

A HANDBOOK DEVELOPED BY  
UNITING FOR CHANGE

**RISE UP**  
A group of six stylized, colorful human figures (yellow, orange, red, teal, blue, and light blue) are depicted in a line, each holding a megaphone. They are all smiling and appear to be shouting or speaking. The megaphones are also colored to match the figures: teal, orange, and blue.  
**SPEAK OUT**

FOR GEORGIA SELF-ADVOCATES

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# Introduction

This handbook has been developed with the self-advocacy Leadership Collective from Uniting for Change with support from Sangha Unity Network (SUN) using a grant from the Georgia Council on Developmental Disabilities (GCDD). This handbook was created to use as a teaching tool and a reference guide for those interested in expanding grassroots self-advocacy networks across the State of Georgia.

You'll find information about self-advocacy with activities that will help you grow as a self-advocate. Area Networks can use this handbook to strengthen the community of self-advocates as Uniting for Change grows across Georgia.



We appreciate the ongoing support from the following organizations who continue to assist with the expansion of self-advocacy in Georgia:



# How to use this Handbook with Self-Advocates



## The Journey Begins...

This handbook has been developed and will be continuously revised with individual advocates throughout the State of Georgia.

This handbook is intended to support the development, growth and sustainability of Area Self-Advocacy Networks and Uniting for Change, the State Self-Advocacy Network. The growth of self-advocacy in Georgia will create grassroots change among services, supports, and perceptions (often misconceptions) related to people who have intellectual and developmental disabilities.

The information provided within this handbook includes strategies to build empowerment, develop skill sets, cultivate legislative/systems change, educate community members, and celebrate successes. Stories, graphics, and videos will help guide our understanding of advocacy within our varied and diverse communities. Advocacy, especially self-advocacy, is a process of becoming and will require ongoing practice, starting over, and engagement.

Our journey will begin with a strong support structure to sustain advocacy for one's self, policy/system development, and building more inclusive communities. We will incorporate the Five Accomplishments described by John O'Brien, Connie Lyle O'Brien, and Beth Mount to create a mutual understanding by all participants. Our hope is to provide more opportunities to support individuals who experience intellectual/developmental disabilities in the State of Georgia to take control of their lives, their services, and their citizenship within their local communities, state, nation, and the world.

The allies and supporters of this project understand that advocacy for those who experience intellectual/developmental disabilities occurs within a broader civil rights movement.

# What is Self-Advocacy and How Did it Begin?

The definition of *advocacy* is the act or process of supporting a cause or proposal: the act or process of advocating something.

## ADVOCACY



Wikipedia defines self-advocacy as “the civil rights movement for people with developmental disabilities, also called cognitive or intellectual disabilities, and other disabilities.”

Self-advocacy is also an important term in the disability rights movement, referring to people with disabilities taking control of their own lives, including being in charge of their own care in the medical system.

Self-Advocacy:  
Know Yourself,  
Know What You  
Need, Know How  
to Get It

The self-advocacy movement is people with disabilities speaking up for themselves. It means that although a person with a disability may call on the support of others, the individual is entitled to be in control of his/her own resources and how they are directed.

It is about having the right to make life decisions without undue influence or control by others. Basically, people control and direct their lives guided by their gifts, talents, hopes, and dreams.

In the United States, the self-advocacy movement started in Oregon in 1974 at a conference where the term “**People First**” originated. Since then the self-advocacy movement has grown across the United States into many diverse groups of advocates who experience a variety of disabilities. These groups work towards building connections and relationships among people who experience disabilities and the larger communities with whom they are connected.

## WE VALUE

Being people first  
Making our own decisions  
Believing in us as people  
Having others believe in us as people

## PRINCIPLES OF SELF-ADVOCACY

Empowerment  
Equal Opportunity  
Learning & Living Together  
Institutions are Bad for People  
Non-labeling

## Being a Self-Advocate

We've talked about self-advocacy and why it is important. We want to talk very specifically about the role of the self-advocate:

- Who is a self-advocate?
- What does a self-advocate do?
- What is expected of you as a self-advocate?



**This is important for each self-advocate to know to be clear about what is expected and what it means to be a self-advocate.**

The Uniting for Change Leadership Collective Members believe self-advocates are expected to:

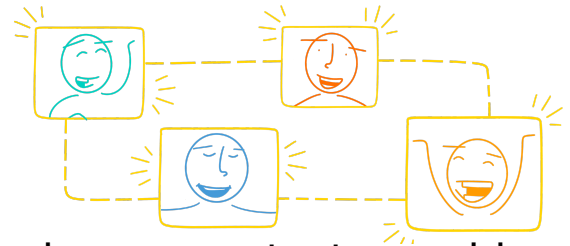
- Engage in and with community
- Spend time together
- Share ideas
- Spread the word
- Educate others
- Show Up!
- Know your responsibilities and follow through.
- Speak up!
- Be clear about what you need to participate
- Fight for your rights
- Do not back down



# How to Be a Member of a Self-Advocacy Network

Since self-advocacy is about people with intellectual and developmental disabilities having control over choices and decisions, it is important for advocacy networks to have control over their work from the beginning.

The network belongs to the members.



All members must be seen, valued, treated as competent, capable adults who are willing to speak up and ask questions as they arise. Self-advocates ask for whatever is needed to fully participate. Allies and supporters should be available to assist as needed.

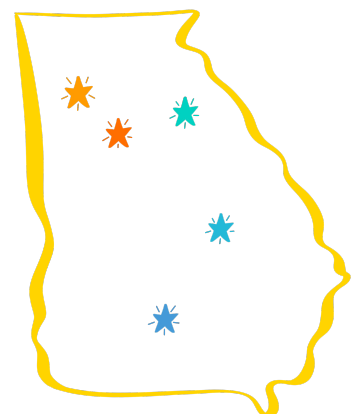
Uniting for Change grew out of a grant from the DD Council to Sangha Unity Network in 2017 to expand self-advocacy across Georgia. A group of self-advocacy leaders came together to create Uniting for Change as a statewide network with a mission of **uniting Georgians and influencing change by speaking up and taking control of our lives.**



Uniting for Change envisions a community where all people belong and are heard. A place where people are involved, speak out, make their own choices, are seen and treated as equal, and true to their destiny.

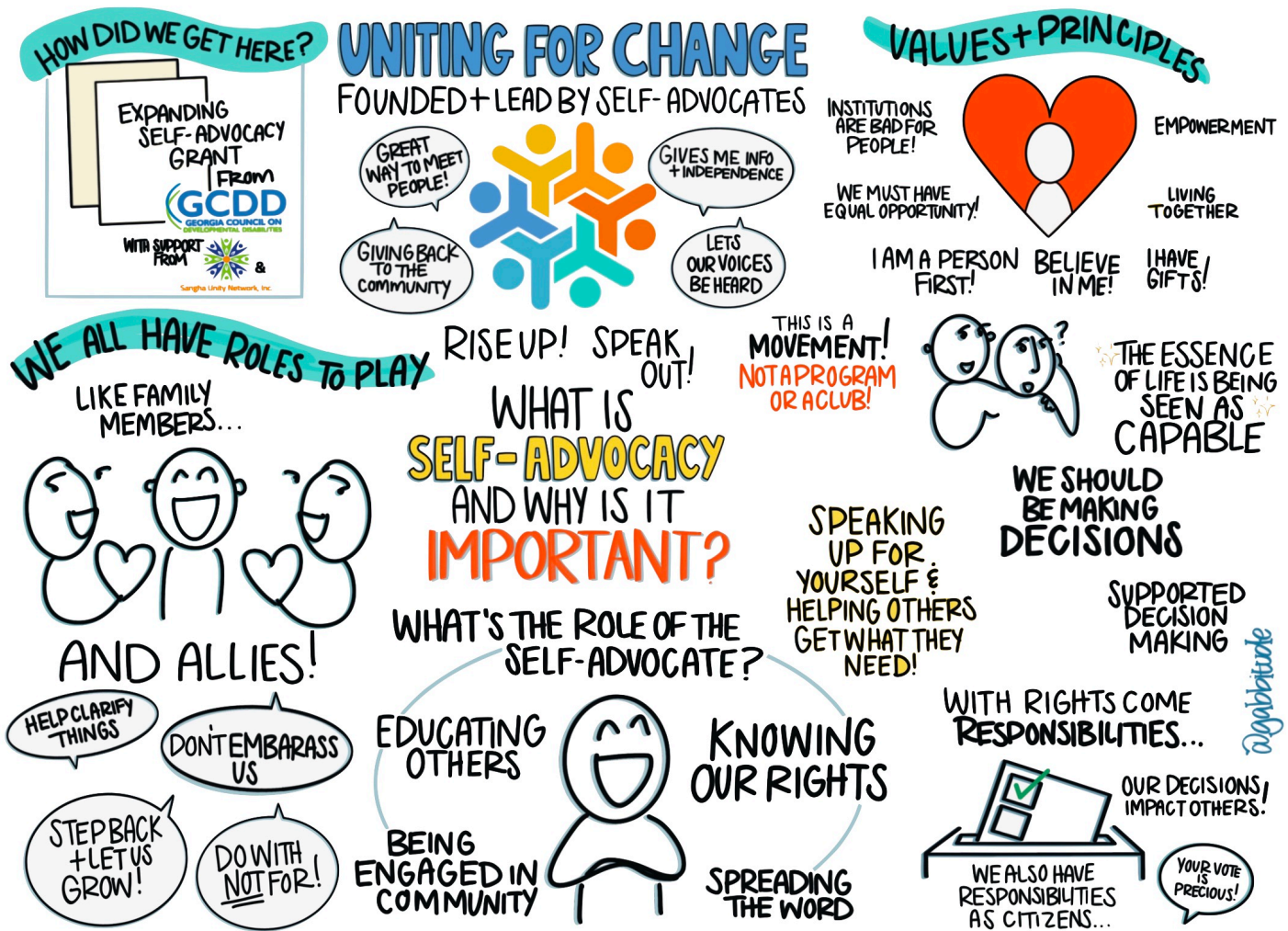
We're now growing networks in 5 areas of the state:

- Northeast Georgia Area
- Northwest Georgia Area
- Metro Atlanta Area
- Middle Georgia Area
- South Georgia Area





The illustration below shows more about [Uniting for Change](#) and self-advocacy:



There is a basic understanding that is needed when starting a self-advocacy group. It is important to make sure that all members understand the purpose of an advocacy network, why meetings are necessary, and what the group intends to do together.

Members must be supported to work together to create the group's mission, vision, role expectations, value statements, action plans, and mutual agreements. Group or mutual agreements should be created early in the process for everyone to understand and agree on how the group will work. A focus of the group is needed, and creating group goals and action plans will help the group achieve agreed upon outcomes.

# The Five Accomplishments & Experiences



John O'Brien and Connie Lyle O'Brien

The Five Accomplishments create the space for us all to move toward daily experiences, which include things to work towards and ways we can talk with allies/supporters about the best ways to support us as individuals:

## COMMUNITY PRESENCE:

How can we show up more, be more present in local community life?

## COMMUNITY PARTICIPATION:

How can we expand and deepen relationships?

## HAVING VALUED SOCIAL ROLES:

How can we have more valued social roles and be respected?

## PROMOTING CHOICE:

How can we have more control and choice in life?

## SUPPORTING CONTRIBUTION:

How can we learn more, develop competencies, and contribute?

These five areas help frame the development and sustainability of Uniting for Change. The belief that every person has the right to choose, to develop capacities, to contribute, and be viewed as a valued member of his/her community is at the core of any advocacy.

Self-advocates want to move away from being isolated, secluded, rejected, lonely, kept apart and away, having negative reputations, old labels and stories, being restricted, having no power, being seen as incompetent, unproductive, and unable (as seen in this image and toward the Five Valued Accomplishments):



Will our ideas reinforce old patterns of isolation, rejection, powerlessness, and poor reputations?

- Moving away from a past characterized by:
- ▶ Isolation, seclusion, and separation by location, activities and schedule
  - ▶ Rejection, loneliness always on the outside, ignored
  - ▶ Old stories, negative reputations, labels; negative self-fulfilling prophecies
  - ▶ Limited voice, restriction, lack of representation, no power
  - ▶ Unproductive, severely ignored, undeveloped; no resources, low expectations

### THE FIVE ACCOMPLISHMENTS PROVIDE A GUIDE FOR THE DEVELOPMENT OF A PERSONAL VISION

By John O'Brien and Connie Lyle

The five accomplishments provide a framework for assessing our ideals about the future.

Increasing opportunity in these five areas of life is clearly the intended outcome of the Personal Futures Plan process.

Will our choices lead to relationships, dignity, choice, real contribution, and inclusion in community life.

Moving toward daily experiences which include:

- ▶ **COMMUNITY PRESENCE:** How can we increase the presence of a person in local community life?
- ▶ **COMMUNITY PARTICIPATION:** How can we expand and deepen people's relationships?
- ▶ **ENCOURAGING VALUED SOCIAL ROLES:** How can we enhance the reputation people have and increase the number of valued ways people can contribute?
- ▶ **PROMOTING CHOICE:** How can we help people have more control and choice in life?
- ▶ **SUPPORTING CONTRIBUTION:** How can we assist people to develop more competencies?

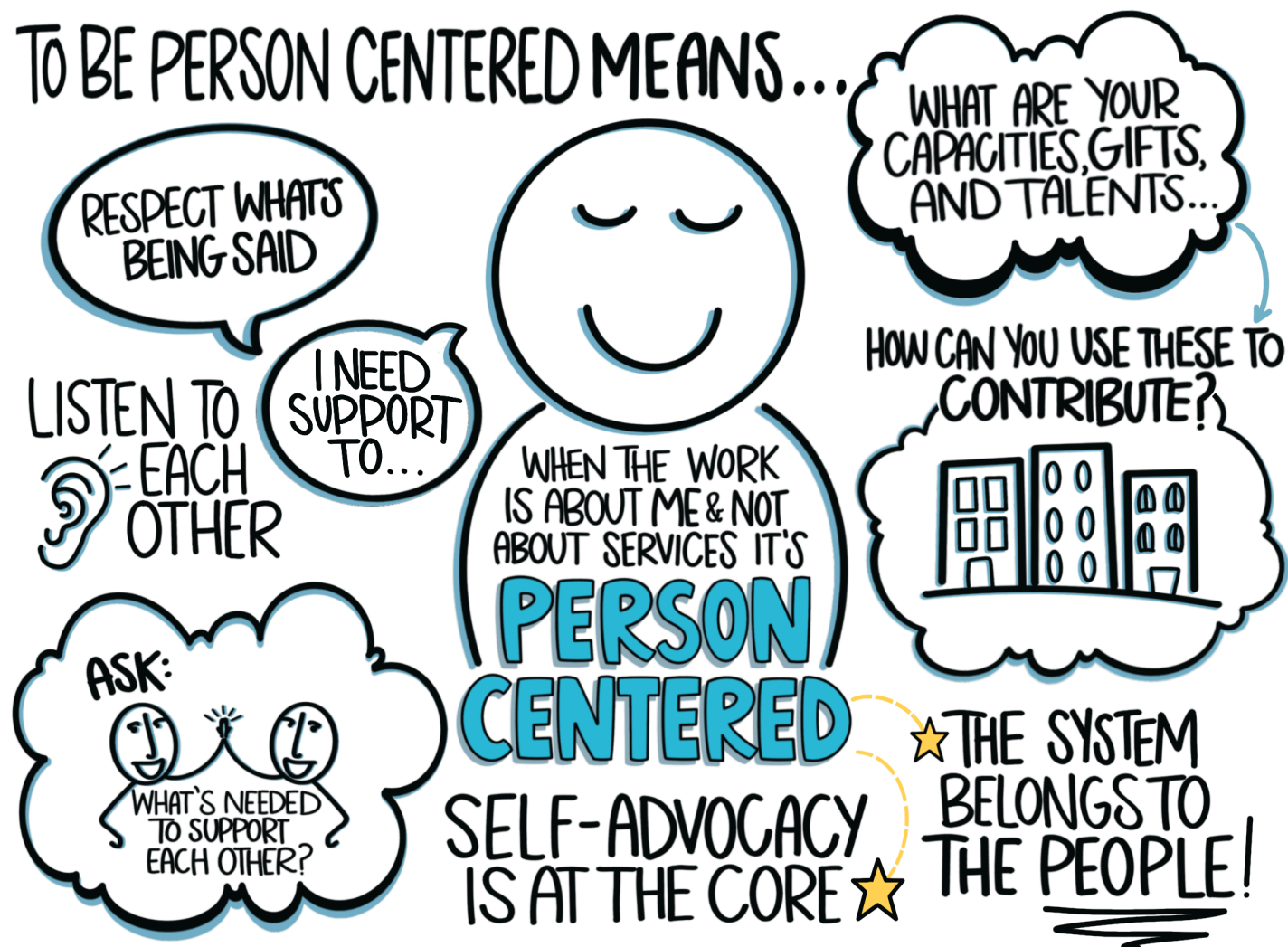
# I'm the Person, at the Center of my Life

We all need support in making decisions at different points in our life. When we think about person-centered services we believe that the person is at the center of any and all decisions made about how he or she spends their time, who they spend their time with and how hopes and dreams are acknowledged.



Each of us as our own person, makes our own decisions. We should always be considered competent to make our own decisions,

## TO BE PERSON CENTERED MEANS...



even if we have a legal guardian. We should always be at the center of every conversation that involves our present and our future. Person-centered services should be based on assisting us in developing new skills that will enhance and grow our opportunities for building new relationships and living the life we choose. Services must be driven by the people they're designed to support and guided by trust and respect and a belief that everyone has strengths, abilities, and gifts to offer their community. Within person-centered practices, it is necessary to identify barriers that are present so that supports can be created to address them.

With supports, we should identify what actions, beliefs, and/or behaviors we may need in order to have the life we choose. We decide who we want as our allies and supporters. We identify and explore our choices related to how we want our future to look.

**A better life is not just based on having a better plan.**

## **My Choices, My Decisions**

To have choice you have to have opportunities to determine your preferences and then have control over those preferences. Autonomy is having the control when pick what you want to do, when you want to do and with whom you would like to be included.



A choice is when a person can pick between MORE than two options. You choose one thing over another, for example a hamburger instead of a hot dog, or going to movie instead of going shopping.

A decision is a bit different. A decision is when you make up your own mind about something and you decide what you want. So you may decide to take a shower or a bath in the morning or in the



evening. No one tells you whether or not you can take a bath or a shower or when.

Supported Decision Making is a process that can be used to gain control over your life and how you want your life to look based on your hopes and dreams for your present and your future. With Supported Decision Making you choose people you trust to help you around medical and/or financial decisions for example. The people you choose to help you will support your decisions with others in the community.

[See Activity #2](#)

## **Rights and Responsibilities**

One of the goals of advocating for yourself is to speak up for yourself. In order to do that, it is important for you to know and understand your rights and responsibilities as a citizen of your community.



The rights that persons with disabilities have include; equality before the law, freedom of speech, respect for privacy, the right to both marriage and family, the right to education, the right to health, and much more.

As self-advocates we have a civic responsibility as well, especially around advocating for systems change and policy development.

### **Right of Communication**

This includes the right to understand information by asking for more information if needed, the right to be heard, and the right to say

“No.” You also have a right to your own opinion and to express yourself in the most appropriate way for you.

## Right of Relationships

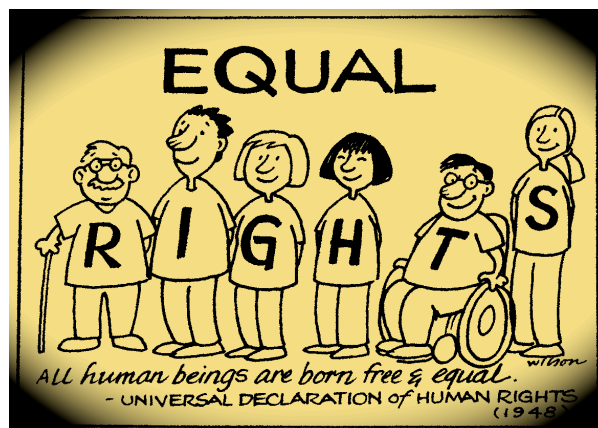
This includes the right to be married, have children, and to choose your own friends.

## Right of Home Life

This includes the right to your own privacy (private spaces and privacy around mail and personal information), where you live, who you live with, how you decorate your home, what and when you eat, and the right to feel and be safe. You have the right to your own belongings and no one has the right to go through your things.

## Right of Citizenship

This includes the right to your own beliefs, access to places in the community, employment with a fair salary, and to vote. Also included is the right to contribute and be welcomed into the community. You have the right to be present and participate in all community activities you choose. You have the right to be treated like any other citizen.



**Most of all, you have the right to be treated with dignity & respect!**

See Activities #4 & #5

Along with your rights, you also have **responsibilities**. Being responsible is when you respect the rights of others and understand that your choices and decisions have consequences.



When you act in a responsible way, you do not take away the rights of others and you are respectful of other's opinions, property, and space.

You act responsibly when you help others and take care of your obligations, like communicating clearly and respectfully, paying bills, getting to work on time, taking medications you decide with your doctor, supporting family, purchasing groceries, or other things you need, etc.

It is also important for you to take responsibility for communicating what you need in a respectful manner. As self-advocates you have a civic responsibility as well, especially around advocating for systems change and appropriate policy development related to the needs of those individuals who experience intellectual/developmental/physical disabilities.

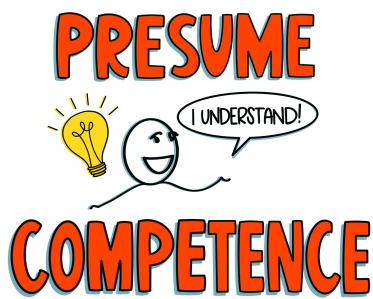
[See Activity # 6](#)

## **Power to the People**

As advocates you must always speak up related to the things that you can do. You have the right to participate in what you want based on your hopes and dreams for your life, even though you may need help at times.

It is important to remember and remind others that everyone communicates. It may just be in a different manner like with gestures





or eye gaze or sign language or running away or a communication board. These methods of communication are all just as valid as using speech. People frequently make false assumptions and hold onto old stories about the abilities of others either by the way people look, communicate, or act.

Through advocacy, we must educate the broader community that everyone should be presumed competent no matter what disability he/she experiences. When you are advocating for yourself, here are some tips to teach others:

**You could say *“It’d be a good idea to...”***

- Talk to me as an adult using a typical tone of voice you use to speak to any adult.
- Ask me before giving assistance.
- Speak to me directly.
- Ask me for my preferences and ask the best way/manner to assist me.
- Not assume that I do not understand what you are saying.
- Not pretend to understand what I’m saying if you don’t get it.
- Not limit my opportunities to contribute.
- Avoid speaking for me. If you are needed to help me interpret, DO NOT change the meaning.
- Not make decisions or choices for me.
- Not provide more support than is needed.



When advocating for yourself or others it is necessary to understand the importance of speaking up. It can certainly be hard and it may be difficult to find the words to express what you want or need to say.

You have more power when you are heard and it's up to you to ask for support as needed in any given situation. Remember, each person has unique abilities and gifts to offer, and when people are brought together in networks of advocacy, empowering experiences happen. When people are presumed to be competent and empowered, they continue to grow by building on their current strengths and abilities, as well as providing direction for what they need.

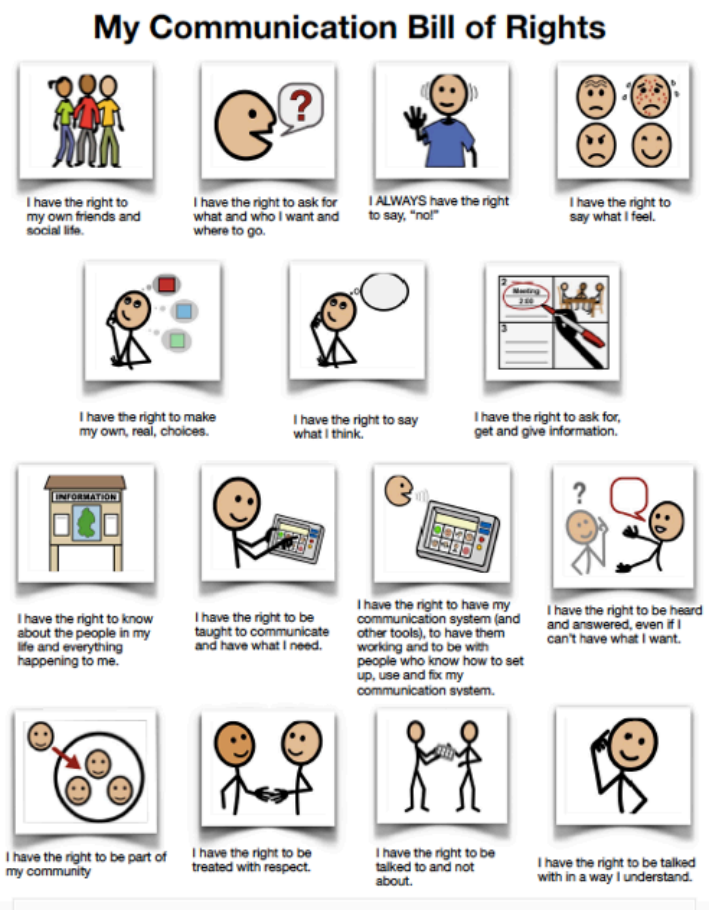
See Activity #7

## Developing Communication Skills

As self-advocates, we have a responsibility of using our words and other means of communication to let folks know what we need, what we think, and what we hope for. Whether we use words, gestures, behaviors, changes in facial expressions, or communication boards, what we say is powerful.

Communication is a basic human right and it is the way in which we let our choices be known, develop relationships, learn, express how we feel, and make sense of the world around us. We have a right to say NO!

We have a right to ask someone to slow down when they are speaking to us.



We each have our stories, opinions, and ideas and it is important that we find ways to ensure that people are listening to us in whatever manner we communicate. We have a right to a functional and independent way to communicate. Our allies and supporters can assist folks in the community in better understanding us by modeling how they listen and interact with us. Find folks you trust to help you in developing your communication skills.

We as self advocates also need to learn to listen well to others. We do this by not interrupting and by asking folks to repeat what was said if we don't understand what they said. It is ok if we don't understand what is being said.

## **Civic Engagement**

Every self-advocate has the same rights as any other citizen. As a citizen it is important for each of us to be involved in political advocacy. We can go to town hall meetings, Chamber of Commerce meetings, write letters to our government officials, use other forms of social media to state our views, and actually meet with our politicians in person. Civic engagement is any activity that works to address a public concern.

Civic engagement simply means to actively participate in our democratic processes, like voting. When we think about civic engagement we learn about how government works at local, state, and federal levels. We also find ways to let the people we elect hear what is important to and for us. All elected officials should have an understanding of the priorities of people with disabilities.

Think about the following questions as you think about how to increase your civic engagement:

- How do I engage with my community?
- How do I stay updated with current events and news?
- How often do I vote?
- How do I use social media to be civically engaged?
- How would I choose to make a difference in my local community?

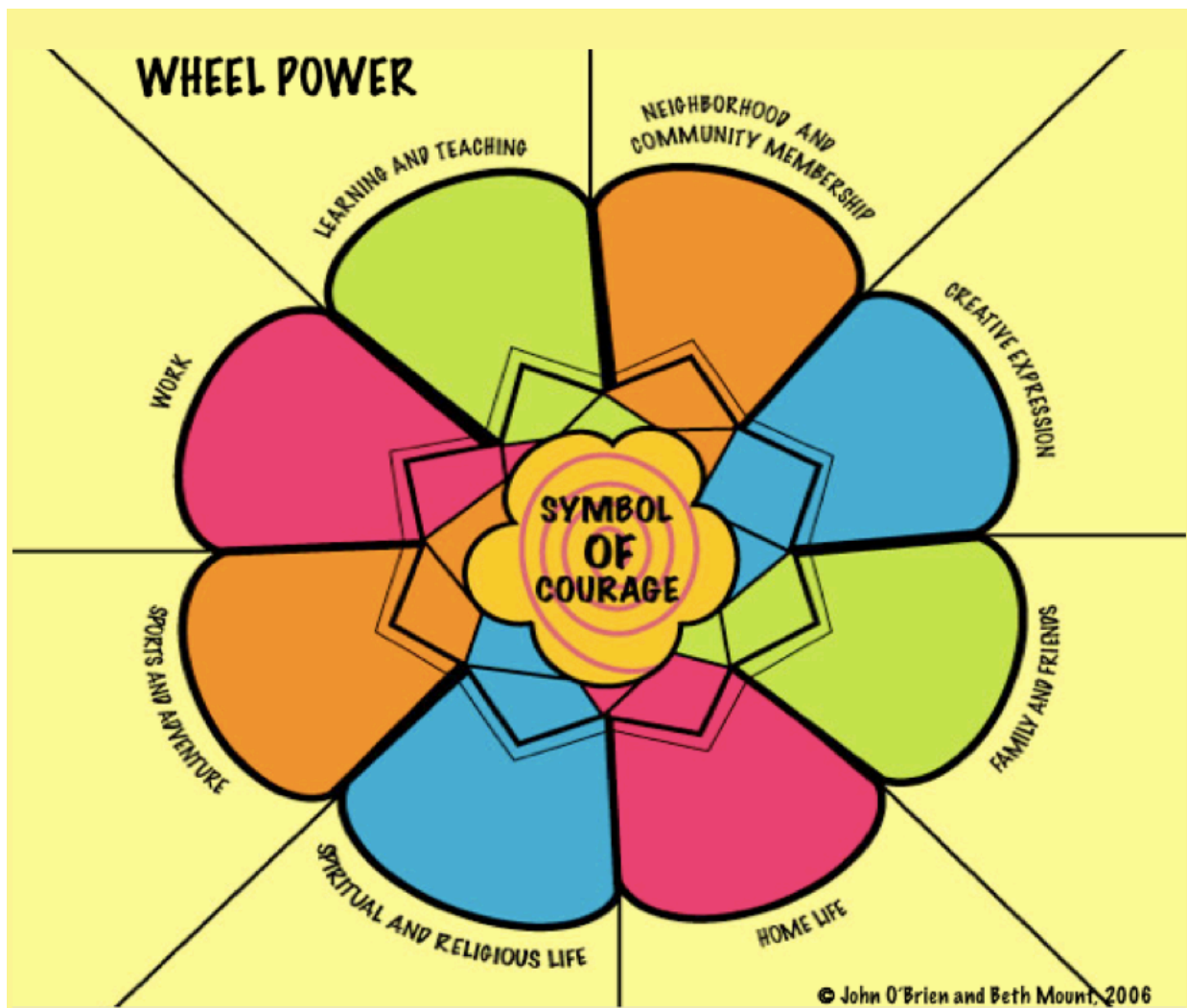
People with disabilities must use their voices to be part of the decision making process that impacts our lives. We must fight to remove any and all barriers that negatively impact our participation in civic engagement. By ensuring the right of folks with disabilities to participate in all civic engagement activities, we ensure the rights of all citizens.

## Wheel Power and Courage

It is important to know that all people need supports at different times during any day and over a lifetime. People who support you may be paid employees, allies, or other supporters. You may consider a paid employee as an ally.



It takes courage to speak up for yourself in all areas of your life. Speaking up for you means that others provide the assistance that you have requested and chosen for yourself. It is also important to know your rights and to have confidence in standing up for your rights. Advocating for yourself means you do things during the day for yourself and are responsible for asking for assistance as needed. Using this tool can help you let others know what you want to learn to do in each of these life areas.



See Activity # 3



## Activities for U4C Area Networks:

The following activities can be used to help let people know what matters to you in your life journey. They will help others know what what your goals are, what your hopes and dreams are and what you want to learn. These activities will help you find your voice as a self advocate so that you can **RISE UP AND SPEAK OUT!!**

Ask your supporters and allies for assistance with activities if needed!

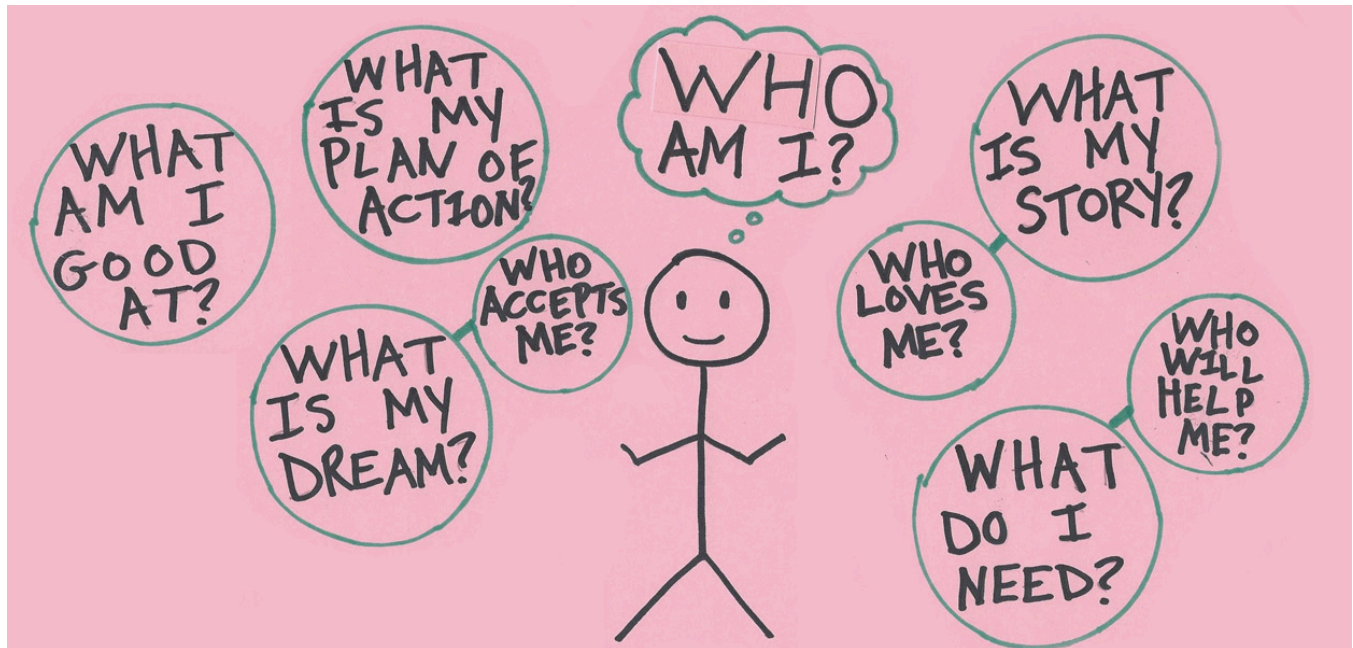
### Suggested Materials:

paper, markers, paint, magazines, glue sticks, any other visual support supplies.

Activity #1: How I'm an Advocate	23
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## Activity #1: How I'm an Advocate

THINK ABOUT YOURSELF...



Create posters with responses to the following questions:

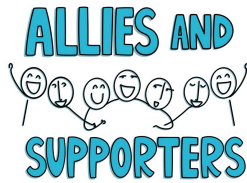
- What does advocacy mean to you?
- What is my story?
- What is my dream?
- What am I good at?
- How do I advocate?
- What do I need and who will help me?

## Activity #2: My Choices, My Decisions

Brainstorm ideas around the following questions indicating if you are making choices or decisions and who supports you if you want support with choices and decisions. You can use these sheets to take notes:

Create posters with responses. Add pictures that reflect all of the choices you make each day.

- Who are my supporters/allies who know it's my choice, my decision?
- Who do I turn to for support?



Think about the Allies/ Supporters in your life.

Write who they are in your handout.

ASK YOURSELF:

Who do I look to for support?\*

Who wants good things for me?\*

Who can I call on when I need advice?\*

\*These are your allies/supporters.

Think about your typical, ordinary day.

ASK YOURSELF & record:

Decisions I make myself during the day

Decisions OTHERS make FOR me during the day?

How do you want this to change (if you do)?

- What decisions/choices do I make during a day?
- What do other people decide for me?
- How do I want this to change?



### Activity #3: WHEELPOWER and Courage


Identify what activities, people, opportunities, roles, etc. that already exist in each part of your Wheelpower and opportunities for growth, new roles, and connections. Think about the courage it takes as a self-advocate.

#### How are you already involved in these areas?

- Work
- Learning & Teaching
- Neighborhood & Community Membership
- Creative Expression
- Family & Friends
- Home Life
- Spiritual & Religious Life
- Sports & Adventure

 What already exists?
Work
Learning & Teaching
Neighborhood & Community Membership
Creative Expression
Family & Friends
Home Life
Spiritual & Religious Life
Sports & Adventure


#### What more could be possible?

 What could be possible?
Work
Learning & Teaching
Neighborhood & Community Membership
Creative Expression
Family & Friends
Home Life
Spiritual & Religious Life
Sports & Adventure

## Activity #4: Understanding Your Rights

Write each of the rights we discussed on a piece of chart paper and then brainstorm all of the examples you can think of for each right.

MY RIGHT to...	Examples:
Communication	
Relationships	
Home Life	
Citizenship	



## Activity #5: My Rights Statement

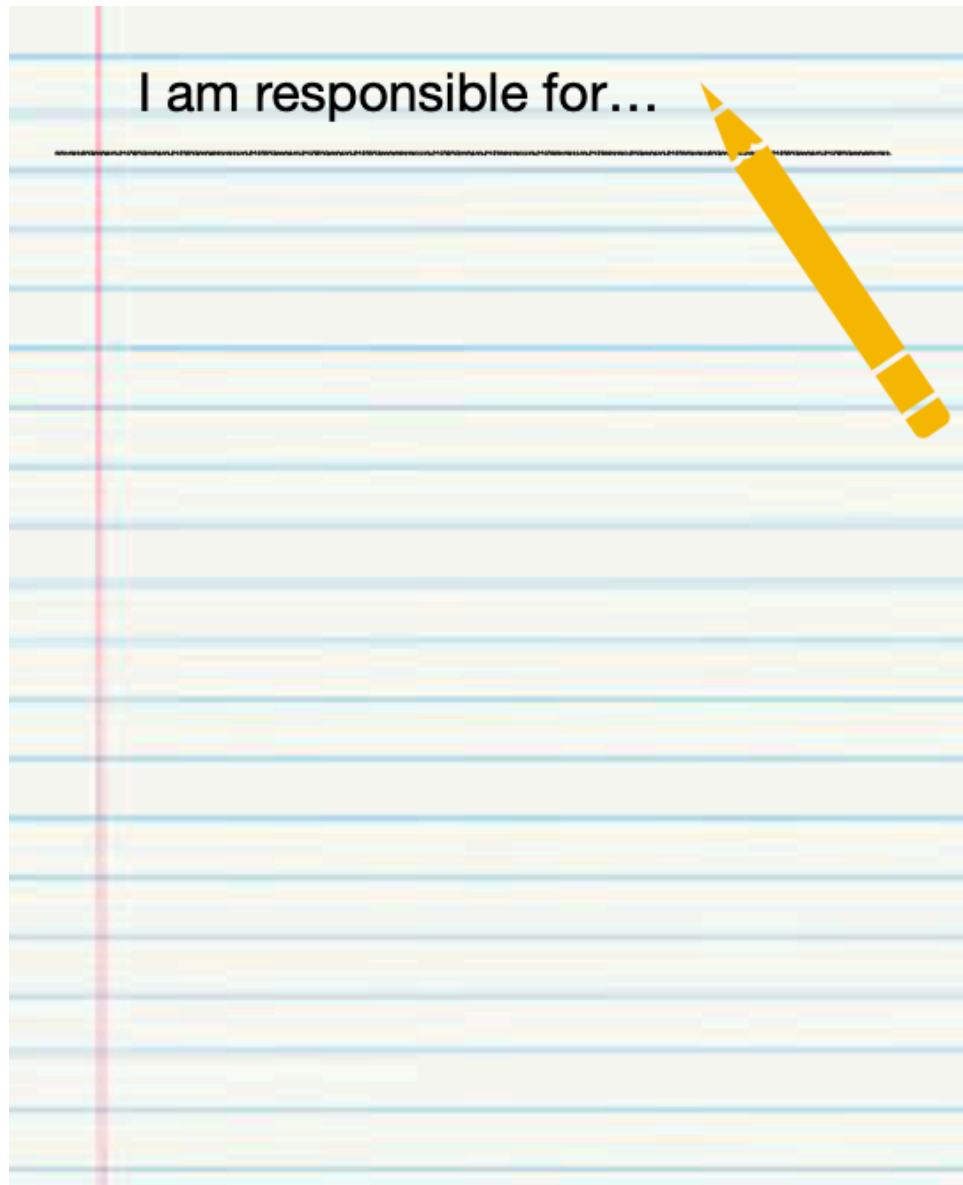
Create your personal rights statement and write on chart paper or copy paper. You can use pictures to help you create personal rights statements.



The image shows a template for a 'My Rights Statement' on lined paper. The paper has horizontal blue lines and a vertical red margin line on the left side. The text 'My Rights Statement:' is written in a large, black, sans-serif font at the top left. A yellow pencil with a white eraser and a sharp lead tip is illustrated diagonally on the right side of the page, pointing towards the top right corner.

## Activity #6: Understanding My Responsibilities

Review the discussion of responsibilities and then think about all of the responsibilities you have. Talk about which responsibilities are the most meaningful for you and why.



I am responsible for...

The image shows a worksheet with a light gray background and horizontal blue and yellow lines. A vertical red line is on the left side. The text "I am responsible for..." is written in black at the top. A yellow pencil is positioned diagonally on the right side of the page, pointing towards the text. Below the text, there is a horizontal line for writing.

## Activity #7 : I am Competent

Identify examples of when you felt like you were being treated as someone who was incompetent. Using chart paper list some examples.



Role play some scenarios of examples and act out how to respond when someone is presuming you are not competent. What would you say if:

- Someone told you when to go to bed?
- Someone told you that you could not take a bath?
- Someone told you that you had to go sit in a doctors office for someone else's appointment?
- Someone told you that your friend cannot go back to your bedroom during a visit?
- Someone told you that you had to go to a certain church or mosque or synagogue?
- Someone told you that you could not work where you wanted to work?
- Someone told you that you could not listen to the music you enjoyed?
- Someone told you that you could not watch the TV show you wanted to watch?

## Activity #8: I Have Power

Identify examples of when you felt powerless and alone. Use paper to list some examples.

Then identify and write out examples of when you felt empowered and supported.



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This is just a beginning guide to get you started on your self-advocacy journey. Remember that **ALL PEOPLE MUST** have the opportunity to **RISE UP & SPEAK OUT!**

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contact us



Uniting Georgians and  
influencing change by  
speaking up and taking  
control of our lives

**uniting for change**



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