

The Art of Impact:

A Handbook for Self-Determined Living

by Scott Michael Robertson, PhD

Your journey starts here...

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NACDD
National Association of Councils
on Developmental Disabilities

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Foreword by Donna Meltzer

Renowned anthropologist Margaret Meade once wrote about advocacy. She said, “Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has.” I couldn't agree more! I believe that Ms. Meade understood the power of advocacy well. She also understood what is inside each of us that, can effect change.

Serving as the CEO of the [National Association of Councils on Developmental Disabilities](#) (NACDD) since 2012, I work each day with committed individuals like each of you to create change and make our world a better place for *all*. Sometimes we enact change through new laws and policies, sometimes through education and strong school curricula and sometimes by speaking out to groups of people or by talking with people one-on-one. Change is also created by simply being ourselves while silently showing others who we are and what we are about by living the life we choose.

All of these pursuits for advocacy are equally important. It is up to us to figure out for ourselves which ways work best for each of us. The

goal is to become an advocate and to inspire others to create change too. Self-advocacy means finding ways to speak out about change that can help you and others.

The Art of Impact explores the power of self-advocacy. It presents the thoughts of a core group of committed leaders on NACDD's Self-Advocate Leadership Circle. Scott Michael Robertson, Ph.D., wrote this book with input from these Leadership Circle members. The book shares tips, tools, and strategies for advocacy to help you live a self-determined life and become an advocate for change.

We've titled this eBook *The Art of Impact* because self-advocacy it's more than an action, it's an art form. *Art* is the expression or application of creative skill and imagination. The NACDD's Leadership Circle is full of creative skill and imagination and is growing daily! They are expressing their views and creating change through their own aesthetics. Some of the Leadership Circle members have artfully crafted testimony or presentations. Other members have given public performances, such as at comedy shows. Knowing all this creativity, we had to share it with you! We also

wanted to emphasize our art theme through this book's cover created by someone empowered by self-advocacy.

On behalf of [NACDD](#) and its Self-Advocate Leadership Circle, I invite you into this book. You can begin your own journey into self-advocacy or feel inspired to take your journey further. I hope you will learn something new from the examples shared here. We encourage everyone to speak up for themselves. We want you to lead a healthy and meaningful life and stay involved in your community.

Enjoy!

Donna A. Meltzer
CEO, National Association of Councils on Developmental Disabilities

Foreword by Dan Ohler

Have you ever had someone tell you that their job is to represent you, or to speak for you? Have you ever said, or wanted to say, "I can speak for myself"? If so, this book has been developed just for you!

[The National Association of Councils on Developmental Disabilities](#)

(NACDD) has made self-advocacy a priority, evidenced in part by their creation of a Self-Advocacy Leadership Circle and other

initiatives designed to foster the growth of self-advocacy that will span the nation.

At OPTUM, we are proud to have partnered with NACDD in funding the development of this e-book to reach as many people as possible. We believe that every person has the right to speak for themselves and the right to be involved in the decisions that impact their life. This eBook, titled *A Handbook for Self Determined Living*, is available on a computer or a variety of mobile devices, including an iPad or a Smartphone; of course, it can also be printed for people that would prefer a paper version. It was written by a self-advocate, who himself was assisted by people just like you that wanted to speak for themselves and to help you understand how to become your own advocate. Their stories are included in this handbook.

President Franklin D. Roosevelt, a man who himself had disabilities, was quoted: *“The test of our progress is not whether we add more to the abundance of those who have much, it is whether we provide enough for those who have too little.”* All of us at OPTUM, as well as our partners at NACDD, want you to pursue your dreams and have a

great life. We hope that you find this handbook helpful in your efforts to become a self-advocate. This is your life and you have the right to speak for yourself and to be involved in the decisions that impact your life. If you are ready to get more involved in the decisions that impact you, this handbook is a great place to start. *Your journey begins here!*

Dan Ohler
Vice President for State Government Programs, OPTUM



OPTUM is a leading health services company committed to making the health care system better for everyone.

Chapter 1: An Introduction to Self-Advocacy

About this Book

This e-book is your guide to self-advocacy and healthy living in your community. It will help introduce you to self-advocacy. Those of you who already know about self-advocacy can learn more about it. You can learn how to practice and improve your self-advocacy skills. You can also learn tips from veteran leaders.

In the first chapter of this e-book, you will read about what self-advocacy is. You will learn about how people from diverse backgrounds self-advocate every day. You will also learn about your rights and what it means to live in the community.

In the second chapter of this e-book, you will read about the Self-Advocates Leadership Circle. The members of this group come from several states around the U.S. and the territory of Guam. They have achieved success with self-advocacy in many different ways. They will write about how they learned about self-advocacy and what it means to them.

In the fourth chapter of this e-book, you will read about leadership. You will learn about what it means to be a leader in your community. You will also learn about how to start and run groups and organizations.

What does living in my community mean?

You have a right to participate actively in your local community and live a healthy life. Your community means where you live, work, go to school, and visit. It includes all of the people and places around you. Stores, restaurants, and offices are all part of your community. Parks,



museums, stadiums, and arenas are part of your community.

Libraries, community centers, and hospitals are also part of your community life.

Practicing faith is an important part of living in the community for many people. Communities often have churches, synagogues, temples, and other places of worship. Attending these places in the community is a way of life for many people. It can also help them stay connected with their friends and family members.

Going to school is also key to staying connected with your community. Communities include schools for children and

adolescents. Communities

also often include schools

for adults, such as

colleges, universities, and

vocational schools. They

learn new knowledge and



skills in these schools to help to get a job. The places where people work can also be an important part of the community.

Self-advocacy can help you to participate actively in your own community. You can speak up and advocate for what you want to do in your community. You can advocate for making your own choices in life. You can also speak up and advocate for the rights of other people.

How can I vote in my community?

Voting can help you to speak up for what you believe. Voting is the most important civil right for citizens in the United States. It is fundamental to the American democracy.

The right to vote means you can help decide whom to elect to the government. Some people vote by going to a place in their community like a school, library, or police station. Other people vote by mail or with an absentee ballot.



The first step in voting is registering to vote. You can register to vote at the library or the Board of Elections. Some communities also let

you register to vote online. If you need help registering to vote, visit your town hall or city hall. You can also visit the website www.vote411.org.

How do I stay healthy in my community?

Staying healthy and well is essential for you to live in the community. You need to be healthy to be able to visit places, talk to people participate actively. You also need to be healthy to enjoy your activities while living in the community.

Places in your community can help you stay healthy. You might go to the doctor's office for check-ups to make sure you stay well. You might also visit your doctor or a hospital to help you get better when you get sick.

Health and fitness places can also help you to stay healthy. Many people have memberships to gyms,



recreational centers, and pools. They exercise by using fitness equipment or playing indoor sports like swimming. Other people stay healthy by jogging, playing outdoor sports like baseball. Sometimes, people add other activities to make staying healthy and fit fun. They might take photographs of places they visit while exercising and staying fit.



Eating healthy foods can also help you stay fit. You can include fruits, vegetables, and protein to maintain good health. Drinking water and other healthy

liquids can also help you stay healthy. Your doctor can help you select nutritious foods for your diet.

While enjoying a healthy diet, make sure to get a good night's sleep. Stay away from activities that are not healthy. For example, refrain from smoking cigarettes or e-cigs. Your doctor can help you take steps to quit smoking if you need help.

How does good language make communities welcoming?

This book and other guides use respectful language to refer to people with disabilities. Respectful language respects the dignity and value of people. It refers to people as real persons with feelings, beliefs, and hopes and dreams.

Language that is not respectful can demean the lives of people with disabilities. It also harms their sense of self and self-worth. Slurs like the r-word have no place in our society.



You can advocate for others to use respectful language. When people do not use respectful language, you can speak up to express your concern. You can teach them about what respectful language is. You can also let them know how important it is to you and many other people.

What does self-advocacy mean?

Self-advocacy means speaking up and advocating for what you want in life. You use your voice to help make what you want to happen in your life. You also work with others to make that happen. Knowing how to self-advocate can help you participate in your community and live a healthier, fulfilling life.

Self-advocacy has a few different important parts to it. Self-advocacy requires that you:

- Know yourself well.
- Know your rights and resources.
- Learn how to express yourself well.
- Serve as an active leader.

The first part of self-advocacy is getting to know yourself better. Getting to know yourself better means thinking about all that makes



you, you! What do you do well and not do well in life? What are your dreams and goals for your own life? What are your beliefs and values?

The second part of self-advocacy is getting to know your rights and resources. Getting to know your rights means learning about federal and state laws that protect your rights. Getting to know your

resources means learning about what can help you exercise your rights. It also means finding resources that can help improve your self-advocacy.



The third part of self-advocacy is getting to know how to express yourself well in life and work with others. Expressing yourself well means sharing what you need and value in a way others understand. It also means listening to what others have to say. Effective self-advocacy requires that you learn how to negotiate with others and make your case. You cannot simply tell others what to do.

The fourth part of self-advocacy is becoming an active and engaged leader. Leadership can mean leading things in your life and driving your life forward. Leadership can also mean starting a group to help others achieve self-advocacy. It might also mean helping to run groups or organizations.

Self-Advocacy 101	
Self-Advocacy is...	Self-Advocacy is not...
Exercising your voice.	Letting others speak for you.
Working with others to help get your needs met.	Commanding others to meet your needs.
Listening to what others say.	Tuning out what others have to say.
Expressing yourself clearly.	Expressing yourself without clarifying your thoughts.
Knowing your rights.	Relying on others to know your rights
Knowing your resources.	Not knowing about your resources
Advocating for healthy living for yourself	Not advocating for your right to a healthy life.

How diverse is self-advocacy?

You join a very diverse group of people who self-advocate every day.

People in self-advocacy like you come from many diverse backgrounds. You represent differences in race/ethnicity, nationality, heritage, and religion. You also have differences in your ages, abilities, gender, gender identities, and sexual orientation. However, you all have a common goal to take direction of your lives.

Self-advocacy means something different to everyone in life. For some of you, self-advocacy might mean advocating for where to live and work. For others of you, that might mean advocating for the rights of other people.



Self-advocacy also means something different at different stages in life. For students in middle school or high school, self-advocacy might mean advocating for what classes you take. It might also be about advocating for your participation in clubs, school activities, and sports.

For those of you who have finished high school, self-advocacy might be about where you want to work and live. Self-advocacy might help you ask for supports or help to get your job done. It might also be about advocating for your right to find a partner in life and raise a family.

This is your journey. Self-advocacy means taking control of your life. It also means doing what you need to do to help you realize your dreams.

What are my rights?

You have the right to access the opportunities that are available to all Americans. You have the right to vote in elections if you are a citizen. You have the right to live in an apartment, house, or other place in your community. You have the right to go to school and get a job. You also have the right to make friends, find a partner, and raise a family.



However, this was not always the case for many people with disabilities. People with disabilities in our country have often found barriers that stopped us from accessing opportunities. Schools, workplaces, and events were often not accessible to people with disabilities. People without disabilities often did not want to accommodate people with disabilities.

In 1990, the Americans with Disabilities Act (ADA) helped change all this. The U.S. Congress passed the ADA to improve opportunities available for all people with disabilities. The ADA protects our civil rights. Other laws help ensure that we can vote and participate in our communities.



The federal government has a law called the Developmental Disabilities Act. This law helps protect the rights of people with intellectual and developmental disabilities. Many states have also passed similar laws. Some laws ensure that all students can attend

school with supports. Other laws help people to find and keep their jobs and travel safely on airplanes and trains.

The Councils in states and their partners often run programs called Partners in Policymaking. These programs teach people with disabilities and families about policy. They learn about how to advocate for better federal and state laws and rules. This experience helps them advocate for supports that promote inclusion and independence. To learn more about these programs, contact the Council in your state or territory.

Chapter 2: NACDD's Leadership Circle

What is NACDD?

The National Association of Councils on Developmental Disabilities (NACDD) is a national organization. NACDD serves as the national voice of Developmental Disabilities Councils. All 50 states, the District of Columbia and 5 U.S. Territories have a Council. NACDD represents the Councils' interests at meetings with federal officials and other leaders. NACDD also helps the Councils to do their work. They run webinars, trainings, and a national conference each year.

NACDD also partners with other national organizations to help them do their work. For example, NACDD made this e-book in cooperation with OPTUM. OPTUM is a national health services company. OPTUM works to bring quality healthcare to everyone.

The Councils work on how to improve services for people with disabilities. They also support work to improve advocacy for people with disabilities. Members of the Council come from three roles. Most Council Members are people with developmental disabilities or their

family members. Other Council Members represent state agencies in the government and partner agencies.

Members of NACDD's Self-Advocates Leadership Circle have served on the Councils in their home states. They have also served as leaders in their home communities. You can also find more about your own Council in your state or territory by visiting NACDD's website.

What is the Leadership Circle?

This second chapter is about NACDD's Self-Advocates Leadership Circle. NACDD started this leadership group in 2014. Members of the Leadership Circle come from several U.S. states and Guam, a U.S. territory. They are strong leaders who have advocated for themselves and others. They have diverse experiences and backgrounds.

Members of the Leadership Circle have achieved success in school, work, and advocacy. Many of them have led or started new organizations. Other Leadership Circle members have advocated for laws to improve opportunities for people with disabilities. They joined

the Leadership Circle after their Councils nominated them. NACDD selects new members to join the Council from a pool of nominations.

You will learn more about life achievements of the Leadership Circle members in this chapter. You will also learn firsthand from their stories and experiences. They will also share what self-advocacy and living in the community mean to them.

Leader: Santa Perez
Home State: Nevada



Santa Perez owns her own house in Nevada.

Santa is the mother of a 13 year-old son.

Santa thinks that self-advocacy is very important to being active in life in the community.

Santa has served as the president of People First of Nevada, a statewide group with seven chapters. Santa has also served on the Nevada Governor's Council on Developmental Disabilities. In 2013, NACDD awarded Santa their Champions of Equal Opportunity Award.

The Interview

What do you like most about yourself?

"[The] best [part] about me is being a mom. It took a long time, but I love it."

What does the word self-advocacy mean to you?

"Self-advocacy means knowing who you are, showing who you are, and defending who you are. [I'm a] fighter and will never back down if I know something [is] not right."

Leader: Aaron Snyder
Home State: Wyoming



Aaron Snyder works as a comedian and a motivational speaker in Wyoming. He has served on the Wyoming Governor's Council for People with Developmental Disabilities.

When meeting new people, Aaron self-identifies quickly as a speaker with cerebral palsy. Aaron feels a need to disclose because people can make judgments about his disability. Aaron thinks that self-advocacy is important to have a strong voice for people with disabilities.

The Interview

What is most important about your personal life story?

"I'm doing what I enjoy of doing disability [themed] comedy" [and] challenging] stereotypes of people who have disabilities. It's about being who you are. There is a lot of pressure to not be yourself."

What do you want other people to know about self-advocacy?

"Their voice in the world matters regardless of what one says."

Leader: Sandy Houghton
Home State: Massachusetts



Sandy Houghton was featured in the documentary, *The Sandy Houghton Story: An Inspirational Journey*. She started working with people with disabilities when her daughter was diagnosed with Alpers Syndrome. She started an open door club as a local self-advocacy group.

Sandy has written a book called *Wealth of Relationships*. She was also the first recipient of the Barbara Gopen Fellowship.

The Interview

Why is living in the community important to you?

"I have lived in the town of Hadley, Massachusetts most of my life. ... The community is important to me because I have connections in the town I grew up in. It has a family history."

Do you self-advocate at work or in school?

"At times it can be hard to self-advocate at work for something I might need to make my job easier. ... Sometimes it takes a co-worker to up on my behalf."

Leader: Eric Stoker

Home State: Utah



Eric serves as the Vice Chair of the Utah Developmental Disabilities Council. He also serves on the Board of the Utah Parent Center. Eric has worked as a basketball manager, library aide, and janitor.

He has testified at the Utah State Capitol on behalf of the Council and services for people with disabilities. In 2014, NACDD awarded him their Champion of Equal Opportunity Award.

The Interview

What is most important about your personal life story?

“Teaching and telling others about autism when I speak up at Weber State [is important]. It's been hard because people don't understand my disability.”

How have you helped other people improve their self-advocacy?

“I spoke at West Jordan High's Special Ed classroom about self-advocacy. I also helped mentor South Valley's People First group on voting.”

Leader: Shiloh Blackburn
Home State: Idaho



Shiloh earned an associate's degree from the Ricks College and a bachelor's degree from Idaho State University. She studied mass communications. Shiloh has served on the Idaho Developmental Disabilities Council and testified before the state legislature.

Shiloh served as the treasurer of the Idaho Self-Advocate Leadership Network. She also served as president of the group when it transitioned to an independent nonprofit organization.

The Interview

What does living in your community mean to you?

"[It] means living in my own home with the supports to do so. ... It shows me how independent I have become."

Why is self-advocacy important to you?

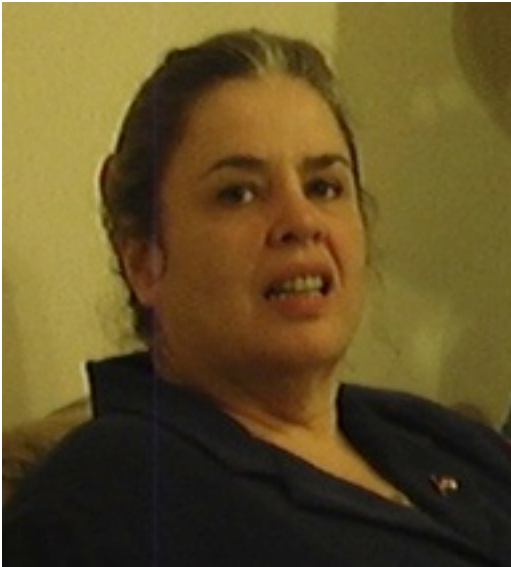
"It's taught me a lot about myself and shown me some strengths and weaknesses I have. It's given me a purpose in life, a way to 'pay it forward' by helping and serving my peers with disabilities. "

Leader: Erlinda (Lynn) Tydinco
Home Territory: Guam



Lynn serves as the president of People First of Guam. She also serves on the Guam Developmental Disabilities Council. Lynn is in her second term as Chair of the Council. She has worked as a telephone operator, and statistics coordinator. Lynn has also worked as an office manager and entertainment promoter.

Leader: Janice Cathy Enfield
Home State: Missouri



Cathy Enfield is the vice president of People First of Missouri. She serves on the Missouri Developmental Disabilities Council and chairs the Home and Community Living Committee. Cathy has also chaired the Board of Directors of Missouri Protection and Advocacy Services. In 2008, she received the Anita Carroll Self-Advocate of the Year Award.

Cathy has served as the vice president of Self-Advocates Becoming Empowered. She has also served on the Planning Committee for the Disability Policy Seminar. Cathy advocated for better access to technology. She also advocated for the Senate to ratify the CRPD, a treaty on disability rights.

Leader: Kathy Bates
Home State: New Hampshire



Kathy Bates has worked as a teacher, writer, advocate, and public speaker in New Hampshire. She has also served as the Chair of the New Hampshire Developmental Disabilities Council. Kathy has a degree in elementary education with an emphasis on special education from St. Andrews Presbyterian College in North Carolina.

Kathy served as the group leader for the Leadership Series of the New Hampshire Institute on Disability. She also served as an advisory board for New Hampshire People First and as SALT's facilitator.

Leader: Carrie Raabe
Home State: Arizona



Carrie Raabe serves as the chair of the Arizona Developmental Disabilities Council. She is the first person with a developmental disability to serve in this role. During high school, Carrie served on the speech and debate team and the forensics team.

Carrie has presented at TASH's conference and at the Arizona Department of Education. She has also presented at Northern Arizona University (NAU) and Arizona State University. Carrie has served as a disability expert for NAU as a workgroup member.

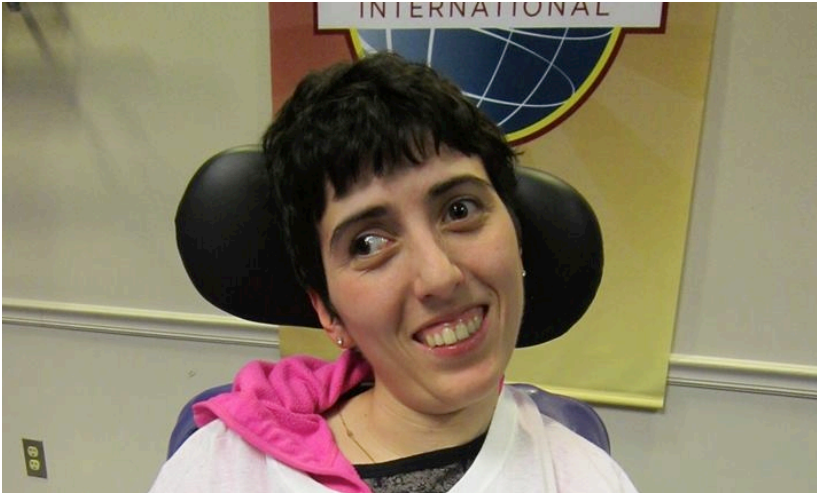
Leader: Cindy Bentley
Home State: Wisconsin



Cindy Bentley grew up living in foster homes and the Southern Wisconsin Center. In 1991, Special Olympics awarded her their International Female Athlete of the Year Award. She carried Wisconsin's banner in the 1995 Special Olympics World Summer Games. She has also served as a Global Messenger for Special Olympics since 2000.

Cindy has worked as an advocacy specialist for 14 years. She has presented to more than 4,500 students and spoken around the country. Cindy co-founded People First Wisconsin. She was the first self-advocate to serve as its President. During her life, Cindy has had dinner with two U.S. Presidents.

Leader: Marisa Laios
Home State: Virginia



Marisa Laios is a 2013 graduate of Virginia's Partners in Policymaking program. She is also a 2011 graduate of the Virginia Youth Leadership Forum. She received her associate's degree in general studies from Northern Virginia Community College.

Marisa has served as Vice President of the Arc of Northern Virginia. Marisa is a member of the Virginia Developmental Disabilities Council and Voices of Virginia, a People First chapter. Marisa volunteers with a lost dog and cat foundation. She has also served on several workgroups about Medicaid and a settlement with the U.S. Department of Justice.

Leader: William Lovell
Home State: Tennessee



William Lovell has worked at Walmart since 2002. He attended Buffalo River Services vocational development program after high school.

William is a member of People First Tennessee and the Lewis County Historical Society.

William assists Meals on Wheels and the heritage festival in Tennessee. He is a certified trainer for Person-Centered Planning through the People Planning Together Project. William helped lead his chapter of People First Tennessee during a rough period for the group. In 2008, he received the Self-Determination Award for Tennessee.

Leader: Kelly Holt
Home State: Utah



Kelly Holt lives with her sister and father in Utah. She is self-employed as a beauty consultant. Kelly has served as the chair of the Utah Developmental Disabilities Council. In 2008, the Council awarded her their Self-Advocate of the Year Award. NACDD awarded her their Champions of Equal Opportunity Award in 2012.

Kelly has served on the Advisory Council for the Center for Persons with Disabilities. She has also served on the Board of the Disability Law Center. In 2005, she inspired Utah Governor John Huntsman to name March as National Disability Month. She spoke out about how respectful language matters. Kelly has also spoken out against bullying. Kelly advocated for a law, HB-230, that removed unwelcoming language.

Chapter 3: Learning and Practicing Self-Advocacy

Improving your Communication

As you read in the earlier chapters, our communication is very important to strong self-advocacy. How we speak with and listen to others can change whether we are successful when we self-advocate. How we communicate by writing or pictures can also affect how we self-advocate.

Some people have found public speaking helpful to improve how they communicate with others. Public speaking is like any skill that gets better with practice. It can feel very uneasy at first when you set out with little experience. However, public speaking can become much easier when you do it regularly.

Try practicing public speaking with your friends and family members.



Try speaking at first to smaller groups of people. They might even be people you know well and who have supported you. You can even do mock speeches in front of a friend or family member. With support, you can speak regularly to small groups. When you feel comfortable, you might start speaking to larger groups. You could speak at conferences and rallies, for instance.

Practice can also help you learn to express yourself better in writing or with pictures. If you write more often, you will find it easier to write letters, emails, and documents to help you self-advocate.

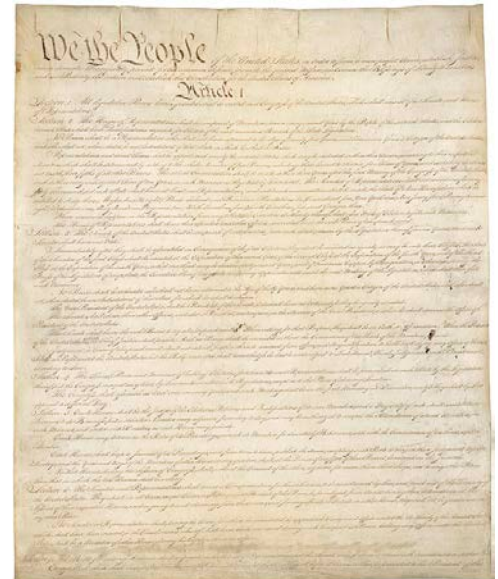
Interviewing can be another way to practice how you can communicate. You can try interviewing friends and family members to learn more about them. Before you do this, think of some questions to ask them. You might want to practice asking interview questions in a mirror first before you interview someone.

Learning About Your Rights

You have many rights protected by federal and state laws. Some of these laws are national (called federal laws). Other laws are for your

state or territory. Your local town or city may also have its own laws called *ordinances*. All of these laws protect your rights to go to school, work, and live actively and well in your community.

You can learn more about your rights under these laws through many activities. You can read about your rights by visiting websites, watching educational videos, and reading books. (The last chapter about resources shares some of these books, videos, and websites.)



You can also learn about your rights by talking to your friends and family members. You and your friends and family members can discuss your rights together. You can also have mock sessions in which you do role-play how about how laws protect your rights.

For example, you could do role-play about your rights when speaking with policy officers or going to court. You might also do role-play about your rights where you work or go to school. Your family

members and friends can also share with you books that can teach you more about your rights.

You can also learn more about your rights by visiting a resource center. If you are a person with a disability, you can call or visit a nearby Center for Independent Living (CIL). More than 500 CILs around the U.S. provide information on how to help people with disabilities live independently.

Learn more about yourself

Knowing your self well is very important to self-advocacy. Sometimes, we think we know ourselves better than we really do. Many activities can help us learn more about ourselves.

These activities can teach us to think about what we do well and what we do not do as well. We can also learn to think clearly about our goals, aspirations, and dreams and what will help us to get there.

This includes supports and services that can help us live healthy lives in our communities.

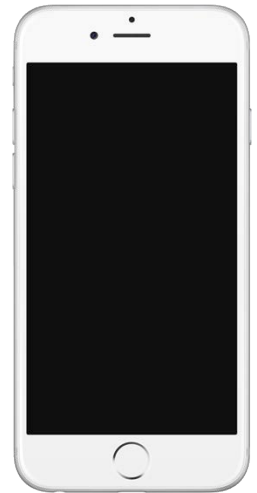
Sometimes, participating in an interview can help us to learn more about ourselves. The person interviewing us might ask us questions we might not have thought about that often. The interview might also help us think about our goals and dreams, and how we could accomplish them.

Learn about leadership

Leadership is also a key part of doing self-advocacy and living actively in the community. It is so essential to effective self-advocacy that we dedicated a whole chapter to it. You can read more about how to be a good leader for yourself and others in chapter 4.

Help from technologies

Technologies can help you to become an effective self-advocate. Many people now use apps on their computers, smartphones, and tablets. These apps help them communicate and learn to socialize better. Apps can also help you learn how to vote and become a leader.



Chapter 4: Becoming an Effective Leader

This fourth chapter is about becoming an effective leader. Those of you who are new to leadership will learn about how to be an effective leader. Those of you who already serve as leaders can also find good tips to improve your leadership.

How can etiquette help my leadership?

Professional etiquette is about handling ourselves well when we work and meet with other people in our activities. It is also about showing others respect when we speak with them. You can think about professional etiquette as a set of unwritten guidelines. These guidelines often do not usually have a formal written form like laws do. Yet, professional etiquette is just as important for our activities.



Meeting others' expectations for how we present ourselves is a big part of professional etiquette. For instance, others may expect you to wear certain clothes for meetings with leaders. You may also want to

make sure your hair looks presentable. This might mean using a comb.

You will usually want to wear formal clothing to meet with legislators, their staff, and other officials. Big meetings (known as conferences) often expect you to wear formal or semi-formal clothing to events. Sometimes people call this clothing style *business casual*.

However, these big meetings may also have casual events that do not require formal clothing. For example, some conferences have dances or events like karaoke. If you have any doubt about what to wear, you can always ask others attending the conference or event.

How can mentors help me be a leader?

Learning from other experienced leaders can help you become a better and stronger leader. An experienced leader who shares common interests may be interested in serving as your mentor. This means that they will act as a guide.



Mentors will be there to help you handle challenges, and they will provide advice. You can meet mentors at conferences and other gatherings of people. You may also meet mentors through your friends or while talking online.

Sometimes, some people may be a better fit to be your mentor than other people. A good mentor is someone who can listen to you, broaden your views, and help you grow. Good mentors should also be willing to learn from you, as well. They can learn from your experiences to help themselves grow.

Mentors often wish to give assistance as a way to pay it forward for help they received. Many of you mentors have had their own mentors to help them handle challenges in life.

How can teamwork help me become a leader?

A major part of your leadership is learning to work with other people to get things done. You may work with others on groups or at meetings. Many people call this teamwork. Sometimes, people may call this by a complex word called *collaboration*.



You can practice teamwork by working with others on group projects. You can work with other persons to write an article together. This article might be

for a newsletter, a book, your group, or something else.

You could also work with others on other projects. You might build or create things together, such as a large artwork or photography project. You might also volunteer with a group of others at a community center, shelter, or other place.



How can I start and lead a group about self-advocacy?

Helping lead a group for self-advocacy can help you practice your self-advocacy. It can also help you meet other people interested in self-advocacy. People in self-advocacy groups often share many interests in common with each other.

If you find a group for self-advocacy in your state or territory, ask them about how you can get involved. Tell them why you are interested in joining the group. Share your own personal story with the members of the group. Then, listen to and learn from the group members' stories.

You can tell the group about what you want to help them accomplish. You can talk about what you do well and how you can help the group to get things done. Talk to them about your leadership skills and what else you can contribute to help the group be successful.

You can also start a new group for self-advocacy with help from other people you know. They may be leaders in your state or people in other states who run groups. You may also be able to get support from your state government or other organizations.

How can I meet with policy makers?



You can meet with policy makers from your state or territory to express your views on issues.

They may be officials from the Governor's office, agency

leaders, or legislators. You can also meet with policy makers from the federal government.

Usually, you will want to call their office or make an appointment on their website. Sometimes, you can also meet with policy makers at town hall meetings and similar forums. Below is an example of an email sent to make an appointment with a state legislator:

An Email to Schedule an Appointment

To: darrowoodlawn@ms.gov
From: slagdon@gmail.com
Subject: Scheduling an appointment

Dear Mr. Darrow,

I would like to make an appointment to meet with you. I would like to meet to discuss the SB502 bill.

Let me know if I could meet with you this week. I am available to meet after 1 pm on any day this week.

Thank you.

-Sarah

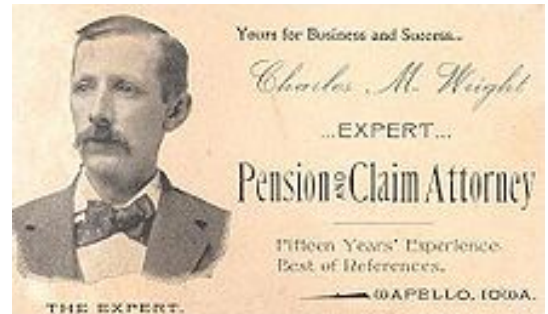
Sarah Lagndon, Biloxi, MS

Sometimes, elected officials may not be able to meet with you when you visit. However, their staff members will meet with you. The staff members can share your thoughts with their bosses.

Make sure you bring a business card or other way to contact you to the meeting.

The staff member or elected official may want to contact you to meet with you

again. They may also be interested in meeting with other people you know who can talk more about your issue.



If you belong to a group, your group may often meet with policy makers. Ask your group leaders about how you can get involved. You might attend meetings with other members from your group. You could also help prepare notes and other documents that your group might need for the meeting.

Meeting Public Officials	
Do...	Don't...
Prepare for your meeting.	Come to your meeting without preparing.
Dress professionally.	Dress too casual.
Bring your notes with you.	Leave your notes at home.
Practice meeting with others.	Forget to practice with others.
Find transportation to the meeting.	Have no way to get to the meeting.
Take notes during the meeting.	Have no way of taking notes during the meeting.
Listen actively to the discussion.	Speak over others without listening to them.

You can also contact public officials by writing a letter. In this letter, you can express your view on an issue. Below is an example of a letter written to a state representative.

A Letter to a Legislator

Richard Appleman
50 Fern Drive
Jackson, MS 39202

June 1, 2015

The Honorable John Blackridge
PO Box 542
Jackson, MS 39202

Dear Representative Blackridge,

My name is Richard Appleman. I live in the eastern section of Jackson, MS in your district. I have cerebral palsy.

I write to you to express my interest in increasing funding for services. Mississippi needs better services to help people with disabilities. We need services to help us get and keep jobs. We also need better services to make sure that we can live well in our own community.

I ask you to please show your support for SB502. SB502 is a new bill that increases funding for services.

Thank you for reading my letter.

Sincerely,

Richard Appleman

Setting an example in your leadership

Leadership is also about setting an example for others to follow.

Many other people will look up to you as a strong leader. They might see you as a role model for others. This is particularly true for young people.

You can set a good example by showing respect for others when you lead. You can also learn and help others practice good etiquette.

Appendix

The Sandy Houghton Story

Film Trailer Number 1:

<http://www.youtube.com/watch?v=APK-UbdF8Fk>

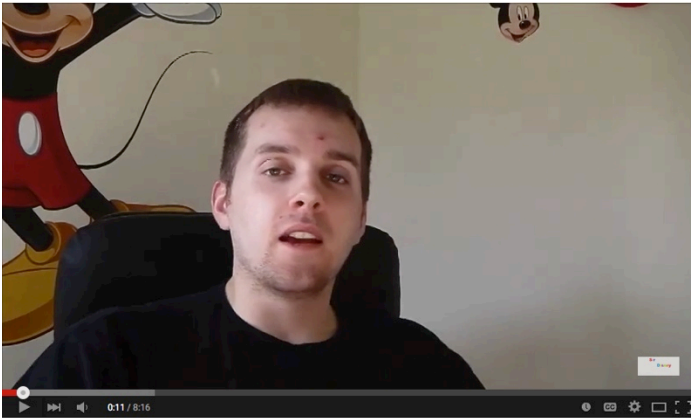
Film Trailer Number 2:

<http://www.youtube.com/watch?v=aMaBlc5jh3w>

Film Trailer Number 3:

<http://www.youtube.com/watch?v=RrPjRqIBkBQ>

Aaron Snyder's Disability-Themed Comedy Shows



Comedy World video (2010):

<http://www.youtube.com/watch?v=YJzmTsOS7Dw>

Sir Disney video (2014):

<http://www.youtube.com/watch?v=eSfzqrCNTEw>

Eric Stoker's Testimony before the Utah State

Legislature

[Chairwoman, ranking member and members of the committee, thank you for the opportunity to appear before you today. My name is Eric Stoker and I am the vice-chair of the Utah Developmental Disabilities Council.]

I am here representing the Council and to thank you for your past support of programs that promote opportunities for people with disabilities. Today, I ask you for support in this year's legislative process to continue the basic programs at DSPD that helps each year thousands of families and individuals with disabilities across Utah.

I am here today because I know the basic supports and services like respite care, self-administered services, support for people to remain out of more expensive institutions, and other programs work—these programs work well.

DSPD works closely with us on the Council. We consider at each Council meeting how to improve each program.

DSPD's basic budget is basic—many families are waiting for support—to cut services from these core programs may place families in higher cost needs later or even in crisis.

We support the Governor's budget this year for DSPD. Paul Smith, DPSD's director, will give you the details of each program. I am here to give the statement of support and to let you know we work every day build better programs that provide just a bit of assistance families need. This support makes all the difference.

We ask for your continuing support to Utahns with disabilities and their families that need DSPD's services.

Thank you.

Sandy Houghton's Testimony to the U.S. Administration on Intellectual and Developmental Disabilities (2010)

My name is Sandy Houghton. I am a self-advocate and I also work for the Massachusetts Developmental Disabilities Council as a leadership trainer and self-advocacy liaison. I want to speak about the importance of teaching self-awareness and social communication skills to students in transition.

First, I'd like to take a moment to tell you a little bit about myself.

Growing up as a middle child, I experienced firsthand the challenges a student with a disability faces. My older brother could do no wrong. My little sister had the looks and the brains. But I was the disabled kid. I did not have the same opportunities that my brother and sister had. I didn't have the friends or social experiences they had such as sleepovers, big birthday parties, or attending school dances.

As for my school years, the way that I talked, walked and dressed made me a target for bullying. It was difficult to succeed in an environment that did not offer any services to support my needs. It was near impossible to make friends. There were some caring teachers that offered support, but as a whole, systems were not in place to help me. I graduated at the bottom of my class. And I struggled as a young adult to find meaning and purpose in my life. Unfortunately, this sounds no different than what most students with disabilities still face decades later.

I was fortunate as an adult to connect with people who helped me to eventually find an identity and a purpose. It was a long and often

painful experience. But I am a better and happier person for it. And what I learned from that journey is that the skills that were most important for me to grow didn't come from a textbook or a classroom. They came through developing what professionals today refer to as "soft skills". Joining a self-advocacy group, being a member of the DD Council and serving as a Gopen Fellow provided me a great opportunity to hone these skills, and I have dedicated my career to working with people with DD to also develop these skills in order to succeed in life.

As a self-advocate who teaches self-advocacy and leadership to people with developmental disabilities, I believe that it is critical to teach self-awareness and social communication to students in transition. Youngsters and teenagers without disabilities learn these skills through peer interaction, social opportunities, school sports, and the like. Skills such as making and keeping friendships, being a good listener, being a team player, and being assertive as opposed to aggressive are what contribute to future success as an adult. It is through these experiences that students get to put such skills to practice and build self-confidence. But the school environment

provides little or no opportunities for most people with disabilities to develop these skills.

While it is true that many of these skills are introduced in the home, in today's society many households rely on two incomes, parents are inundated with multiple responsibilities trying to support the household and take care of their other children, on top of trying to navigate the complicated systems to find support for their children with disabilities. There is little time to teach soft skills to a child with a disability in the home. The workforce that students in transition are preparing to enter, have an expectation that they will possess the fundamental skills needed to work with others, and that they understand the importance of basic things that we all take for granted, like good hygiene practices.

The leadership series that I created and teach to adults with disabilities uses an interactive learning environment that focuses on the person, teaching them about themselves, about their strengths and abilities. It introduces different ways that people communicate. The way our body language speaks to people even when we don't,

and how attitudes and feelings influence our behavior towards others. It teaches students how to work together, how to dress for success, and how to be part of a team. This program improves a person's self-esteem, increases confidence to try new things, and assists them to develop the soft skills needed to succeed.

I struggled to get where I am today, and it pains me to see that young people are still facing the same struggles decades later.

Understanding who we are, making a good impression and exercising basic social principles are a recipe for success. I propose that ADD must invest time and effort to develop and expand similar trainings and programs for students in transition, as well as young adults.

Focusing on soft skills will enhance opportunities for students and young adults with disabilities to improve their social skills, increase their self-confidence and be productive members in the workforce.

About the Author

Scott Michael Robertson, PhD, works as a health and disability policy consultant. Scott has served as the Founding Vice President of the Autistic Self Advocacy Network (ASAN). ASAN is a national nonprofit organization. He has also served as the Joseph P. Kennedy, Jr. Fellow in the U.S. Senate. Scott worked as a staff member for Senator Tom Harkin.

Scott has given more than 130 presentations. He has presented 22 keynote addresses. Scott has also authored several peer-reviewed articles. In 2012, U.S. Health and Human Services Secretary Kathleen Sebelius appointed him to the Interagency Autism Coordinating Committee. The American Public Health Association awarded him their Jay S. Drotman Memorial Award in 2011. PAR awarded him their Community Leader Award in 2013.

Scott earned his PhD in information sciences and technology at Penn State University. He was a Google Lime Scholar. Scott received his master's degree in human-computer interaction from Carnegie Mellon

University. He earned his bachelor's degree in computer science at Rensselaer Polytechnic Institute. Scott graduated Summa Cum Laude.

Acknowledgements

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