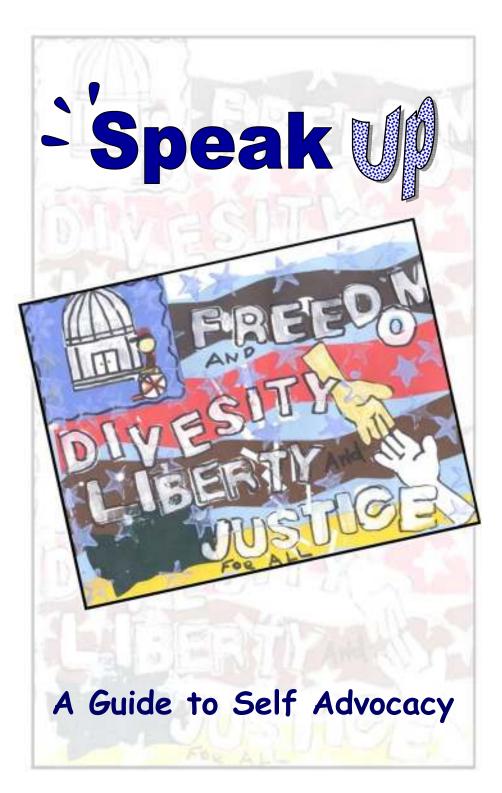




The Arc of Washington State Advocates for the Rights of Citizens with Developmental Disabilities





### A Guide to Self Advocacy

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Concept and content created by Self Advocates in Leadership (SAIL)

Special thanks to Dale Colin, Dewey Mee and Emily Rogers for their vision and guidance in developing this booklet.

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#### A word from the artists...



#### Artist: Mary Jo Sizemore

"The stripes in the background represent the different colors of people around the world. The hands represent advocacy/reaching out."



#### Artist: Elizabeth Glidden

"This picture is about having to make your own decisions about what path you choose in your life."



#### Artist: Clara Link

"To me, this photo represents self advocacy. Among so many pink tulips, there I am, the beautiful and unique white tulip. It stands out, in front of all the other tulips, and that is what I want to do."

#### Artist: George Adams

"It's about self advocacy, going to the state capitol and speaking up. I put the whole concept of the picture together in my head and then painted it."

#### Artist: David Stadden

"My mom was in Olympia while I was in school reading a book about the Legislature. I was thinking about the state capitol where mom goes, and the two bills she was talking to people about. "

For more information, contact:

The Arc of Washington State 2638 State Avenue NE Olympia, WA 98506 888.754.8798 ♦ www.arcwa.org

This booklet is funded by a grant from the Washington State Developmental Disabilities Council.



### Self Advocacy Initiative

The Self Advocacy Initiative Project, funded by the Washington State Developmental Disabilities Council, promotes self advocacy efforts throughout our state.

The project offers presentations and workshops for beginners and seasoned advocates, as well as technical assistance to advocacy groups and individuals interested in writing letters, learning about specific issues and hosting legislative receptions or "coffees."

For more information about strengthening and supporting self advocacy in your area, contact: Emily Rogers ♦ 1-888-754-8798 emily@arcwa.org





I am so pleased that you have decided to learn more about self-advocacy! Self-advocacy means different things to each person. Since we all have lives of our own, our reasons for learning to advocate for ourselves and others are unique.

It is important that we speak up, or otherwise communicate our desires. By doing this, we begin to take back the power to direct our own lives and rekindle the dreams we each have.

Throughout this booklet you will have the opportunity to hear the stories of several people and how they have advocated for themselves. Be encouraged, you can do it too! On these pages you will also find images that mean self-advocacy to their creators.

You are at the beginning of a wonderful journey of self-advocacy! Enjoy the ride, there will be ups and downs but in the end you will look back and say what an incredible experience it has been, indeed!

In the spirit of Advocacy

Emily J. Rogers

Longtime Washington State Advocate and Chair of SAIL





### IF YOU...

...Need support to live, work or be active in your local community. (Support might come from people such as: family, paid staff, payee, case manager, or a teacher.)

### OR

...Receive in-home personal care, health care, housing assistance, communication aides, mobility aides, employment support, education or any other paid service.

#### OR

...Attend meetings in which your life is the topic — such as your job, your education, your living situation, or plans for your future.

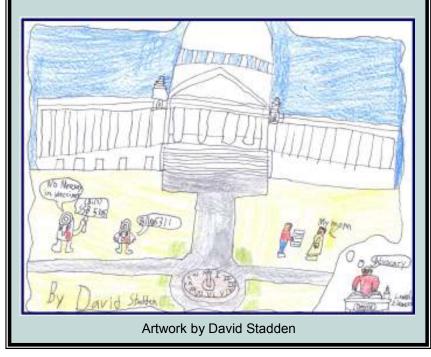
#### OR

...Have a friend, family member or someone you are paid to support who fits one of the descriptions above and you want to learn how to support them in speaking up for themselves.

### ... THEN THIS BOOKLET IS FOR YOU

#### **TIPS FOR GREAT SUPPORT**

- Ask us what would be helpful. If we are going to a meeting, we might like assistance beforehand to prepare, such as practicing what we want to say.
- **Be positive.** Help us think of ways to make our ideas and dreams work. If we have barriers, it's more useful to think of ways to move past them than to find reasons we can't.
- Believe in our abilities. We are all more likely to succeed when we build on our talents.
- Help us communicate our thoughts and ideas (if we ask) without speaking for us.



# Supporting Self Advocacy

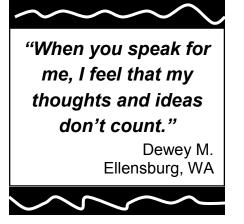


S upporting self advocacy is a fine balancing act. It's giving support without taking over. It's being there to help, but also being okay with taking a back seat.

Many of us who want to strengthen our voices need some support. Maybe it's a ride to meetings, personal assistance or help with scheduling. Mostly, though, what we need is to be heard and respected.

Everyone is different when it comes to what he or she needs to be supported, but there are some general guidelines in supporting self advocacy.

First and foremost, we ask that others do not speak for us or instead



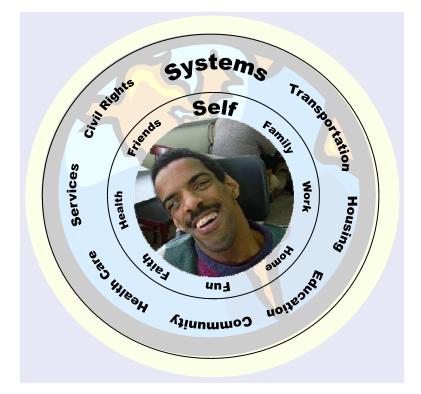
of us. If people who are there to help us also participate in our meetings and activities, it takes away time and opportunity for us to have a voice.

Great support comes from people who understand the importance of their role without overshadowing our presence.

# Change Your Life Change the World



C hange is an inside job. It starts with our personal lives and widens to impact our circle of family, friends, neighbors, local communities, state and nation.



Advocacy skills are tools that help us make a positive difference for ourselves and others. Use them any way you want, from decorating your home and hiring support staff to working on legislation that creates social justice.

## Self Advocacy is Something We All Do



**S** elf advocacy is something we all do when we speak up for ourselves. It can be an everyday thing, like deciding what we are going to wear or eat for dinner. It can also be a big effort, like buying a home, finding a job, or helping to pass a bill into law.



Self Advocacy is a way of thinking about things differently, thinking up solutions for ourselves. We can find ways to get what we want and need... ways that no one else can think of because we already know what works best for us.

Too many people become people pleasers, but they never think to please themselves first. The condition of our homes, the food we eat, the friends we have.... all have to do with getting our point across.

"The ideal is when you get past advocacy as a special event. It's just a natural thing you do." Dewey M. Ellensburg, WA

After a while, it's not even self advocacy anymore. It's just living.



Artwork by George Adams

Central Washington Advocacy Coalition 1-800-240-5978 (v/tdd) Ellensburg

Coalition of Responsible Disabled (CORD) 1-509-326-6355 Spokane

People First of Washington 1-800-758-1123 Chapters throughout the state

Self Advocates in Leadership (S.A.I.L) 1-888-754-8798 A statewide public policy coalition

# What's the Big Idea? Join a Group!



re you interested in advocating for issues that affect other people, such as disability rights, health care, transportation, or funding for services?

The best way to learn the ropes of big systems advocacy is to join a group that has values and goals you believe in.

### **Dale's Story**



I've been involved in advocacy for over twenty years, starting with People First in 1981 and then Self Dale C. Advocates of Washington since Edgewood, WA 1993. I've also been on the board of The Arc, the Pierce County Advisory Board, co-chair of the Self Determination Forum, and the planning committee for Tools for Success.

As part of a project for people moving out of Rainier School. I checked to make sure that people who left the institution were happy in their new homes.

If people had told me in the 1960's and 70's that I would be doing all of this, I would have told them they were nuts. Now, I've got a whole wall of certificates for my advocacy, and I feel good about the work I've done.

# It's About Making Choices... **Not Just Having Them**

e can have lots of choices, but self advocacy V means we are the ones doing the choosing, not someone else.



Artwork by Elizabeth Glidden

Some people use the term "self advocate" to describe those of us who speak up for ourselves, but self advocacy is something we do, it is not who we are.

In this booklet, and in life, we encourage people to think about self-advocacy as an action, not a label.

## Self Advocacy Begins At Home



Advocacy can mean asking for help to tie our shoelaces or joining a group to advocate for better laws. The important thing to remember is that speaking up for ourselves begins at home!



#### Mike's Story

Me and my wife needed to have our home remodeled. The floor in the bathroom was sinking and we were worried.

Mike R. Tacoma, WA

We went to my payee and case manager to see about getting a loan. My payee helped with all the paperwork. We got a loan approved and got started on the house.

We got a lot more than a new bathroom floor. Both the bathroom and kitchen were remodeled with new sinks, cabinets and paint. I feel real good about it.

All my years in advocacy taught me to speak up for myself and get things done. If I did not ever get involved in advocacy, I would have been upset over things, not knowing how to take care of problems. I say to everyone out there — if we can do it, you can do it!

#### Alexa's Story

I love my life. I cherish my family and friends, working at Chili's in Issaquah, and spending time with my boyfriend. Tim was my high school sweetheart and we've been together for about four years.



Alexa A. Bellevue, WA

High school has precious memories for me. That's when I did a lot of fun things and was more independent. It helped me and made me kind of wise.

People say I'm a role model, but I try to bring that down a little and be less in the spotlight. I know I need to buckle down on some things, like if I want to move out and get my own place to live. I am starting a great new job at Starbucks in Issaquah by the QFC. I need a career job so I can move out.

I would say one of my best qualities is that I'm very good at giving advice. People are important to me and I like to be fair and honest with them.

My advice to others is: Sit down wherever you are and think, *what are some qualities about myself*? Really think about what you cherish in your life. What do you want to do in your future? Care about yourself. That's a good place to start.

# **C** Speaking Up

### Speaking Out **9**

The following advice and insights come from people who have had experience speaking up for themselves and advocating for the rights of others. Like you, they are the experts when it comes to self advocacy.

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"The best thing about self advocacy is that you have respect for yourself, respect for others and being independent to do what you want."

Terri R. (Richland, WA)

"Interact with different groups. Research what they are about and find a good fit. You can be part of a group and bring your individual voice.



William F. (Yakima, WA)

Be comfortable and say what's on your mind. You have to go against the grain a little bit. There are nay-sayers who say you can't do it and you have to overcome that rejection.



Larry M. (Seattle, WA)

"Reach for the stars, go for the gusto." Michelle H. (Kennewick, WA)

#### **Terri's Story**

I've been an advocate for individuals with developmental disabilities for three years. I know first hand what it takes for people to get what they want.

In my own life I've had some challenges with in-home providers not respecting my property, my privacy and my rights.

Terri H. Bellingham, WA

Being that I have had past experiences with letting care providers go, I know what it's like to stand up for myself.

"Being independent means being in the drivers' seat." I used my choice and power and had to go through some battles to get what I wanted to become as independent as I possibly can. I felt nerve wracked doing this, but I felt I was having control over what I needed to have control over.

Being independent means being in the driver's seat. Sometimes, this means asking for help. If something isn't working for you, you have to speak up and say something. Be patient and stand up for your rights and what you believe in. From my experiences, I know it's made me a stronger person.

# If We are Silent, Other People will Speak for



We don't speak up for ourselves, how are people going to know what we really want? Can we expect someone to read our minds? Of course not. We have to clue other people in or they will end up thinking they know what is best for us.

Advocating for ourselves also helps other people in similar situations. Maybe you're having a problem getting respect from a service provider or bus driver. By speaking up, you help change the situation, and this helps other people.

"Speak up so other people won't control your life." Chris P. Ellensburg, WA



### "Stand Out and Speak Up"

by Clara Link

I want to stand out and speak up for my rights, I don't want to let other people make all my decisions for me.



I say as self-advocates, we must stand out and speak up for ourselves.



## Follow Your Dreams



### **Clara's Story**

It was a dream of mine to turn my hobby of taking pictures into becoming a professional photographer. It is something I have a gift for and I love doing. With the help of my mother and friends, I started my own business and now I get to live my dream.



Clara L. Tacoma, WA

I have taken pictures for magazines, books, pamphlets, and television programs. One of the projects I'm most proud of is a yearly calendar for the Down Syndrome Community called "Living it Up!"

I also travel around the country and the world, taking pictures and speaking about living with a disability. I have worked hard for my dream, and I am here to help others do the same.

I have a good life and I want other people to have a good life too, because that is their right!

[See Clara's winning artwork on the opposite page.]

#### Adrian's Story

Throughout my life, other people have been negative about me because of my disability. It's been hurtful.

It was hard to deal with being rejected, especially by girls. I wanted to prove to them and myself that I have a lot to offer.



Adrian P. Everett, WA

I want people to accept me for who I am and not look at my disability and think that's me. It took me a long time and a lot of years to understand who I am and to know the good things about myself.

There have been a lot of ups and downs to get where I am today. I have battled tough personal issues and overcome some pretty big barriers. It took courage to feel good about myself when others tried to hold me down. "Nobody can say you can't get that job you want, or relationship you are looking for."

My advice to others is to keep on trying and do not lose faith in yourself. Nobody can say you can't get that job you want, or relationship you are looking for. Believe in yourself and be determined that you can do it.

## It Takes Work to Find Work



inding a job you like, or developing a career that suits you, takes a lot of hard work.

Strong self-advocacy skills go a long way to helping you land a job that lights your fire (or at least gets you moving in the right direction of your goals).

#### Shimika's Story

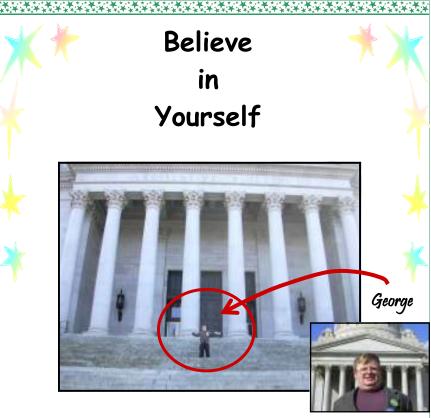
I've worked at Traditions Café for about a year, and I really like it. I go to school at the local college, so I haven't planned much about what I want to do in the future. For now, this is where I want to be.



Shimika B. Olympia, WA

My job makes me feel great. It gives me money to buy clothes and pay back my mom for money I owe her. It makes me proud to work hard and do a good job.

One of the things I really love is being part of fashion shows at the café. I stand on stage and model Free Trade clothes. I like being in the limelight, and the owner of the cafe says I look really good in the clothes.



"I'm a person who helps any way I can. I am an advocacy coordinator for The Arc of Washington State, the state President for Self Advocates of Washington, member of the Kitsap County DD Board and a courtesy clerk for Safeway (going on four years!).

The first time I walked into a SAIL meeting, I was totally blown away. I thought it was really cool that there was a coalition that talked about things that were important. I helped pass four bills that were really important to people with disabilities. I love what I do." — George A., Bremerton, WA