



Disability Advocacy Seminar Series

Session 2: Understanding Advocacy

Ohio Centers for Independent Living (CIL)
Disability Rights Ohio (DRO)

Zoom Housekeeping

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Objectives

- What is advocacy?
- Understanding different types of advocacy
 - Self-advocacy
 - Individual Advocacy
 - Systems Advocacy
 - Grassroots Advocacy

What is advocacy?



- Advocacy is an action that supports a cause, idea, way of doing something, or speaks on behalf of oneself or others
- Today we will learn about four types of advocacy:
 - Self Advocacy
 - Individual Advocacy
 - Systems Advocacy
 - Grassroots Advocacy

A Comparison of

Self Advocacy

You determine what is right for you

You speak up for yourself

You stand up for your rights

Individual Advocacy

Someone else communicates what you have decided is right for you

Someone speaks up for you

Someone stands up for your rights on your behalf

A Comparison of

Systems Advocacy

An established group works to make changes for an entire group or community

The established group may join with other organizations or individuals (coalitions)

The established group works to change specific laws or policies

Grassroots Advocacy

Concerned individuals come together to act on a cause that impacts their lives

The individuals organize into a unified community

The unified community tries to influence political or social change

Self-advocacy

- Why should I advocate for myself?
- Strategies for self-advocacy:
 - Learning the facts
 - Managing emotions
 - Being assertive
 - Finding my voice
 - Believing in myself
- When and where should I advocate?
- Telling my story

Be your own advocate because...

You know your feelings, thoughts, needs, desires and life situation best

You disagree with others, think that rules do not consider your situation, feel you are not treated equally, or you need to express yourself

Speaking up for yourself may help others with similar needs

You don't need to wait for others to speak up for you



What are some examples of times you have been a self-advocate?

How to be an effective self-advocate: True or False

Before going out to public places with my new service dog, I should learn the rules about where I can go with my dog.

True. It is important to learn the facts about an issue that is important to you, so people take you seriously.

Learning the facts

- Do research
- Know your rights
- Ask questions
- Get support from experts, mentors and leaders



How to be an effective self-advocate: True or False

If I disagree with someone, I should yell at them until they agree with me.

False. You should always remain calm and speak respectfully.

Managing emotions

- Identify your feelings toward the situation and individuals involved
- Take ownership of your feelings
- Manage your anger; don't attack or ignore perspectives or opinions that differ from your
- Don't be afraid to express your self-confidence through bold statements and actions. This is being assertive, not aggressive



Being assertive

Being assertive means having or showing a confident and bold personality

Assertiveness shapes the way we deal with others

A lack of assertiveness is a primary obstacle to obtaining the services that we want and need

Assertive people state their opinions, while still being respectful of others

Don't let your fear of upsetting others or being disagreed with hold you back from asserting your position

Practice being assertive in a supportive setting

How to be an effective self-advocate: True or False

If I tell someone what I need, they will just think I'm complaining.

False. You need to speak up for yourself, which means finding your voice.

Finding my voice

No Voice	Chronic Complainer	Effective Complainer
Ignores, pretends or just gets through situations	Whines about problems	Addresses realistic concerns
Is apathetic, "I don't know"	Offers no solutions	Suggests reasonable solutions
Avoids placing responsibility on anyone	Blames others	Accepts responsibility for personal role
Noncommittal tone	Negative tone	Optimistic tone for resolution
Passive attitude that expresses no emotion toward situation	Expresses only anger or dislike	Assertive yet non-confrontational



What type of voice do you have?

What is the best voice for a self-advocate?

Effective complainers avoid:

Complaining all the time

Constant complaining is just whining

Complaining without checking the facts

Do some research before you start to complain

Generalizing

Discuss specific points of disagreement

Complaining to the wrong person

Always try to complain to someone who can fix the problem

Making the complaint a personal attack

Use "I" messages to avoid criticizing directly

Having no suggestions to fix the issue

If you are not part of the solution, you are part of the problem

Letting the issue escalate

Often, problems can be fixed more easily if noticed and addressed quickly

How to be an effective self advocate: True or False

My thoughts, feelings, opinions, or perspectives on an issue or situation in my life only pertains to me so I should just keep them to myself.

False. You are worth advocating for, so believe in yourself.



"No one can make you
feel inferior without
your consent."

Eleanor Roosevelt, longest-serving
First Lady of the U. S.

How do I increase my self-belief?

Self-belief Tips:

1. Learn to believe in yourself by examining and discarding limiting beliefs
2. Say, "NO!" to your inner negative voice
3. Flip your weaknesses into strengths
4. Develop your superpowers by listing your positive characteristics
5. Be your own coach. Tell yourself, "You can do it."
6. Envision yourself as the strong person you want to be, not who you could be in the future

When should I advocate?

When I'm lacking something I need



When there is something I want



When something I believe is being challenged



When my civil rights are not being understood or met



When I'm being discriminated against




When my voice is not heard

Where should I advocate?

- School
- Work
- Medical and healthcare environments
- Community activities
- Public venues
- Municipal buildings and events
- Open forums
- Social media
- Television media

What is your story?

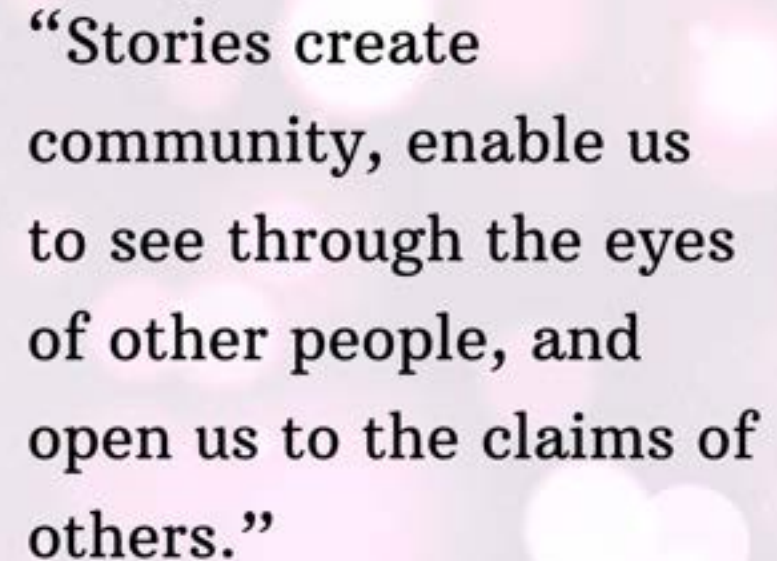
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Stories have the power to
create social change and
inspire community.

Terry Tempest Williams

 quoteoncy



“Stories create
community, enable us
to see through the eyes
of other people, and
open us to the claims of
others.”

PETER FORBES

Why should I tell my story?

Everyone has something of value to share with others



Stories inform, raise attention, demand awareness, and deliver a message



Stories help people relate to situations and feelings they have not experienced for themselves



You don't need to wait for others to speak up for you

Stories suggestions:

My personal story

- Consider using a hook to draw people in
- Include important events, moments or emotions to highlight morals and objectives, emphasize your hook, provide suggestions, or make a conclusion
- Natural progression often equals natural momentum
- Be truthful, avoid exaggerating, and don't try to be an expert
- Use concise details and show emotion
- The way you tell your story and the feelings you express are unique to you, there is no wrong way to tell it

Stories suggestions:

My story about a specific issue

- Keep it relevant to the issue
 - Your story may be different for each issue
 - Focus the timeframe
 - Include specific details
 - Consolidate your opinion
- Think carefully about your audience
- Illustrate the issue with personal events if possible
- Express your personality
- Include emotion
- Link your story to larger social events when appropriate

Story practice

Write your story with 5 important personal facts, opinions, or perspectives

Remember to think about your audience, include specific details and express your personality

The issue:
The city is proposing to change the bus routes so that it no longer stops near the career center where you work every day

Individual advocacy

- Who can advocate for me?
- Dos and don'ts for individual advocates
- How do individual advocates help?
- Telling another person's story



Can you name individuals who can advocate for you?

- Family members
- Friends
- Caregivers
- Teachers
- Counselors
- Doctors and nurses
- Bosses
- Co-workers
- Community leaders
- Legal representatives

Let's not forget peer advocates

Unique advocates because they have many shared experiences

May have already advocated for something you need

Know the system

Have contacts

Want to help make the advocacy process easier

How to practice individual advocacy

• Do:

- Act on behalf of, for, and most importantly **with**, an individual
- Acknowledge their dignity, worth and value
- Provide support when an individual is in need
- Take time to research

• Don't:

- Act on behalf of your needs or what you think is best for the individual
- Assume they are helpless without your assistance
- Provide support only when it is convenient to you
- Just present your opinions

How do individual advocates help?

- Listen to your views and concerns
- Help you explore your options and rights (without pressuring you)
- Provide information to help you make informed decisions
- Help you contact relevant people or contact them on your behalf
- Accompany you and support you in meetings or appointments
- Believe in you

Telling another person's story

- Listen to the individual
- Determine the message
- Consider the issue the story is responding to
- Hone the story for the audience
- Be specific
- Capture the voice and spirit of the individual, not your own

Systems advocacy

- What is it?
- Methods of advocating



What is systems advocacy?



- Working to create change within a system, agency, jurisdiction, government, etc.
- Speaking out on policies, laws, rules, benefits, and/or practices that affect many people with a common interest
- Typically conducted by organizations or agencies that include and represent the interests of the individual, individuals, or group the policies, laws, rules, or practices affect

Methods of advocating

1. Making legislative contacts
2. Lobbying
3. Testimony
4. Rallies
5. Petitions
6. Forming coalitions

1. Making legislative contacts



Making connections: Build relationships

1. Find out who your representatives and senators are:
 - State: www.legislature.ohio.gov/legislators/district-maps
 - Federal: www.house.gov/representatives/find-your-representative and www.senate.gov/senators/senators-contact.htm
2. Join their mailing list
3. Reach out, introduce yourself, give a testimony

Phone campaigns

Establish a phone tree

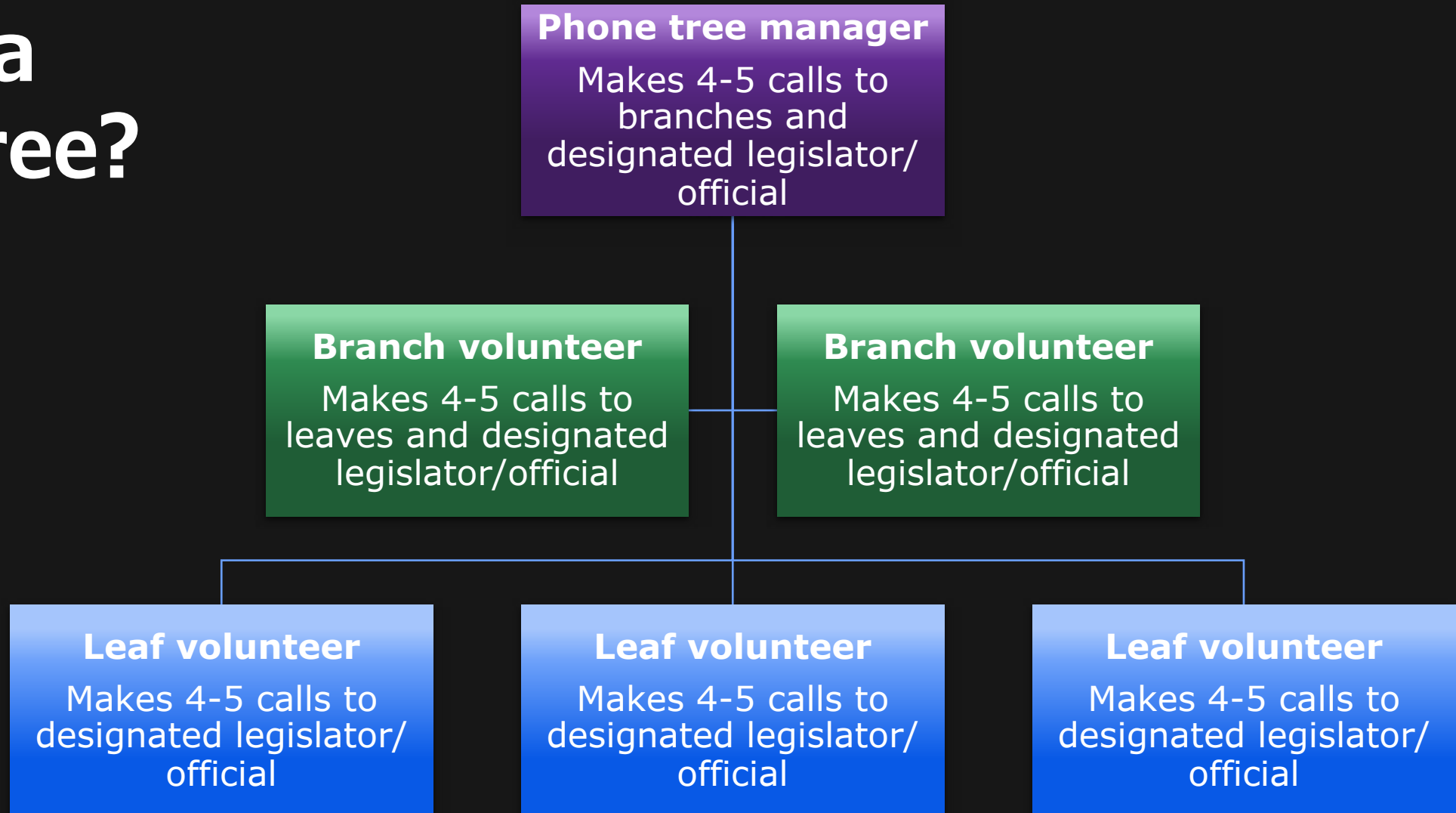


Select a date and time when all participants will call the designated elected officials



Create a standard message/script that all participants will use when making calls

What is a phone tree?



Letter writing

Elements of your letter:

1. Your name and address
2. The recipient's name and address
3. Introduction
4. Story
5. What needs to be changed
6. Conclusion



Introduction

- 1 Paragraph
- Introduce yourself (maximum 2 sentences)
- Clearly state the purpose of the letter without writing “I’m writing this letter because...” e.i. what is the problem (1 sentence)
- Give the recipients one action item they can do immediately to start making changes (1 sentence)

Story

- 1-2 Paragraphs
- Keep it relevant to what the letter is about
- Illustrate the issue in the story
- Make it expressive
- Make it personal
- If appropriate, link your story to a larger societal situation

What needs to change

- 1-2 Paragraphs
- Outline how the system works now (maximum 3 sentences)
- How the current system affects you (maximum 2 sentences)
- How would you change the system (maximum 3 sentences)
- How would system changes affect your life (maximum 2 sentences)

Conclusion

- 1 Paragraph
- Restate the problem (1 sentence)
- Describe how it impacts your life (1 sentence)
- Tell the recipient how they can help (1 sentence)
- Thank the recipient

Letter writing practice

Write a letter (outline) with an introduction, a relevant story, what needs to change, and a conclusion

Remember to think about the recipient, state the problem, include specific details and express your personality

The issue:
The state legislature is proposing cuts to Medicaid waiver services in the recently proposed budget

Join a meeting

- Sign-up for legislators' or legislative committees' mailing lists
- Search legislator's social media- websites, Facebook, Twitter for scheduled meetings
- In-person
- Virtual
- Always request accommodations

Getting a personal meeting

- Introduce yourself
- Clearly convey the reason for your meeting
- Be persistent
- Be prepared
- Be personal
- Follow with a thank you

2. Lobbying

A subset of advocacy with a very narrow focus, to present information meant to influence a voting body in a specific direction



The difference between advocating and lobbying

Advocating:

Educating a legislator or person on an issue — for example, sharing stories and statistics — but not asking them to take a specific action

Lobbying:

Asking someone directly to support or oppose an action, such as convincing a legislator to vote a specific way

3. Testimony

Telling individual stories or
representing an issue as a collective

Systems advocacy testimony: True or False

Giving testimony for systems advocacy is the same as telling my story when I advocate for myself.

False. Giving testimony through systems advocacy is a form of storytelling that attempts to influence laws, policies or issues that affect groups of individuals. Telling a personal story to advocate for yourself or another individual tries to create change for only yourself or that individual.



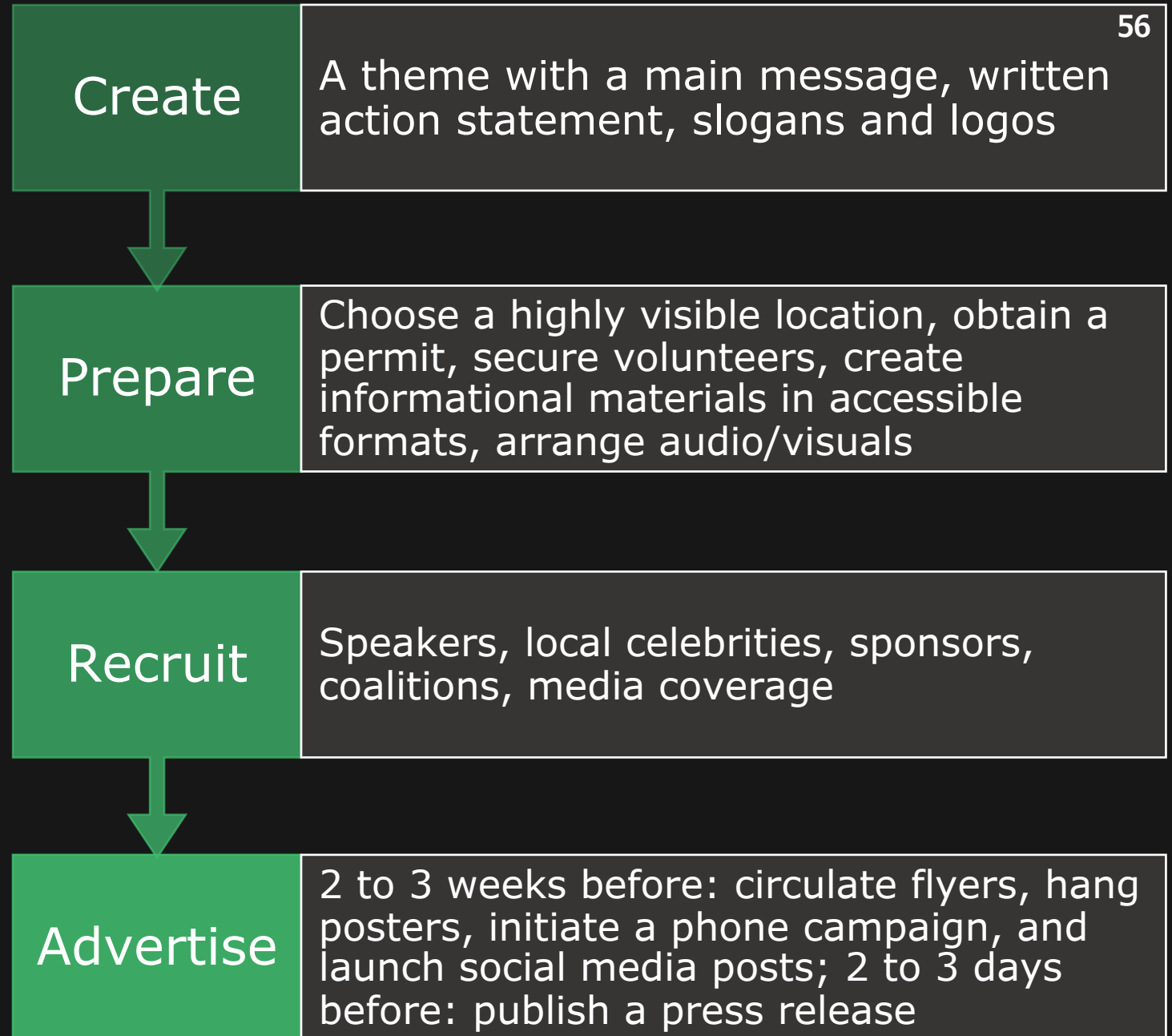
What are some ways to provide testimony ?

- Speaking to legislative bodies during public meetings or formal sessions
- Holding a public forum with media attention
- Getting a voice at the table
- Speaking at rallies or public demonstrations

4. Rallies

Rallies are a form of demonstration where people gather to show public concern for a cause, or express the opinion of a wide cross-section of society

How to coordinate a rally



5. Petitions

- A petition is a document presenting an organization or group's call to action on an issue that individuals sign to show widespread support on an issue
- It is an effective way to influence change with decision-makers, affect policies, or raise awareness
- You can reach current supporters as well as gain new constituents

How to create a petition

Choose a topic and write 1 to 3 paragraph statement explaining:

- The problem
- The solution
- The action you want done

Dedicate most of the document for signatures including:

Names
Email and street addresses
Phone numbers (optional)

Create an online and print version

Important petition considerations

- Is it a government or non-government petition?
- Do you need a certain quantity of signatures or specific information for each person that signs?
- Does the petition sheet have to be certified?
- Does the petition signer have to meet certain eligibility?
- Is there a timeline for collecting and submitting the petition?



How to circulate a petition

Identify locations with large concentrations of individuals who would be interested in your cause

- Indoor venues
- Dense residential areas
- Locations that attract media attention

Recruit carriers to go to these locations. Have multiple individuals canvassing areas at the same time. Return to areas on different dates and times

Set up tables at locations with heavy foot traffic, large public venues, rallies, public meetings, etc. If required, obtain permission to set up tables before arriving at a location or event

Post an online version on websites and social media, and distribute through email

6. Forming Coalitions

- A coalition is a group of organizations who share a common interest/goal
- Forming a coalition empowers people in many communities, gets more perspectives on an issue, combines resources and ideas, and strengthens voices
- Members of a coalition may also include grassroots advocacy groups and interested individuals

How to form a coalition

- Form partnerships with a “core group” of organizations
- Leaders from each organization will establish connections and act as decision makers
- Recruit new members by publicizing the coalition:
 - Posting on social media
 - Use relevant hashtags. Like: #CareCantWait or #CripTheVote
 - Connecting with the community resources of each organization
 - Advertising your group with flyers
 - Reach out to more stakeholders via email, phone, or letter writing

How does a coalition function?

Meet

Hold regular meetings to discuss new information and brainstorm ideas

Mission

Develop a mission statement to represent the group's goals and values

Action Plan

Make sure your plan is realistic. Try breaking big goals down into small steps

Divide and Conquer

Use your resources by splitting up the work among group members

Inclusion

Always be inclusive and give everyone a chance to speak

Celebrate

Take time to review, celebrate and publicize your work

Growing a coalition: brand and market

- Branding:
 - Brainstorm a coalition name or key phrase that captures your cause
 - For example: “Better At Home” to support Home and Community Based Services
 - Use it as a hashtag: #BetterAtHome
 - Create a logo that represents your group and your mission
- Marketing:
 - Tell your story on podcasts, blogs, websites, and social media
 - Write letters to your local newspaper for the opinion or letter to the editor section
 - Publicize your meetings and update the public on your work

Grassroots advocacy and Community organizing

- What is it?
- How does it work?
- How to organize communities to advocate?
- Virtual methods
- ADAPT: a community organizing case study



What is grassroots advocacy?

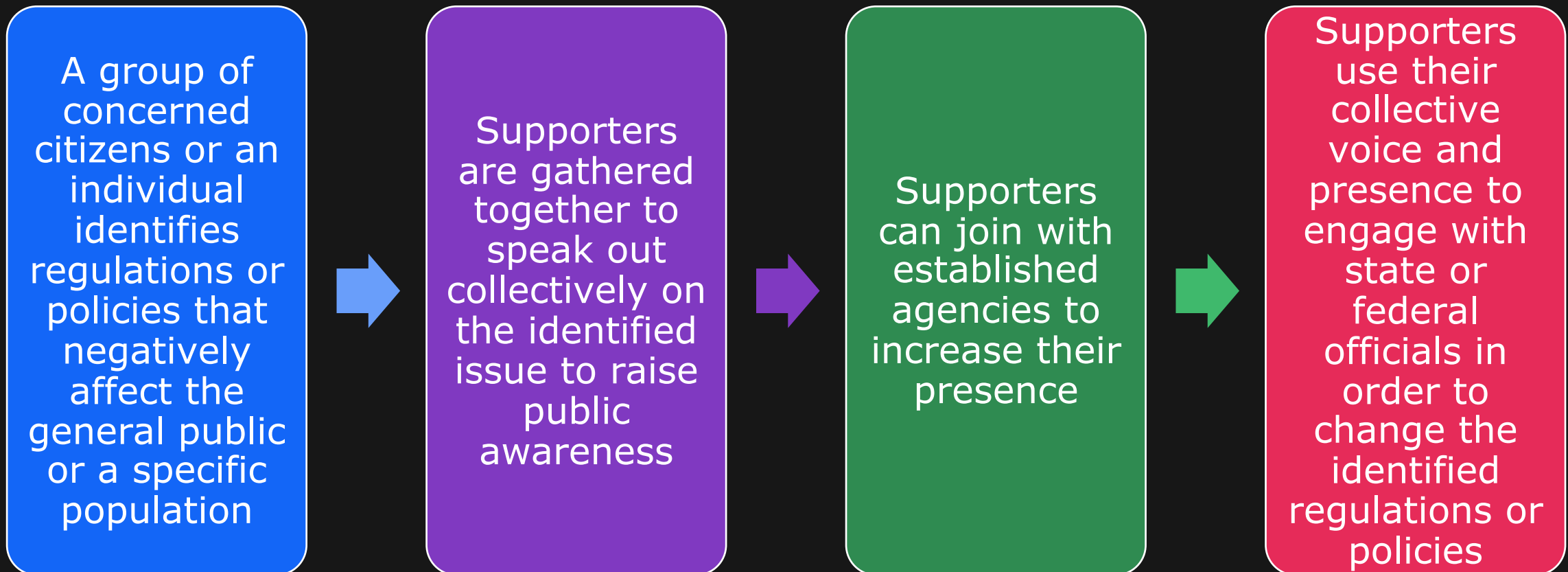
- Gathering together the general public to speak up about an issue
- Individuals connect with elected officials to express their personal opinions and perspectives
- Individuals combine their voices to raise awareness
- Can be used to influence public perception, affect regulations, and challenge public policy

Organizing grassroots advocacy: True or False

Established organizations or agencies must organize grassroots advocacy efforts.

False. Grassroots advocacy is most often started by an informal group or a single concerned individual but can join forces with established agencies.

How does grassroots advocacy work?



How do you organize supporters?

- Surveys- phone, in-person, social media
- Flyers- in-person, by mail, virtual
- Signed petitions- in-person, by mail, virtual
- Door-to-door canvassing
- Local meetups
- Town halls
- Marches
- Rallies
- Fundraising events



Virtual methods to create a grassroots movement

- Create a website
- Email individuals and groups who might be interested
- Email elected officials
- Facebook posts
- Create Facebook groups
- Text message chains
- Mass tweeting to elected officials
- Virtual townhalls
- Create a podcast or YouTube channel





ADAPT

- Organized by Wade Blank
 - Heritage House Nursing Facility
 - Started Atlantis
- Americans Disabled for Accessible Public Transportation
- Americans Disabled for Attendant Programs Today
- Money Follows the Person

ADAPT: Americans Disabled for Accessible Public Transportation

~Founded July 5-6, 1978

- Wade and nineteen disabled activists held a public transit bus "hostage" on the corner of Broadway and Colfax in Denver, Colorado. ADAPT eventually mushroomed into the nation's first grassroots, disability rights, activist organization
- For seven years ADAPT blocked buses in cities across the US to demonstrate the need for access to public transit. Many went to jail for the right to ride

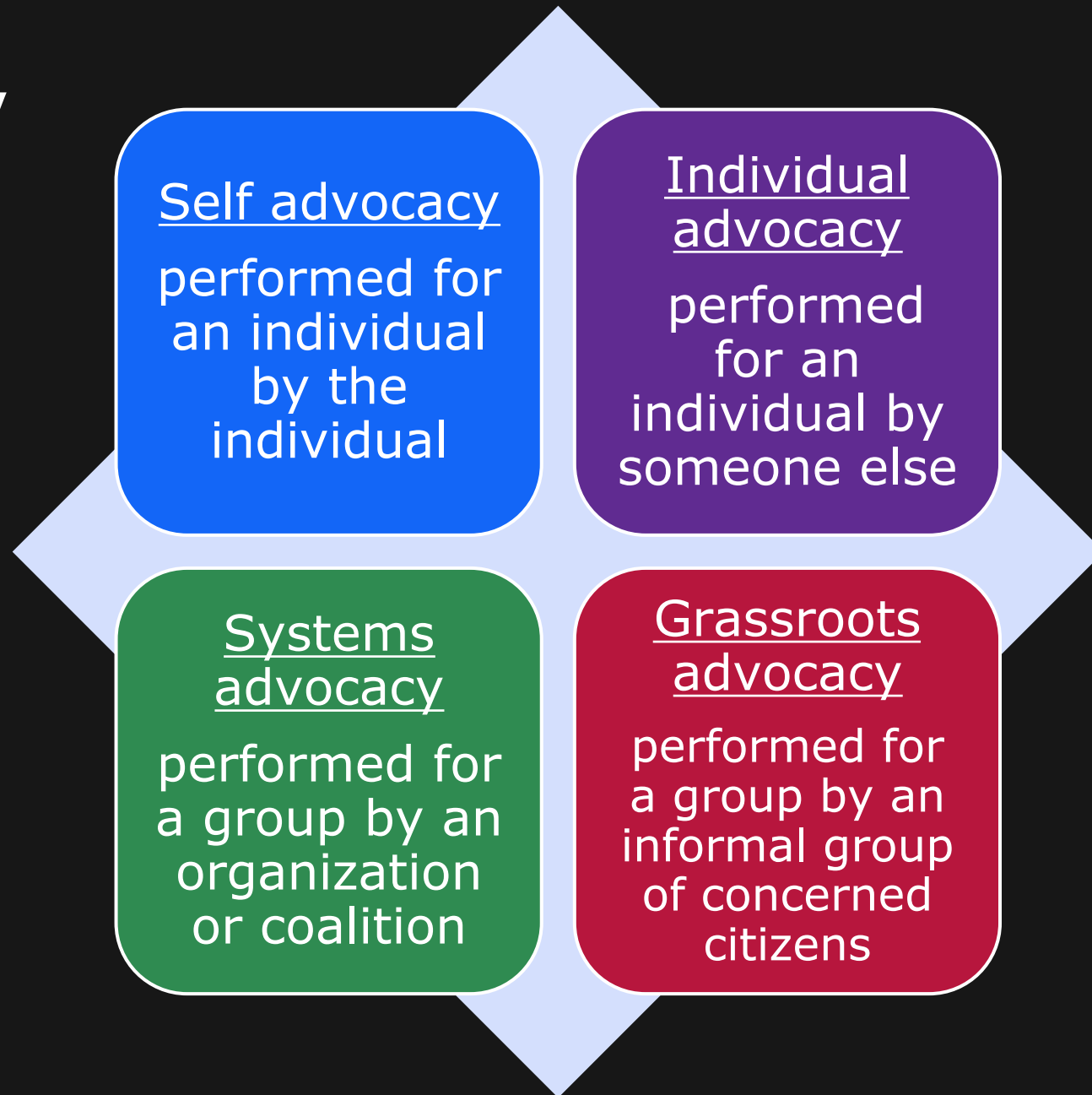


- In the spring of 1990, the Secretary of Transportation, Sam Skinner, finally issued regulations mandating lifts on buses
- ADAPT played a major role in gaining passage of the Americans with Disabilities Act, ADA, particularly in ADA's stringent requirements relating to accessible transit, and its being seen as a civil rights law

ADAPT: American Disabled for Attendant Programs Today

- In 1990, after passage of the Americans With Disabilities Act (ADA), ADAPT shifted its vision toward a national system of community-based personal assistance services and the end of the apartheid-type system of segregating people with disabilities by imprisoning them in institutions against their will. The fight continues to this day
- Nationally ADAPT focuses on promoting services in the community and sees attendant services as the cornerstone to community-based services for people with severe disabilities

Summary



Thank You!

- Contact Us!
 - Maria Matzik, ACIL: maria.matzik@acils.com
 - Maria Sutter, LEAP: msutter@leapinfo.org
- Please join us for our next seminar:
 - **Disability Law, Part I**
 - **Wednesday, February 15, 2023**
 - **2- 4pm EST**
- Many thanks to our interpreter and captionist
- Resources for the information in this presentation are listed on the slides at the end of this presentation
- Recordings, transcripts, and copies of the presentation will be available after the series is complete. You'll receive more info by email

Resources

- 2001 IL NET, an ILRU/NCIL Training and Technical Assistance Project, *Systems Advocacy: Using Your Power to Effect Change* April 5-6, 2001 Philadelphia, PA https://www.ncsilc.org/wp-content/uploads/2013/03/SystemsAdvocacy_EffectChange.pdf
- *Chapter 33. Conducting a Direct Action Campaign | Section 9. Conducting a Petition Drive | Main Section | Community Tool Box. (n.d.)*. Retrieved from <https://ctb.ku.edu/en/table-of-contents/advocacy/direct-action/petition-drive/main>
- *How to Organize an Effective Petition Campaign –. (2020, March 26). AAUW : Empowering Women Since 1881.* <https://www.aauw.org/resources/policy/advocacy-toolkit/organize-petition-campaign/>

Resources

- The Self-Help Alliance. (n.d.). *Self-Advocacy Curriculum*. <https://cmhawwselfhelp.ca/wp-content/uploads/2016/10/AdvocacyCurriculumApril2010.pdf>
- *Self-advocacy - self help & peer support - self help*. (2016, November). Retrieved from <https://cmhawwselfhelp.ca/wp-content/uploads/2016/10/AdvocacyCurriculumApril2010.pdf>
- Unwired, G. (2022, April 18). *Grassroots Advocacy and 5 Effective Campaign Strategies*. Grassroots Unwired. <https://www.grassrootsunwired.com/grassroots-advocacy/>

Resources

- Watkins, J. (2022, October 30). *Wade Blank 1940-1993, Disability Rights Movement Advocate Remembered*. <https://abilitychicagoinfo.blogspot.com/2017/07/wade-blank-1940-1993-disability-rights.html>. Article published by the Ragged Edge- July/August 1993. The Reverend Wade Blank, 1940-1993 is a tribute to Wade Blank written by Justin Dart in 1993. Press Release in 1993: The President's Committee on Employment of People with Disabilities Justin Dart, Chairman.
- *What is Grassroots Organizing*. (n.d.). Community Catalyst. Retrieved from <https://www.communitycatalyst.org/resources/tools/grassroots/what-is-grassroots-organizing>