

# The Art of Impact:

## A Handbook for Self-Determined Living

*by Scott Michael Robertson, PhD*

YOUR JOURNEY STARTS HERE...



**NACDD**  
National Association of Councils  
on Developmental Disabilities



**OPTUM**<sup>TM</sup>

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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

# **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](http://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.

<b>Self-Advocacy 101</b>	
<b>Self-Advocacy is...</b>	<b>Self-Advocacy is not...</b>
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:** 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:** 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:** 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."

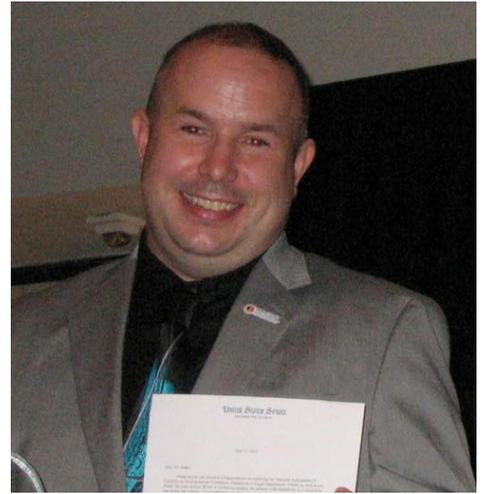
Why is self-advocacy important to you?

"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:** Chris Blake

**Home State:** Connecticut

Chris Blake has been active as a self-advocate for many, many years. He had a brain injury at a very young age, has intellectual disabilities and some significant speech challenges. As a child, his parents were active in advocating on his behalf, and as an adult he has become a strong advocate for himself and others in the state. He is very well known by self-advocates, agencies and providers. In 2012, he was invited by the DDS commissioner to serve on a committee designing the new mission for the agency. This is



where I first met Chris, and was amazed at his passion for the issues and his sense of fairness and justice. He has been active with the CT Cross Disability Alliance since its first meeting in 2012 and is actively involved in the advocacy efforts of the Alliance with Medicaid, DDS and the legislature. He takes an active role on at least three committees of the Supporting Families Community of Practice where he has made significant contributions to their work.

Chris lives in his own apartment in East Haven, CT and has support staff as needed. In 2014, he developed his own job description and then convinced one of the area providers to hire him. Chris is now employed in a paid consultant position by SARAH Tuxis Inc. as a policy liaison, and also serves on their Board of Directors. He is the first self-advocate to serve in this role.

**Leader:** Diana Braun

**Home State:** Illinois

As an eight year old child, Diana Braun found herself living in a state-run nursing home in Freeport, Illinois. Taken away from an abusive family, Diana and her brothers and sisters were scattered. At 12, she was sent to the Dixon Developmental Center. She vowed to one day close state run institutions and has devoted her life to doing just that. In her own words, "Institutions are not a safe place to be."

At 19, Diana left Dixon. After meeting Kathy Conour at a sheltered workshop, a friendship began that lasted 42 years. She took on the ambitious job of personal assistant to her friend and housemate, Kathy. Fearful of being shut away in a nursing home or forced into an institution, they escaped the system. Determined to live independent, non-institutionalized lives and to earn more than menial wages at a sheltered workshop, Diana and Kathy moved to Springfield, built a house and successfully integrated into the community. The relationship between Diana and Kathy was documented in a film called *Body and Soul* that is described as:

"*Body & Soul: Diana & Kathy*, a PBS award winning film, looks at an unusual, symbiotic relationship between two people some would call profoundly disabled. In the film, two of the country's most remarkable advocates for people with disabilities, Diana Braun, who has Down Syndrome, and Kathy Conour, who has cerebral palsy, met three decades ago and vowed to fight to live independent lives. Told in an intimate, verite style, the film is a story of a compelling, creative friendship."

This film has inspired countless audience members by telling a story of determination and courage that led to two women living life on their terms. Kathy passed away in 2009, but Diana has carried the legacy of self-advocacy on. Diana and Kathy paved the way for disability rights to be seen as human rights, and as such, were awarded with an Illinois Human Rights Commission award in 2005.



**Leader:** Adonis Brown

**Home State:** North Carolina

Adonis Brown is a leading advocate for justice and equality for people living with disabilities. He focuses his efforts to promote socio-economic empowerment, independent living and community inclusion. Adonis co-chaired the NC General Assembly's Developmental Disabilities Transitions Task Force, contributed to the designation of the NC protection and advocacy organization from the Governors Advocacy Council for Persons with Disabilities (GACPD) housed within state government to Disability Rights NC, a private not-for-profit and served on its board from 2007 through 2012. Adonis currently serves as President for The Arc of North Carolina and serves as Associate Chair for the NC Council on Developmental Disabilities. Adonis has also served on the Mayor's Committee for Persons with Disabilities from 2002 through 2009. Adonis created EnVisioned Independent Living in 1998 to provide independent living and life skills consultation, provide mentorship, advocate for community inclusion and equality in areas of housing, education, recreation, transportation and employment.



Adonis is passionate in his efforts to change perceptions, promoting high expectations for all people. He works to eliminate low expectations and promotes the value of people with disabilities being fully included and contributing members of their community.

Adonis, for a time, worked closely with the Association of Self Advocates, NC (ASANC), serving on the board of directors. As a person with a disability, he seeks and serves in leadership roles designed to impact policy and opportunity. His efforts included supporting all with disabilities to be included in the self-advocacy association. He educated the board of directors regarding strong governance. He worked with members and the board of directors to strengthen the visibility and impact of ASANC. Adonis shares his personal story and uses current data and other information to strengthen his message. He actively mentors other self-advocates.

Adonis mentors self-advocates to be prepared when meeting with members of the public, potential employers, state-level policy makers, state and national level legislators. Examples include local, national and international experience to train and mentor individuals with disabilities to better communicate their personal story and message with the intent of creating more awareness and changes in policy and practices.

**Leader:** Monica Cooper

**Home State:** Arizona

Monica Cooper was born in Illinois, and took the adventure of a lifetime as a child when she moved with her family to Israel for three years. She now lives in Arizona and enjoys reading, cooking pasta and arts and crafts—especially crocheting. She tried telemarketing once, and wasn't a fan.

As an outspoken self-advocate, Monica is laser-focused on inclusion in all aspects of life. "I believe that all people with disabilities should have the same opportunities as everyone else," she says. "All my life I was always given the opportunity to do something for myself. I've always made my own choices."

She attributes that in part to growing up in general education classes alongside able-bodied schoolmates. Monica is a big believer in educating others, both individuals and those with disabilities.

Monica isn't afraid to speak up to share her view and to fight issues for the benefit of others. After blazing through causes from ending the use of the "R" word to supporting service animals and minimum wage laws, she's ready to tackle the limited opportunities for recreation among people with developmental disabilities like herself.

"Keeping quiet doesn't get you anywhere," she said. We agree, Monica.



**Leader:** Morgan Davis

**Home State:** Oklahoma

Morgan Davis is currently a student at Rose State College (RSC) in Oklahoma City, where she is studying Special Education. Recently Morgan was appointed to the Oklahoma Developmental Disabilities Council (ODDC). In addition to that, Morgan is a graduate of the Oklahoma Youth Leadership Forum, the ODDC's high school leadership and advocacy program for students with disabilities. She is also a stakeholder on the Oklahoma Communities of Practice, discussing ways of helping to support families.



Morgan plans on continuing her advocacy by attending Partners in Policymaking (PIP), the ODDC's adult disability advocacy training program. Morgan has begun speaking to audiences about her experiences as a person with a disability. She spoke to Teacher Assistants about disability awareness and most recently at the Take Root: Red State Perspectives On Social Justice, speaking about sexuality and disability.

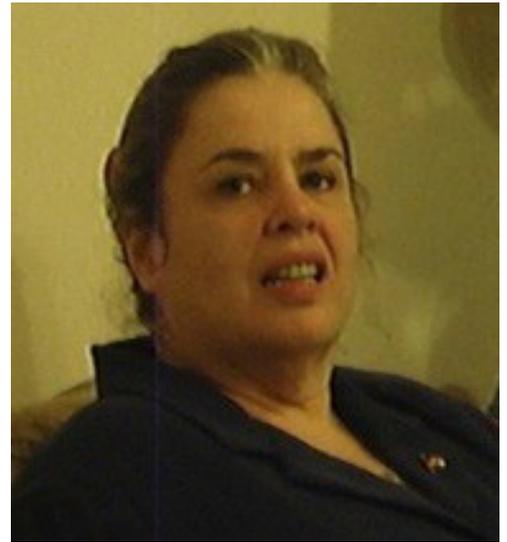
When Morgan isn't attending class or meetings, Morgan enjoys hanging out with her friends and indulging in her love of pop culture.

**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:** 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.



**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:** Tina Jackson

**Home State:** Kentucky

Tina Jackson's reality for the past 30+ years has been one of PEG tube feedings, total silence due to stroke and increasing issues with vision and balance. Yet, she feels blessed to live in a time of great advancements in technology. When she was born, the doctor saw that when she cried she turned blue around the mouth. By 18 months, her mother noticed that when she crawled she was pulling herself with her right hand and foot across the floor. An enlightened pediatrician took one look at her and said two words that were completely unknown to Tina's family...Cerebral Palsy. At that point, Tina began her formal education of learning to be an independent person.



Between the 1980s and '90s, she worked in the fields of social work and medical records. It was during this time period that Tina suffered a number of physical setbacks, from the onset of seizures to having a stroke. Several new disabilities resulted, including the loss of her speech and part of her vision, as well as problems with eating and drinking. Swallowing tests showed she was aspirating and this led to the placement of a PEG feeding tube. Soon after this, Tina decided that she could no longer work in the traditional work force. By 2000, more assistance was needed due to progression of CP, post stroke central nervous system damage and vision/balance problems. She used a small cart for assistance in balance, which allowed her to continue being ambulatory and active in the community. Vocational Rehabilitation gave her a communication device which allowed her to be a speaker at several events including keynote speaker at the Perkin's Center graduation in 2011. She was a governor appointed member of Kentucky's Commonwealth Council on Developmental Disabilities and is an active volunteer at her church. Tina and her husband have co-chaired a committee for the past 14 years that organizes the annual Appalachian Bike Tour Scholarship Ride. She is currently self-employed in marketing and selling a patented assistive device, The Jackson Peg Tube Stand, invented by her husband to assist people in regaining/maintaining their independence.

At 59, Tina considers herself blessed to be able to continue being productive and enjoying life. She has joined a Crossfit group to gain strength and flexibility and recently competed in a regional event. She also did her first "truck pull" and has learned to use a rowing machine and to toss an atlas ball with one arm. She says that the hard times are softened by her successes and that she is grateful for the strength she has gained from them.

**Leader:** Jennifer Kamer

**Home State:** Oklahoma

Jennifer Karner is currently a student at Oklahoma City Community College (OCCC), where she is studying Child Development. She is a student employee of OCCC's Child Development Center, working with Preschool Teachers, Teacher Assistants, and Preschool-aged children.

Jennifer is a member of the Oklahoma Developmental Disabilities Council (ODDC) as well as a student in the ODDC's Partners in Policymaking (PIP) program.

PIP is a disability advocacy program for individuals with disabilities, parents and/or family members who have children with a disability, and professionals. Jennifer is a 2009 graduate of the Oklahoma Youth Leadership Forum (YLF), which is a leadership and advocacy program designed for high school students with disabilities. She has returned to YLF for several years, acting as a mentor to students.

Jennifer has presented nationally on subjects concerning disability and disability advocacy. Her topics include self-advocacy in the hospital and in higher education. Recent conferences include the 2014 Self-Advocates Becoming Empowered (SABE) Conference, Transition University, and the Association of Interdisciplinary Studies National Convention in 2015.

Jennifer is involved in her church, playing trumpet, and is an avid runner, participating in many 5Ks and recently completed her first 10K. She enjoys spending time with her family and friends.



**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 associates 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:** Kathy Leigh

**Home State:** Florida

Kathy Leigh is a self-advocate who has owned her own home since April 1, 2000 and lives independently in her community with supports. She has been a Council member since August of 2010, and served in numerous capacities with the Council. Kathy moved to Florida to live with her sister in 1992. She initially attended the local Arc, but by 1994, Kathy was living in her own apartment and working for Boone Waste as a receptionist. She left Boone Waste late in 1994 when the company transitioned to a computerized process. She secured employment as a greeter at WalMart in 1994, and retired after nearly 15 years of employment. She later worked as a receptionist for the Arc for five years. Since 2012, Kathy has performed some consultant work as a receptionist, and more fully vested her energies into the work of the Florida Developmental Disabilities Council as an active, appointed member.



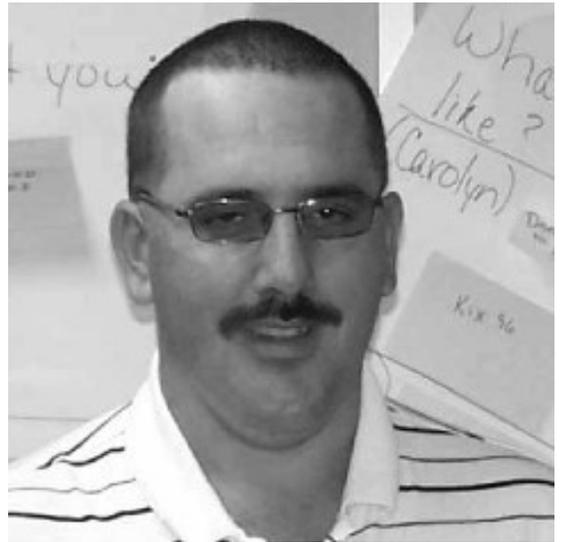
Kathy has conducted a number of presentations in surrounding counties for such entities as the Arc and an institution in order to share information and build interest in inclusive community living and supported living. She has served as a panelist for Support Coordinator Statewide Training, explaining transitioning into supported living and the impact on her life. Kathy also served as a Charter Member of Lions Clubs International in her community. She was engaged in many of these activities long before coming to the Council. She has also been featured in her local newspaper and in newsletter articles, speaking on such topics as living with disability and what it means to dream and succeed. Kathy is a Florida Partners in Policymaking graduate, and she has participated in state and national events such as the annual NACDD conference and Florida SAND annual conference.

**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:** Santa Perez

**Home State:** Nevada

Santa Perez owns her own house in Nevada. Santa is the mother of a 16 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:** 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:** Robbie Reedy

**Home State:** Minnesota

Since the age of 18, Robbie lived in group homes, including living in a “rough place” for seven years. He enlisted the help of family and “great friends” to move out of that environment and is “now very happy to be where I am in life.”

Robbie likes music, being with people, enjoys a good cup of coffee and is working on his first book.

Robbie is thoughtful, reflective, and reserved, yet speaks from experience and directly to the issues that impact individuals with developmental disabilities and families. He is an exemplary model for self advocates. He has always wanted to be a self advocate and life circumstances have given him opportunities to hone the self advocacy skills that he seems to come by so naturally.

As a Partners graduate and Council member, Robbie has effectively demonstrated to other people that anyone can do what they put their heart and mind to. He teaches by example and is open to learning more from individuals around him. At his graduation from Partners, Robbie said that he “learned a lot. I have new friends to teach me about disability even though I don’t have any kids. You parents have taught me.”

Robbie is a Partners in Policymaking graduate. During the Partners training program year, he freely shared his story, acquired a new network of like minded individuals, and was not reluctant to encourage other self advocates to speak up and be heard as the policymaking process was explored at county, state, and federal levels of government.

Robbie is currently serving as co-chair of the Council’s Public Policy Committee where he will add his input and opinions as policy issues are discussed.



**Leader:** Tricia Riccardi

**Home State:** Florida

Tricia Riccardi is a self-advocate, wife and mother of a three year old. She has been a Council member since September of 2010. In this time she has been very involved and attended everything possible. In 2011, she was selected as co-chair of the Self-Advocacy Leadership Task Force, and then became chair of the Task Force in 2012, where she continued to serve through 2016. Tricia also served as a member of the Community Living Task Force from 2012 – 2016.



Tricia was voted in as a member-at-large in 2012 and served the full two-year term on the Executive Committee. After serving as a member-at-large, she served as vice-chair of the Council from 2014 – 2016. She has participated in the Maryland Alliance for Full Participation conference, two annual NACDD conferences, two Disability Policy Seminars, and two SABE (Self Advocates Becoming Empowered) conferences. She is a graduate of the Delaware Leadership Institute. Most recently, she became a 2016 Florida Partners in Policymaking graduate and received the 2016 Partners in Policymaking annual award.

Tricia holds a Bachelor's degree in Public Administration with a minor in non-profit management. She worked for Easter Seals in the administration department from 2004-2005, and she founded and operated a non-profit to assist people with disabilities from 2006-2010. Tricia stated that she believes the biggest accomplishment of her time on the Council was getting income limits into the state plan. She noted that it will impact so many self-advocates if we can bring about this change.

**Leader:** Ross Ryan

**Home State:** Oregon

Ross Ryan is a paid Community Advocate who represents people with intellectual and developmental disabilities across the state of Oregon. In his role as a Community Advocate, he speaks on behalf of other people with disabilities that cannot speak up for themselves.

He currently is a member of many committees that drive important systems and policy change including the Oregon Employment First Executive Order Stakeholder Group, the Oregon Health Authority, Ombuds Advisory Committee, the Intellectual and Developmental Disability Budget Stakeholder Group, the Oregon Medicaid Advisory Committee, the Office of Developmental Disability Services Individual Support Plan Revision Work Group, and the Department of Labor Work Group. He is the lead for Oregon's Developmental Disability Advocacy Days at the State Capitol, the co-creator of Oregon "peer-to-peer" employment project to transition people out of sheltered workshops, a leading voice in the Lane v. Brown Settlement Agreement and a well-known local, state and national speaker on disability rights.



**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:** Eric Stoker

**Home State:** Utah

Eric Stoker lives with his family in West Jordan, Utah and works for the Utah Developmental Disabilities Council as the Information Specialist. He has served on the Utah Parent Center Board of Directors, People First of Utah Board of Directors and the Consumer Advisory Council at Utah State University representing the voice of self-advocates. Eric is also the consumer faculty for the URLEND program at Utah State University. Eric has spoken nationwide about issues that affect people with disabilities, autism and his life experiences. He received the Champion of Equal Opportunity Award from the National Association of Councils on Developmental Disabilities in 2014. In his free time, he attends Utah Utes basketball and football games with his family and he is also the manager of West Jordan High School's basketball team. He is also an avid train buff and has amazing knowledge about the past and current railroad systems in Utah and throughout the United States. He is also a huge basketball fan.



## **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:** 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:** Andre Williams

**Home State:** Massachusetts

Andre Williams is a young leader in the self-advocacy movement. He is a successful trainer, public speaker and advocate for himself and others with disabilities. Andre has a passion for empowering people with disabilities, possesses an exceptional talent for teaching other self-advocates, and is considered a leader among his peers. In addition to his job as a self-advocacy leadership trainer, Andre is active in Best Buddies and serves as an ambassador for Best Buddies at the National Best Buddies Conference. Andre says, "I like teaching the SALS classes because it allows me to follow my goals in life — [which] is to be passionate about something that I love — being an advocate and teaching others how to advocate for themselves are two of the things I am most passionate about."



Since 2015, Andre has worked as a Lead Trainer for the Self-Advocacy Leadership Series (SALS) sponsored by the Massachusetts DD Council. In this role, he leads and facilitates discussions and group activities focused on the fundamentals of self-advocacy and leadership. Andre has taught over 105 students with developmental disabilities.

Andre also works as a trainer for Massachusetts Advocates Standing Strong, the statewide self-advocacy organization. Andre teaches the Explore, Prepare, Act program providing monthly trainings to individuals with disabilities on how to find a job in the community. In his work as a trainer for the Self-Advocacy Leadership Series, and as a teacher for Explore, Prepare, Act and Independence College, Andre has personally supported and mentored over 150 self-advocates in less than 3 years, and has reached hundreds more through public speaking and his services to Best Buddies.

Andre was selected to begin training the new Legislative Advocacy class under the Council's Independence College program. This program helps people with developmental disabilities learn the important skills needed to pursue a life of independence.

Joining Best Buddies in high school has helped to boost Andre's confidence and opened him up to meeting new people and engaging in new experiences. Upon graduating high school in 2010, Andre began serving as a Buddy Ambassador for Best Buddies International and eventually became a member of their Young Leaders Council. Andre has done numerous public speaking engagements including addressing a crowd of over 2,000 people at the annual Best Buddies Challenge bike ride. As a member of the Young Leaders Council, Andre works with other young self-advocates to develop improvements to the Best Buddies program including by teaching workshops at the International Best Buddies Leadership Conference. Andre is also a member of the Best Buddies Suffolk University chapter, dedicating himself to raising public awareness about the "spreading the word to end the word" campaign.

**Leader:** Betty Williams

**Home State:** Indiana

Betty Williams is a very well-known individual - not only in her local community, but also throughout Indiana and across the United States. She is known for her determination and leadership, commitment to advocacy, and for making a positive difference in the lives of people with intellectual and developmental disabilities.

Betty Williams is the Consumer Education and Training Coordinator at The Arc of Indiana, a position she has held since 2006. Previously, she worked at Achieva Resources as a Workshop Consumer and as a Habilitation Specialist. Ms. Williams has served as Secretary of Self-Advocates Becoming Empowered since 2012 and as a Lay Member of the Indiana Developmental Disabilities Legislative Commission since 1998. She served as President of Self Advocates Becoming Empowered from 2010 to 2012 and as President of Self Advocates of Indiana (SAI) from 2005 to 2010. While President of SAI, Betty was one of the first individuals that Darcus Nims, founder of SAI, sought out to join her with her advocacy efforts. Betty and Darcus traveled across the state to speak with and advocate on behalf of people with I/DD. Betty was actively involved in the efforts that closed Indiana's state institutions, and advocated with Darcus for the people who were moving out of those institutions and into the community.

In 2014, Betty was appointed to the President's Committee for People with Intellectual Disabilities, bringing her advocacy experience and leadership to the national level. She continues her life's work of advocacy in the disability movement through her leadership and commitment to the various committees and taskforces she serves on, as well as maintaining a continued presence in the community.

From a young age, Betty knew that the life she was living was not one that she would have chosen for herself, and in response she adopted the "I can, I will, and I should" attitude when all she would hear was "Can't, won't, and shouldn't." Her dedication to achieving her own independence and helping others achieve theirs led her to a job where she shares those skills with others.

Betty has lead many training sessions and workshops for self-advocates to help develop public speaking skills, as well as other ways that self-advocates can communicate effectively and broadly within their own community. One of Betty's longest lasting impacts is her involvement in assisting with the closure of Indiana's state institutions. She and other leaders of SAI met with people with DD who were living in state institutions to listen to their concerns about the future and help them understand the possibilities. More recently, Betty has worked with the *My Life, My Choice* project to help individuals living in group homes and/or nursing homes explore community living options. Betty not only helped to develop the initial interview questions, but also conducted interviews with teams of self-advocates, as well as provided training to new interviewers as part of a training team.

By continuing to share her knowledge and leadership skills, Betty is providing the education and fundamental tools for self-advocates and be the change they wish to see in their community. Her continued participation in local, state, and national committees help to get those around her thinking in terms of "I can" for everyone, and to ensure that those initiatives are led by self-advocates.



## **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 your 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 Lagdon, 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.

<b>Meeting Public Officials</b>	
<b>Do...</b>	<b>Do Not...</b>
Prepare for your meeting	Come to your meeting without preparing
Dress professionally	Dress too casually
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	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 SB 502. SB 502 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 1: <http://www.youtube.com/watch?v=APK-UbdF8Fk>

Film Trailer 2: <http://www.youtube.com/watch?v=aMaBlc5jh3w>

Film Trailer 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 (March 2014)**

[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, DSPD'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.

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