Brown
United Spinal Association
Member

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Sample Letters

Introduction

It is often said . . .

“The pen is mightier than the sword.”

While one may argue that this is not always the case, as an advocate, you’ll find that no statement holds more truth than this one. Of the many useful tools that are employed by an advocate, none is probably more important than a letter. You’ll find that, as a self-advocate, by sending a letter to support your position, you can and will accomplish many things. For example, letter writing provides a clear and concise way of getting your point across to the business or public entity. It also puts the other party on notice about your concerns and the need for them to change a situation. Letter writing also serves as a way to substantiate and support your position in the event that your matter becomes a legal one.

On the following pages, you will find samples of letters that can be used in your advocacy efforts. Please note some of the suggestions that are made in bold print as well as the reference to different aspects of the law. Keep in mind that while these situations are fictional, they will serve as useful tips in helping you to get your point across.

Sample Letter of Complaint

(1st Letter)

Date

Name of Owner or Manager of Business

Name of Business

Address of Business (Street Address, City, State and Zip Code)

Dear Mr. or Ms. _____:

(If you couldn't get the name of the manager or owner, write: "Dear Sir or Madam" or write: "To Whom it May Concern")

I am writing to complain about the level of physical access at your store, in particular, the lack of a ramped entrance into the building and no accessible parking in the lot. I am a person with a disability and I live in the area of your store. I would like to patronize your business, however the physical obstacles currently in place at your building make it nearly impossible.

Under the Americans with Disabilities Act (ADA) of 1990, places of public accommodation, such as your store, are mandated by federal law to remove physical barriers so that persons with disabilities can access the same goods and services as non-disabled individuals. By not providing a ramp into your store and no handicapped parking spaces, you are not meeting the requirements of the ADA.

When the ADA was passed, it established a provision for businesses to receive tax credits and deductions for removing barriers. By installing a ramp and accessible parking spaces, you will qualify for such tax incentives.

It is my hope that you will take this information and my complaint into consideration and make your store accessible to people with disabilities. I would like to hear from you to discuss this matter in more detail. I can be reached at **(include your telephone number)**. My address is **(include your home address)**.

Sincerely,

Your Name

(If it applies, you may want to add that you are affiliated with an organization or group after your name—for example: **Jane Doe, Student/USA University** or **John Doe, Board Member, Local Independent Living Center, Inc.**)

21

cc: This is where you would want to indicate the name of any individual(s) who



"Of the many useful tools that are employed by an advocate, none is probably more important than a letter."

Sample Letter of Complaint

(Follow-up Letter)

Date

Name of Owner or Manager of Business

Name of Business

Address of Business (Street Address, City, State and Zip Code)

Dear Mr. or Ms. _____:

Sometime ago, I wrote to you about the lack of access for persons with disabilities into your store (see attached letter). To date, I have not heard from either you or a representative from your business.

As I mentioned in my previous letter, that as the owner/operator of a place of business, you are mandated by the Americans with Disabilities Act (ADA) of 1990 to make your store, along with its goods and services, accessible to persons with disabilities. Failure to do so could result in the filing of a formal complaint against your business with the U.S. Department of Justice (DOJ) Civil Rights Division.

It is my hope that you will review this situation more closely and make the necessary changes to your store. Keep in mind, that by removing the barriers that are in place, you are opening your business up to new customers along with their families and friends.

Please feel free to contact me to discuss this matter in more detail. I can be reached at **(include your telephone number)**. My address is **(include your home address)**.

Sincerely,

Your Name

(If it applies, you may want to add that you are affiliated with an organization or group after your name—for example: **Jane Doe, Student/USA University** or **John Doe, Board Member, Local Independent Living Center, Inc.**)

cc: This is where you would want to indicate the name of an individual(s) who may be interested in this issue, or who may assist you with your efforts (for example: **John Q. Citizen, Chairperson, Local Business Association** or

Sample “Thank You” Letter

Date

Name of Owner or Manager of Business

Name of Business

Address of Business (Street Address, City, State and Zip Code)

Dear Mr. or Ms. _____:

I would just like to express my appreciation for your immediate response to my complaint. Your actions are a clear indication that you take the issue of access into your store for people with disabilities quite seriously. It is my hope that more businesses will follow your efforts and make their stores accessible to individuals with disabilities.

Once again, I would like to thank you. By removing the barriers that were in place, I can now benefit from all of the goods and services that your store has to offer.

Sincerely,

Your Name

(If it applies, you may want to add that you are affiliated with an organization or group after your name—for example: ***Jane Doe, Student or John Doe, Board Member***)

cc: This is where you want to indicate the name of any individual(s) who may be interested in this issue and who may have been of assistance to you during your efforts (for example: ***Joe Q. Citizen, Editor, Local Daily Community News***).

Sample Letter

Fair Housing Amendments Act of 1988

Examples: Apartment Buildings; Multi-Family Housing Developments

Publication to Check Out:

Understanding the Fair Housing Amendments Act

Date

Name of Owner or Manager of Business

Name of Business

Address of Business (Street Address, City, State and Zip Code)

Dear Mr. or Ms. _____:

I am writing in regard to accessibility at the Living Apartment Complex. I am a person with a disability and I rent an apartment in your building. I have expressed a need to modify the bathroom and kitchen in order to accommodate my wheelchair and that I would pay for the necessary work myself. However, your manager told me that it is against your company's policy to allow a tenant to make any changes or modifications to an apartment. It is this policy that I believe is in violation of the law.

Under the Fair Housing Amendments Act (FHAA), a landlord cannot refuse to allow a tenant with a disability to make modifications, at the tenant's expense, to the person's unit as well as common use areas. Therefore, the information that your manager gave about making changes to the bathroom and kitchen was incorrect and a violation of federal law.

I wish to be able to stay in my apartment and would like to meet to not only discuss the modifications that I would like to make to the unit (installation of grab bars, removal of base cabinets under the sink), but to provide you and your staff with the correct information on the FHAA and how it applies to disabled individuals.

I look forward to hearing from you to discuss my concerns in more detail. I can be reached at (area code and phone number) and my home address is _____.

Sincerely,

Your Name

(If it applies, you may want to add that you are affiliated with an organization or group after your name—for example: **Jane Doe, Student or John Doe, Board Member**)

Sample Letter

Americans with Disabilities Act (ADA) Title II — State & Local Government Entities
Examples: Town Halls, State Legislatures, Municipal Buildings, Police
& Fire Departments

**Publications to Check Out: *Access: State & Local Government;*
*Understanding the ADA***

The Honorable John Jones
Mayor
Town of Noaccess
123 Route 456
Clarksville, USA

Dear Mayor Jones:

I would like to bring to your attention the lack of sufficient handicapped parking spaces at the town's courthouse. There is only **one** handicapped parking space in a lot that has over 200 parking spaces. I am requesting that more spaces be provided with appropriate signage. I was recently called to serve jury duty, however, I was quite surprised to discover the lack of handicapped parking spaces. Since I use a wheelchair, I had great difficulty with parking at the courthouse, and was quite late for my jury service.

Please know that the Americans with Disabilities Act (ADA) requires that for 200 spaces, at least 6 handicapped parking spaces be provided and at least one of them must be van accessible. This means that all of the handicapped parking spaces should be at least 8 feet wide; the adjacent access aisle for cars should be at least 5 feet wide (access aisles for vans is 8 feet). Signage is also required with the International Symbol of Accessibility.

I have enclosed two brochures to assist you (*Understanding the ADA and Access: State & Local Government*). I would like to meet with you or a member of your staff to resolve this issue so that other disabled citizens in our town can access the programs and services at the courthouse and other town buildings. I can be reached at (555) 987-0000.

Thank you for your cooperation.

Sincerely,

Sample Letter

Americans with Disabilities Act (ADA) Title II—State & Local Government Entities
Examples: Town Halls, State Legislatures, Municipal Buildings, Police
& Fire Departments

**Publications to Check Out: *Access: State & Local Government;*
*Understanding the ADA***

Ms. Susan Doe
Commissioner
Righttovote Board of Elections
123 Lever Street
Righttovote, USA 12345

Dear Commissioner:

I am writing in regard to accessibility for wheelchair users at the polling place to which I have been assigned. I recently went to my polling place at the high school, but there were three steps at the entrance and no ramp was provided. I could not enter the building to conduct my civic duty to vote.

Title II of the Americans with Disabilities Act (ADA) of 1990, requires that state and local governments remove barriers to accessibility, so that persons with disabilities can participate equally in all services, programs and activities as persons who are not disabled. The removal of barriers should first be addressed architecturally by adding a ramp, unless it is truly an “undue burden” financially. If a ramp is too costly, then alternative programmatic solutions are required, such as relocating the election site to a fully accessible building.

Please contact me with any questions you may have regarding this matter. I can be reached at (555) 555-1212; my home address is 123 Rightway Lane, Righttovote, USA. I look forward to hearing from you shortly regarding my polling site.

Thank you for your cooperation.

Sincerely,

What If Nothing Happens?

By now, you're probably saying something like . . .

"All of this stuff is fine and good, but a lot of these guys just don't care."

or . . .

"They'll promise you the sun and the moon, but as soon as your back is turned, it's business as usual. Which means, nothing changes."

Well, if you're saying or thinking this or something quite similar to it, then don't worry—it's quite natural. You see, as was mentioned earlier, the advocacy process can be a long one and at times, quite frustrating. After all, you're asking someone to make a change, and as we all know, most people aren't too receptive when it comes to **change**, especially if it involves dollar signs. **How do you react to the following?**

Resistance and a Bad Attitude

As a self-advocate, you should know that an issue doesn't have to end when the owner of a business "slams the door in your face," or when the local government official is more interested in having his picture taken with you, than actually bringing a town hall into compliance. There are laws, building codes, and regulations that protect your rights as a person with a disability. And, there are measures that can be taken when the telephone calls, scheduled meetings, and letter writing all seem to fail.

Keep in mind, the **ultimate** goal is to change or improve a situation. While legal remedies are often a part of our efforts, they should be the last recourse taken. In other words, if your problem is with the lack of accessible parking at a store, then that is your goal—to add accessible parking, not take someone to court. You should also know that all of your letter writing and documented phone calls would only help your case if it becomes a legal matter. You see, that's where the advocacy steps do work and benefit your cause. They help to prepare you and strengthen your case in the event that your matter/complaint is brought before a judge or mediator.

Good Attitude but No Change

Now, what if you get a business owner or government official who is quite pleasant. They answer your phone calls and respond to your letters, but nothing has changed. The accessible parking/ramped entrance/accessible restrooms still do not exist. Then what do you do?

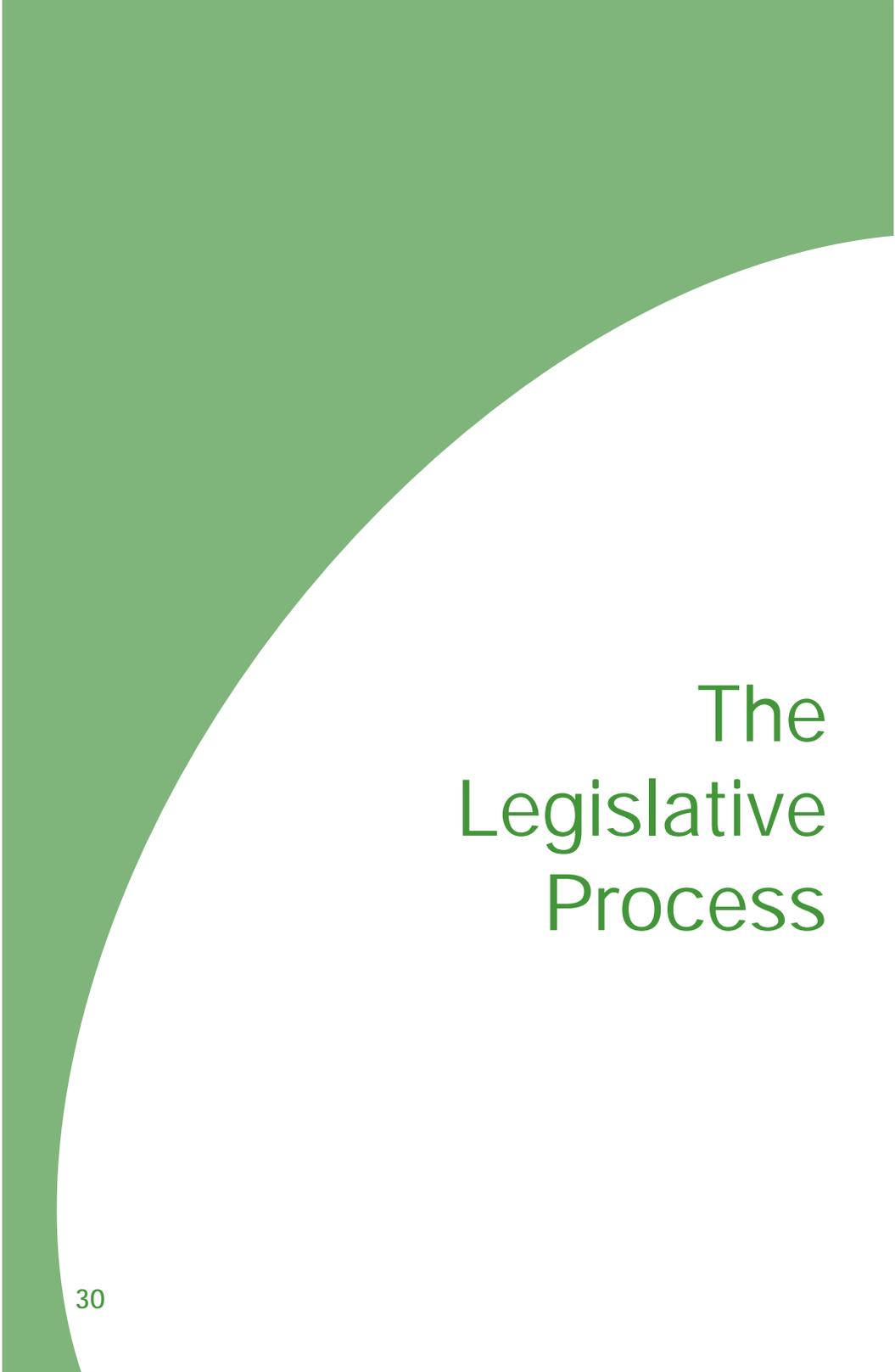
Well, if the storeowner or government official can show you how they are

going to improve a situation and that the reason for the delay is a legitimate one (*i.e., bad weather, waiting for contract approval, etc.*), then the only thing that you can do is wait. Keep in mind, that your checking on the progress of an issue or complaint is okay and perfectly acceptable. In fact, you'll want to make sure that they haven't forgotten about you and remind them that you're not going away. This will even help to establish you as someone that businesses/local officials can work with in a positive way on access-related issues.

Lip Service

In this case, you get a storeowner/government official who is very pleasant and seems quite concerned. However, they don't care in the least about your problem and are basically giving you "lip service," when they try to **explain** why nothing has taken place. In these instances, you'll usually hear something like . . . "***I have to wait for my boss to get back in town,***" or "***Can I give you a call next week, I'm pretty busy right now.***" If this is the case, then you can almost bet that they have no plans to improve access and address your concerns. It is in these instances that legal remedies may be your only alternative to get something done. It is during this time, when all phone calls have been made, and all of your letters have been written (*a first, second and, sometimes third letter*), that you should notify your local advocacy organization or independent living center. If you have notified us, we will want to see any documentation you may have on this matter. Again, your taking the time to address this matter in a positive way will only strengthen your cause. And, having the support may be the extra push needed so the problem is remedied without legal action. If further advocacy steps are taken by our staff and are met with the same roadblocks, this may be the time to take legal action.

We hope this sheds some light on the realities of advocacy. Change and progress can sometimes happen overnight or it can seem to take forever. However, when you see your efforts result in something good for the community as a whole, no matter how simple or small, then it makes the whole process worthwhile.



The Legislative Process

Self-Advocacy & the Legislative Process

So far, you've read about the importance of self-advocacy as it relates to improving accessibility throughout your community, whether it's at your local grocery store, elementary school or town hall. However, effective self-advocacy can also be applied to the legislative process.

As previously mentioned, being an effective advocate requires knowing how and where it is best to exert your efforts to accomplish change. Whether your interest lies in legislative action or enforcement of the Americans with Disabilities Act (ADA) in your community, self-advocacy can help you to achieve your goal. The information highlighted in this section will assist you in your legislative advocacy efforts and serve as tools to use to make your voice heard about the issues that are important to you.

Advocacy & the Legislative Process

Before you begin your self-advocacy legislative outreach efforts, it is important that you start with a basic and fundamental understanding of our legislative process and how it works.

How a Bill Becomes a Law

Step 1: Bill Introduced

Any member of Congress, either a Senator or Representative, may introduce a bill by sending it to the clerk of his or her house of Congress. It is then assigned a bill number and sent to a committee. Each bill is referred to the committee that has jurisdiction over the area affected by the bill.

Step 2: Committee Action

The committee as a whole may consider the bill or the Chairman or Chairwoman of the committee may decide to refer the bill to a subcommittee. Public hearings are usually held to hear various viewpoints on the bill. These hearings may take place at the full committee or the subcommittee level, or both. The committee can vote to report (approve) the bill, with or without amendment, or to kill it. It is during committee action that the most intense consideration is given to a proposed bill.

Step 3: House Floor Consideration

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

Step 4: Second House

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

Step 5: Resolving Differences

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

Step 6: Presidential Action—Final Approval

After both the House and the Senate have passed a bill in identical form, it is sent to the President.

The President may sign the bill into law or allow the bill to become law by letting it sit for 10 days while Congress is in session.

If the President disagrees with a bill, he may veto it and send it back to Congress. If the bill receives a two-thirds vote or greater, in both Houses, the bill becomes law.

Helpful Tips for Communicating With Your Legislators

Communication with your elected representatives can influence the legislative process and its results. This communication, however, will have more impact at certain points in the legislative process than others. If you plan to contact your representatives about a particular bill, be sure to do it before action is taken. Legislators on the committee or subcommittee that the bill has been assigned to can be especially influential, but it is important to contact these members before the committee has made its decision. Contact with your legislator prior to a full floor vote is also critical. Members of the majority party and senior members of the legislature also tend to exert more influence over their fellow lawmakers and the outcome of proposed legislation.

Ways to Influence the Legislative Process

There are many ways to influence the legislative process through communication with your elected representatives. This contact is important and provides your legislator with a human face on the legislative issue. Legislators and their aides have reported that personal communication from constituents, in the form of letters, office visits, and telephone calls, are the most effective ways of influencing a legislator's vote.

Letter Writing

Spontaneous letters from constituents weigh most heavily on the decision a legislator makes about a bill. Some legislators may downgrade the importance of a form letter, so, personal letters on plain stationery, or your personal or business letterhead, are most effective. Handwritten letters are also fine, as long as they are legible. Legislators may actually pay more attention to handwritten letters because they know that a machine cannot reproduce handwritten correspondence. However, if you feel uncomfortable, or simply lack the time to write a personal letter, a form letter is acceptable. Although a personal letter is more effective than a form letter, a form letter is better than no communication.

Try to keep your letter short, preferably to one page, and be sure to spell your legislator's name correctly. Also be sure to include your name and address on both the letter and envelope. This will make it easier for staff members to identify you as a constituent and reply to your letter.

Discuss only one topic per letter, and directly state your position in the opening sentence, citing the bill number and title if applicable. Give the legislator reasons for your position and, where appropriate, use personal experience or a concrete example to make your point. Always be sure to maintain a polite, positive, and constructive tone. Never threaten or beg.

Personal letters are likely to receive a written response from your legislator. Therefore, letter writing presents you with a good opportunity to ask your legislator questions or to take action on a specific issue. Asking questions will increase your chances of receiving a direct reply stating the legislator's position on the issue that you raised. It will also help to develop a relationship between you and the legislator, making future communication more effective.

Finally, remember to write your legislator when he or she takes action you agree with, as well when you disagree. Legislators rarely receive letters of thanks, and this can help strengthen your relationship with your legislator. Also, be sure to send a letter of thanks if a staff member has been particularly helpful to you.

Helpful Tips on Letter writing to the Various Branches of the Government

White House

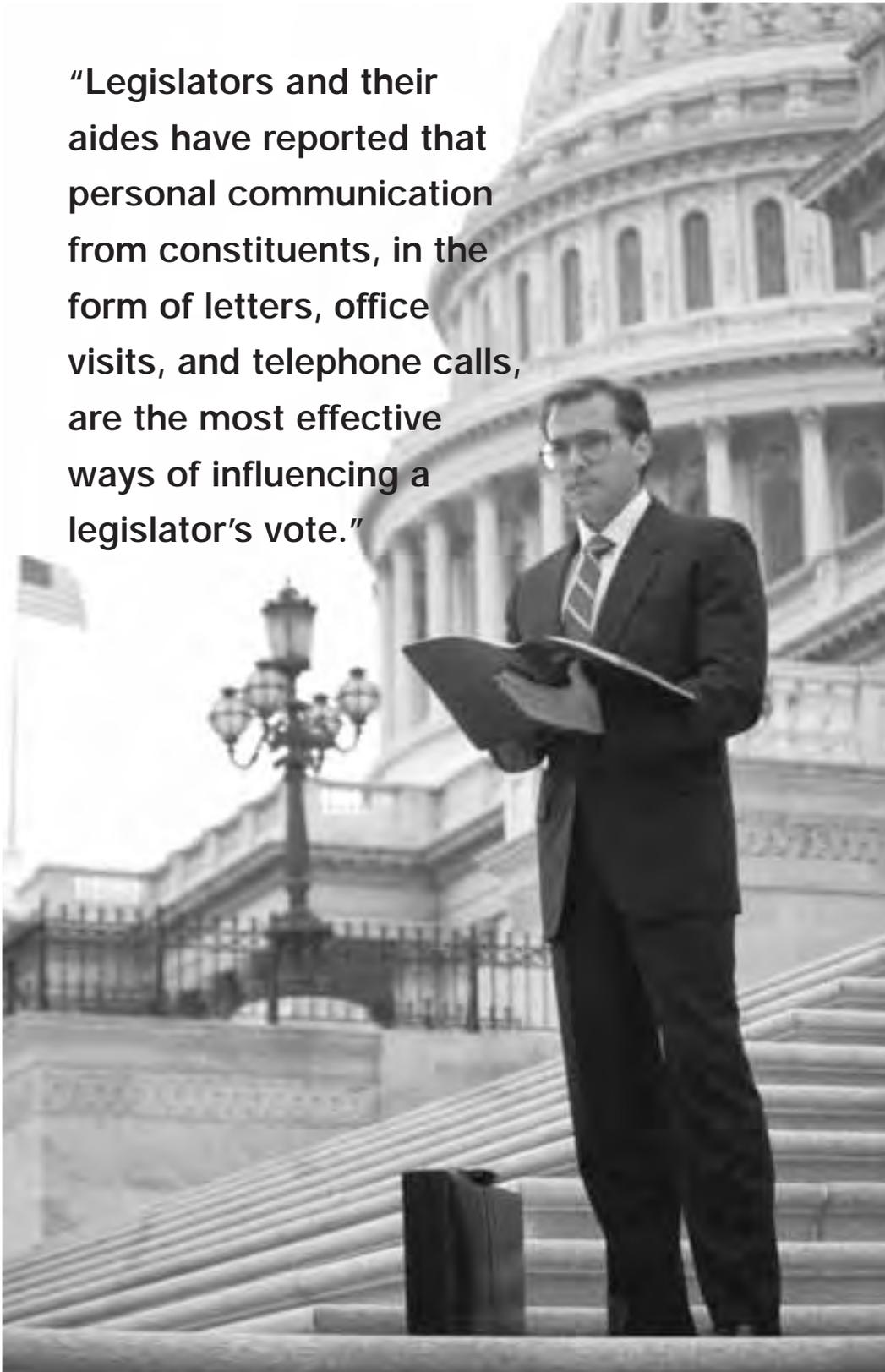
At times you may want to communicate with the White House about federal issues that are important to you. These communications may be used by the President to gauge public opinion.

To write the White House, be sure to address your letter correctly. The proper form is as follows:

**The President of the United States
The White House
1600 Pennsylvania Avenue
Washington, DC 20500**

Dear Mr. President,

“Legislators and their aides have reported that personal communication from constituents, in the form of letters, office visits, and telephone calls, are the most effective ways of influencing a legislator’s vote.”



You can also contact the White House by fax at (202) 456-2461 or, if you have access to the Internet, via e-mail at *President@WhiteHouse.gov*

The United States Senate

To write to any Senator, be sure to address the letter correctly. The proper form is as follows:

The Honorable (insert full name)
United States Senate
Washington, DC 20510

Dear Senator (insert last name),

The United States House of Representatives

To write to any Representative, be sure to address your letter correctly. The proper form is as follows:

The Honorable (insert full name)
United States House of Representatives
Washington, DC 20515

Dear Representative (insert last name),

State Government Elected Officials Governor

To write to your Governor, be sure to address your letter correctly. The proper form is as follows:

The Honorable (insert full name)
Governor of the State of (insert name of state)
City, State, Zip Code

Dear Governor (insert last name),

State Senate

To write to any state Senator, be sure to address your letter correctly. The proper form is as follows:

The Honorable (insert full name)
(Address)

Dear Senator (insert last name),

State General Assembly or State House of Representatives

To write to any state Representative, be sure to address your letter correctly. The proper form is as follows:

The Honorable (insert full name)
(Address)

Dear Representative (insert last name),

Calling Legislators

A phone call is a good way to let your legislator know how you feel about an issue, especially when action is expected within 24 hours and there is no time to send a letter or schedule an office visit. An outpouring of calls can sometimes change the vote of a legislator; however, even a small number of calls can make a difference.

Your opinion is more likely to be counted if you place a phone call to the legislator's capital office, rather than the district office, especially when a vote is imminent. If you are unable to speak to the legislator, ask to speak to an aide who is assigned to your issue. If you are unable to speak to an aide, leave a message with the person who answered the phone. Remember to keep your message brief and to ask the legislator to send you a written response-this will ensure that your call is counted and that you are identified as a constituent.

To phone the White House comment line, call (202) 456-1111 or (202) 456-6213 (TTY/TDD). This number gives you the option of registering your opinion using your touch-tone phone or by leaving a message with an operator.

To phone a member of Congress, call the United States Capitol switchboard at (202) 224-3121 and an operator will connect you directly with the Senate or House of Representative office that you request.

Meeting with Elected Officials

Most legislators travel to their home districts as often as possible, usually at the end of the week, on weekends, and when the legislature is not in session. These frequent trips home give representatives the opportunity to speak with their constituents and get your views on legislative issues. Also, legislators

tend to be less rushed during district visits, which will give you more time to spend making your point.

Before scheduling an office visit with your representative, you may want to consider arranging a small group to make the visit, rather than going by yourself. Some people feel more comfortable speaking to a legislator in a small group. This may also give each member the opportunity to speak about a key point that affects him or her personally.

It is important, however, that the group remains small and organized at all times. Small meetings allow for more detailed discussion of an issue, and it is important not to overpower your legislator. You might only be allotted a small amount of time to meet with your legislator; therefore, it is important to keep a narrow focus and to prioritize your goals for the meeting. A brief, preliminary meeting of your delegation may be useful to define these goals and each person's role in illustrating your group's point. It may help to designate one person as the facilitator of the meeting, with a focus on sticking to your group's key points and time limitations.

When meeting with your legislator, it is important to clearly explain what you want your legislator to do and why you want him or her to do it. Do you want this legislator to sponsor the legislation, or vote for or against it? When deciding what to ask for, it may help to research the positions this legislator has taken in the past on similar issues. Try to give examples of the impact the proposal will have on people in the district. Relaying your own personal experience may also be effective, so long as it helps to illustrate your group's point.

Be well-armed with information, including the bill number and title. Legislators are not specialists—they are generalists. Therefore, it is likely that you will be in a position to educate the legislator on your personal perspective as well as providing information rooted in hard facts. However, if you are presented with a question and you do not know the answer, it is okay to say so. Although chances are that you will know more about the issue than the legislator, as a constituent you are not expected to know everything. Simply offer to find the answer for the legislator and respond to his or her office with what you find.

It is important to spend time with your legislator, even if his or her position is

different than yours. Sometimes, the information you provide can lessen the intensity of the opposition. The most important thing is to remain respectful and polite at all times. Never confront, threaten, pressure, or beg. Although the meeting may become frustrating, an inappropriate outburst will do more harm than good in the long run, and make the legislator reluctant to work with your group again in the future.

Do not become discouraged if your legislator is too busy to meet with you. Instead, ask if you might be able to meet with the staff person responsible for the legislation you are inquiring about. These staff members make recommendations to legislators concerning issues and, given the busy schedule that a legislator keeps, it is important to develop and maintain a good working relationship with staff members responsible for the issues important to you.

Finally, always leave the legislator or staff person with something to look over after you have left—for example, a fact sheet or copies of pertinent articles that have run in a local newspaper. These written materials give the legislator something to refer back to in the future, perhaps when he or she is deciding how to vote on the bill or asking others for their support. Follow up your visit with a thank-you note, and enclose any further information that the legislator requested during your meeting. The thank-you note is also a wonderful opportunity to remind the legislator of any commitments to action that he or she made during the meeting.

To find out who your legislators are on the federal and state level:

- Congress.org: **www.congress.org**
- Project Vote-Smart is a non-profit organization devoted to voter education. Among the services that the organization provides is assistance in identifying your legislators on both the federal and state level. Project Vote-Smart can be reached toll-free at 1 (888) VOTE SMART or at their Web site: **www.vote-smart.org**
- Voter.com: **www.voter.com**
- To contact any US Senator or Representative, call the United States Capitol switchboard at (202) 224-3121 and an operator will connect you to the office you request.

Helpful Web Sites

The Web sites listed below serve as excellent resources for information on disability rights organizations and ADA-related topics.

www.unitedspinal.org—United Spinal Association’s Official Web site

www.usdoj.gov/disabilities.htm—Department of Justice ADA Home Page
—Toll Free Hotline for ADA Technical Assistance—#1-800-949-4232 (v/tty)

www.aapd.org—American Association of People With Disabilities

www.access-board.gov—Federal Agency Committed to Accessible Design

www.ncil.org—National Council on Independent Living

www.protectionandadvocacy.com—Protection and Advocacy Resource
—Disability Rights Network

www.nod.org—National Organization on Disability

www.nmss.org—National MS Society

www.hhs.gov—U.S. Department of Health and Human Services
—Office for Civil Rights

www.projectaction.org—Accessible Transportation Resource

United Spinal Association

75-20 Astoria Boulevard
Jackson Heights, NY 11370

Tel (718) 803-3782

Fax (718) 803-0414

www.unitedspinal.org

Final Thoughts

We hope that you have found the information in this Self-Advocacy booklet useful and that it has provided you with the basic tools that you'll need to make a difference in your community.

Please take the time to review this material. If you need additional information, assistance or clarification on an issue or law, please do not hesitate to contact United Spinal Association at any of our toll-free numbers.

Again, we would like to commend you on your decision to get involved and become a Self-Advocate.

United Spinal Association

75-20 Astoria Boulevard
Jackson Heights, NY 11370-1177
Tel 718.803.3782
Fax 718.803.3782
www.unitedspinal.org

Additional Offices

P.O. Box 42938
Philadelphia, PA 19101-2938
1.800.807.0190

111 West Huron Street
Buffalo, NY 14202
1.800.807.0191

245 West Houston Street
New York, NY 10014
Tel 212.807.3161
Fax 212.807.4018

324 Washington Avenue, SW
Suite 1
Roanoke, VA 24016-4312
Tel 540.342.0032/0336
Fax 540.342.0339

1146 19th Street, NW
Suite 250
Washington, DC 20036
Tel 202.331.1002
Fax 202.466.5011

To order any of United Spinal publications, visit our Web site at www.unitedspinal.org or call our **Publications Hotline** at **1-800-444-0120**

Did You Know . . .

That United Spinal Association does not receive any taxpayer money from the government?

Our programs depend on people like you and the gifts you give. In fact, without generous people like you, our organization could not exist.

For more information on the important programs that you help support, or for information on the different ways that you can make a gift, call **1-800-404-2899** or go to our Web site at: www.unitedspinal.org

Expanding Opportunities for Veterans and All Paralyzed Americans

United Spinal Association
75-20 Astoria Boulevard
Jackson Heights, NY 11370-1177

Tel 718 803 3782
Fax 718 803 0414
www.unitedspinal.org