



Bringing People and Organizations Together to Achieve Change

Coalition Building at Centers for Independent Living

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This resource was developed by the Disability Vaccine Access Opportunities (DVAO) Center in 2024 and is a shared initiative by Able South Carolina (Able SC) and Independent Living Research Utilization (ILRU). More information and resources can be found at the [DVAO Resource Hub](#).



Able South Carolina (Able SC) is a federally recognized Center for Independent Living that represents half of the counties in South Carolina and is a recognized leader in statewide, national, and international programs to increase capacity for disability rights, disability justice, and independent living. Able SC is a disability-led organization seeking transformational changes in systems, communities, and individuals. Since 1994, we've remained a consumer-controlled, community-based, cross-disability nonprofit that seeks to make South Carolina a national model of equity and inclusion for all people with disabilities. To learn more, visit www.able-sc.org.



Independent Living Research Utilization (ILRU) at TIRR Memorial Hermann, founded in 1977, has a long history of providing research, education, and consultation in the areas of independent living, home and community-based services, and the Americans with Disabilities Act. ILRU is operated by community living and disability law experts with disabilities. To learn more about ILRU, visit www.ilru.org.

Introduction

Ed Roberts, a renowned disability rights activist, once said that advocacy was the most important task carried out by Centers for Independent Living (CILs). Although all five core services are vital, individual and systems advocacy are critical in addressing discrimination, removing barriers, and creating lasting change. Advocacy work involves various approaches and tactics, but joining a coalition is a proven and effective way of building power and collaborating with partner organizations with similar interests to achieve change.

The purpose of this guide is to outline how CILs and the disability community can build strong coalitions with public health and related organizations. The guide provides an overview of the key aspects of coalition work and how such an alliance can be an effective way of building disability power and bringing about change in the community. The focus is on issues and barriers impacting public health and individuals with disabilities. While the guide speaks specifically to coalition building in relation to healthcare outcomes, the principles described in the following chapters can be applied to coalition work in general.

This resource guide is a great starting point for those who are new to this work and for seasoned organizers who need a refresher. The guide includes a detailed list of resources, including articles, videos, and books, at the end.

Chapter 1: The Importance of Addressing Public Health through a Disability Lens

It is crucial to understand the hurdles and obstacles people with disabilities encounter when attempting to access public health services before delving into how to form effective coalitions. This chapter discusses the significance of approaching public health and clinical medicine from a disability perspective. Individuals with disabilities often confront obstacles and healthcare disparities that significantly impact their lives. By comprehending these challenges and the role of CILs, people and groups can advocate for healthcare systems that are more accommodating and accessible to everyone.

The Impact of Healthcare Disparities on People with Disabilities

According to the [Centers for Disease Control and Prevention](#), health disparities adversely affect people with disabilities at a much higher rate, often leading to unmet needs and poorer overall health outcomes. People with disabilities are less likely to have access to quality healthcare due to various barriers, including:

- Medical facilities may not be accessible
- Diagnostic equipment such as scales, tables, MRI machines, and others are often inaccessible
- Transportation may not be available
- Providers lack training and awareness of disability issues
- Individuals with disabilities are less likely to receive preventive services such as screenings and diagnostic tests
- People with disabilities have higher rates of chronic conditions such as diabetes, obesity, and cardiovascular conditions

People with disabilities are two to three times more likely to struggle with mental health issues. A [study by the National Council on Disability](#) shows that disparities caused by a lack of access to health care manifest in a variety of ways among people with disabilities. These include:

- 40.9% of people with a disability report they have fair or poor health; compared to 9.1% of people without a disability
- 6.6% of people with a disability have had a stroke compared to 1.5% of those without a disability
- 13.2% of people with a disability have had COPD compared with 3.1% of those without a disability
- 9.0% of people with a disability have had cancer, compared with 5.3% of those without a disability
- 42.0% of those with a disability have experienced depression, compared to 11.6% of those without a disability

The article, [Disability Doesn't Discriminate: Health Inequities at the Intersection of Race and Disability](#) indicates that people with disabilities who are multi-marginalized due to race and ethnicity reported increased health disparities.

The COVID-19 pandemic increased awareness of and worsened disparities facing people with disabilities. Below are some examples.

- Those with intellectual or developmental disabilities, medically fragile, and technology-dependent individuals faced a high risk of being triaged out of COVID-19 treatment when health care was scarce, a practice known as medical rationing.
- Individuals were denied the assistance of critical support persons during hospital stays, especially early in the pandemic.

- Congregate living facilities such as nursing homes were especially hard hit during the pandemic. This resulted in extreme difficulty for CIL staff and other community organizations to serve individuals in these facilities. Consumers faced minimal opportunities to transition out of these facilities to community-based settings.
- The growing shortage of direct care workers before the pandemic worsened as individuals working in this vital occupation faced safety concerns, a lack of access to appropriate protective equipment, and continued low wages. Individuals who depended on these supports also faced safety concerns and serious dangers should they be forced to move to a nursing facility because they could not access caregivers in the community.
- People with disabilities and chronic conditions were at particularly high risk of contracting COVID-19.
- People with disabilities and allies had to fight to be prioritized to receive vaccines.
- Clinics and facilities where vaccines were distributed were often not accessible or accommodating for people with disabilities.
- People with intellectual or developmental disabilities, deaf, hard of hearing, deaf-blind, and blind persons faced profound communication barriers.
- General information about COVID-19 did not include disability-specific information.

The Role of CILs in Advocating for Change

As community-based organizations led by individuals with disabilities, CILs are instrumental in advocating for changes in the healthcare system to reduce disparities and eliminate barriers. Centers can promote the independent living philosophy in a medical model environment and challenge traditional healthcare practices that may overlook or disregard the needs and rights of people with disabilities. CILs are the go-to advocacy organizations in their communities for people with disabilities. Moreover, people with disabilities are the most knowledgeable and best equipped to articulate the barriers and challenges they face when accessing public health and clinical medicine services..

Advocacy and Legal Requirements

It is crucial to emphasize the legal and civil rights requirements related to health and disability. Various federal laws such as the Rehabilitation Act, Americans with Disabilities Act (ADA), and the Affordable Care Act (ACA) directly address physical, programmatic, and communication access. According to a brief from the ADA National Network, under the Rehabilitation Act, all organizations receiving federal

funds, including health departments, must provide services in a manner that is accessible to persons with disabilities. Additionally, all providers have responsibilities under the Americans with Disabilities Act. These regulations provide a framework for outreach, education, and advocacy. There is a need for organizations such as CILs to collaborate to ensure that legal standards are met, resulting in better access to healthcare and improved outcomes.

Chapter 2: Overview of Coalitions

What is a Coalition?

A coalition is a group of diverse organizations that collaborate to achieve a common goal or objective. Usually, these coalitions are formed to address significant issues or challenges. For instance, a coalition may be established to advocate for and work towards the passage of legislation. This approach is particularly effective in disability advocacy and the work done by CILs. By forming coalitions, CILs and other organizations can pool their unique strengths, resources, and perspectives to create a powerful force for change and advocacy, while also strengthening the power of the disability community.

Coalitions are made up of a diverse group of individuals, such as advocacy groups, non-profit organizations, community service providers, neighborhood associations, healthcare professionals, policy experts, and sometimes businesses and governments. It is essential that coalitions at CILs also include individuals with disabilities who have been or could be impacted by the focus area or issue concerning the coalition. These organizations come together to achieve a common goal: policy reform, increased public awareness, and improved service delivery. Each participant chooses to join the coalition because the work aligns with their mission. (Source: Organizing for Social Change. Bobo, Kendall, and Max, 2010).

Why Coalitions Form

Building a coalition involves bringing together individuals and organizations with a common interest or goal and agreeing to work together to achieve it. Coalition building is a powerful strategy to address health challenges and barriers facing people with disabilities. Through coalition building, organizations can combine their resources, expertise, and influence to create a greater impact than they could achieve alone. There are various reasons why an organization might decide to form a coalition, including:

- Increasing the visibility and credibility of a cause or issue: a coalition can demonstrate broad support and a diversity of perspectives, helping to

attract media attention, public awareness, and the attention of policymakers

- Pooling and coordinating resources and efforts: A coalition can reduce duplication of efforts, share information and best practices, and access new sources of funding and technical assistance
- Enhancing capacity and reach: A coalition can expand its members' skills and knowledge, tap into new networks and audiences, and foster innovation and creativity
- Creating momentum: A coalition can generate more energy and enthusiasm, inspire collective action, and amplify its members' voices and power

There are many benefits that are realized by working with a coalition. Some of these include:

- Effective and sustainable change: a coalition can produce changes in policies, systems, and environments that address the root causes of a problem or issue and benefit the whole community
- Foster collaboration and partnership: a coalition can build trust and relationships among its members, promote a culture of learning and sharing, and create a sense of community and belonging
- Empower and mobilize the community: a coalition can engage and involve diverse stakeholders, especially those who are most affected by the issue, and enhance their leadership and advocacy skills
- Create a unified front that can address complex issues more effectively

Organizations with similar interests can reap many benefits when they join a coalition. One of the primary advantages is the collective impact that results from collaboration among multiple organizations working towards a common goal. Joining a coalition allows organizations to combine their resources, expertise, and networks, creating a stronger and united force. This can improve and strengthen the overall effectiveness of coalition member organizations' programs, initiatives, and advocacy efforts.

One of the benefits of forming a coalition is that member organizations can increase their visibility and influence. By presenting a united front, a coalition can get the attention of policymakers, government officials, funders, and the broader community. The increased visibility often strengthens advocacy efforts and can also create opportunities for increased funding, partnerships, and collaboration.

Lastly, joining a coalition can benefit organizations as it provides a platform to amplify their impact, share resources, and collectively work towards creating positive change in their communities. The diverse perspectives within a coalition can lead to better problem-solving and new approaches to addressing challenges and barriers. Overall, coalition membership can help organizations achieve their goals more effectively. (Organizing for Social Change. Bobo, Kendall, and Max, 2010. [Creating High Impact Coalitions, Harvard Business Review](#)).

When Forming or Joining a Coalition May Be the Right Choice

Coalitions are a strategic approach that can help organizations increase their impact, resources, and reach. They can be particularly useful in addressing complex and significant issues that impact people with disabilities, such as health care, affordable and accessible housing, employment, and transportation. These issues cannot be tackled by one organization alone, but multiple organizations coming together can make them more approachable. By forming a coalition, CILs and other partners can collaborate with organizations from different sectors, such as housing authorities, healthcare providers, and other organizations, to create comprehensive solutions.

Coalitions can also be a powerful tool when seeking to influence policy and make legislative change. This process can be difficult and lengthy, requiring sustained efforts and support from many organizations. Coalitions can bring together a variety of stakeholders, each bringing their own influence and expertise. This collective voice is more likely to be heard and influence policymakers, making this approach to systems advocacy an effective strategy for working towards change that benefits people with disabilities.

In addition, coalitions can benefit member organizations by enabling them to share resources and build capacity. Centers often operate with limited resources. By joining forces with other organizations, CILs can share costs, expertise, and even personnel, leading to more efficient operations and more significant impact. (Organizing for Social Change. Bobo, Kendall, and Max, 2010.)

Challenges Faced by Coalitions and Potential Strategies to Overcome Them

Despite the potential benefits of coalitions, they can face various challenges, such as competing priorities among members, communication issues, and limited resources. Disagreements and a lack of consensus can also derail plans when working with several organizations. To overcome these challenges, it is essential to establish clear, mutually agreed-upon goals and encourage open and frequent



communication. Building mutual respect and understanding among coalition members can also help to resolve many of these issues. Sharing the workload among all participants is crucial. Finally, allowing all participants to contribute to developing coalition goals and strategies is essential.

To realize the benefits of working in a coalition, members must understand group dynamics, recognize, and value each member's unique contributions, support a culture of inclusivity, and ensure that the voices of people with disabilities are central in all discussions. Building trust and relationships among members is also key to the coalition's success.

Effective coalitions operate with a strategic approach. This involves detailed planning, setting achievable and measurable goals, and developing a clear roadmap. Everyone involved in the coalition should have an opportunity to participate in setting goals and evaluating progress on an ongoing basis. The coalition must also inform participants about accomplishments, setbacks, and changes in the approach used.

Transparency in leadership and management is crucial for effective mobilization and management of resources. The coalition's workload should be shared equitably among members, and communication should be regular to keep everyone informed and the coalition moving forward. Conflict management should be a priority, and the coalition should promote a respectful and inclusive atmosphere where differing views are valued.

It is vital to measure the impact of a coalition on the issues it was formed to address. A clear strategy and goals, and an easy way to measure progress toward achieving them are essential. The coalition should identify and establish indicators showing progress toward its goals and an evaluation process for assessing its effectiveness. [Evaluating Coalition Progress and Impacts](#).

Measuring and demonstrating success might include indicators such as the number of people impacted, changes in policies or practices, or other relevant metrics, such as:

- Increased membership in the coalition
- Greater awareness in the community of the issues the coalition came together to address
- Policy change
- Increased public awareness of disability issues
- Improved access to services for people with disabilities

Lastly, it is crucial to ensure the sustainability of a coalition. Although it may seem impractical to think about how the coalition will be maintained long-term when starting one, it is necessary for the organization that is building a coalition to consider several issues. Initially, the founding organization(s) will likely decide the overall purpose, broad goals, and who will be invited to get things started. However, it is almost certain that the leadership will change, goals will be adjusted, and new organizations will join in over time. The coalition may change its meeting schedule, location, and the way it operates. The coalition must be open to new ideas, and implement a process for evaluating and measuring progress. Funding and resource development may become more of a concern as time passes. Thinking about and long-term sustainability at the start, keeping them in mind as the coalition forms and moves forward, and being supportive of these changes will help ensure the coalition's sustainability. (Organizing for Social Change. Bobo, Kendall, and Max, 2010).

Signs of an Effective Coalition

An effective coalition can be recognized by a few key indicators. These include having clear and shared objectives, active and engaged participation from all members, robust and efficient communication strategies, and the ability to deliver measurable impacts through its activities. For CILs, the effectiveness of a coalition is also evident in the tangible improvements it brings to the lives of people with disabilities, as well as in raising awareness of these issues within the broader community. The author of [Five Principles for Building Successful Coalitions](#) suggests that thriving coalitions have the following characteristics.

- **Unity and trust:** Members of the coalition share a common goal and work together to achieve it. They trust each other and are committed to the cause.
- **Effective communication:** Communication is open, honest, and respectful. Members listen to one another and are willing to compromise for the good of the coalition.
- **Clear goals and objectives:** The coalition has a clear vision and mission statement. Members understand their roles and responsibilities and work towards achieving the goals.
- **Diversity and inclusivity:** The coalition is diverse and inclusive. Members come from different backgrounds and have different perspectives. This diversity helps in generating new ideas and solutions.

- Flexibility and adaptability: The coalition is flexible and adaptable. Members are willing to change their approach if something is not working. They are open to new ideas and feedback.

Chapter 3: Building an Effective Coalition

Is a Coalition the Right Choice?

Before building a coalition, it is important to determine if it is the right approach for the Center. However, this is not a simple decision as building a coalition requires a significant amount of time, effort, financial support, and a long-term commitment. Although bringing multiple organizations together to enhance resources, capacity, and visibility may sound enticing, it is essential to understand the work involved in this effort to achieve success. It requires individuals with strong leadership skills who understand the dynamics and steps involved in building a coalition.

If a CIL decides to establish a coalition, they should expect to provide staff time, financial support, and other resources to develop it. CIL staff and leadership must understand that shifting to this collaborative approach will fundamentally change the way the organization responds to a problem or issue in the community, as it will depend on others to achieve change. However, if successful, the benefits and rewards of working within a coalition make this approach worthwhile.

Defining the Purpose and Focus of the Coalition

Once it has been decided that forming a coalition is the right course of action, the next step is to define its purpose and focus clearly. The purpose should align with the core values and needs of the target community, which in this case includes staff at CILs, advocates, and people with disabilities. A well-defined purpose for the coalition will facilitate the recruitment of organizations and individuals, unify members around the purpose, and guide future actions. The following points should be considered while defining the coalition's purpose.

- Assess the immediate and long-term needs of the community. Think about the problem and how it impacts the community. Consider what a coalition could accomplish by working together to address the problem or issue(s).
- Determine achievable goals that align with these needs. These will be the coalition's initial goals and help explain the purpose and what it will accomplish.
- Create a mission statement that encapsulates these goals. This statement should clearly state the problem and solution. For example, The SC



Disability Public Health Coalition exists to remove barriers facing people with disabilities related to health that led to poor outcomes.

It is important to have a clear understanding of the issues that a coalition will be addressing, beyond just a mission statement or purpose statement. Knowing this information can help with recruiting members and organizing the group's initial meeting. Some examples of potential issues that the coalition may address could include:

- Enhancing accessibility in medical facilities, clinics, and hospitals
- Improving healthcare access and affordability for people with disabilities
- Providing educational opportunities and training for health professionals

Each issue should be considered based on its impact on the community and the coalition's ability to address it and make progress.

What Resources Are Needed to Start the Coalition?

When starting a coalition, it is important to be aware of the resources that will be required. Initially, these resources may be simple and include a meeting space, access to technology such as email, social media, or phone to conduct outreach, a small amount of funding to cover snacks and materials for the first meeting, etc. Some of the essential things that will be needed when establishing a coalition include:

- Volunteers and staff with diverse skills to help in the coalition's work
- Funding to cover operational and activity-related expenses
- Physical resources such as a meeting space and office supplies
- Digital resources, including a website, social media presence, and email for outreach and communication

Securing these resources will require fundraising, obtaining grants, and partnerships with other organizations.

Identify and Engage Key Partners

Gathering suggestions and feedback from other organizations that will play a significant role in the coalition will be crucial. Identifying and engaging stakeholders interested in or affected by the coalition's goals will provide valuable insights during the development process. These stakeholders may include:

- People with disabilities from varied backgrounds

- Healthcare providers
- Policymakers
- Educational institutions
- Community leaders
- Other organizations concerned about the coalition's focused goals and issues
- Local government, such as the local public health department

Developing the coalition will require understanding the stakeholders' interests, potential contributions, limitations, and concerns.

The Importance of Diversity in Coalition Membership

Intentionally planning for and working to ensure diversity among coalition members will be crucial for inclusive and effective advocacy. A coalition should be representative of the community and those whose work it will impact. When thinking about a coalition focused on disability and health, C should work to include:

- Representation of a wide range of disabilities
- Membership from varied cultural, ethnic, and socioeconomic backgrounds
- Diverse professional expertise and experiences

Diversity is a crucial component of building a successful coalition. By prioritizing diversity, the group can benefit from several advantages.

Firstly, diversity brings different perspectives, experiences, and skills to the coalition. This can boost the group's creativity, innovation, and problem-solving abilities. Coalition members from diverse backgrounds can provide insights and solutions that may not be obvious to others. They can challenge assumptions and biases that may hinder the coalition's progress.

Secondly, diversity enhances the coalition's credibility, legitimacy, and influence, especially when the goal is related to social justice, equity, or inclusion. By representing a broad and diverse range of stakeholders, the coalition shows that its goals are essential for the broader community. Coalition members from diverse backgrounds may also have access and deep connections to different audiences and decision-makers. They can tailor their messages and strategies accordingly.

Lastly, diversity helps promote a culture of learning, respect, and collaboration within the coalition, strengthening the relationships and trust among the coalition members. By valuing and appreciating the diversity of members, the coalition can

create a positive and supportive environment where everyone feels welcome, heard, and empowered. Diverse coalition members can also learn from each other and share their knowledge, resources, and networks, [Creating and Maintaining Coalitions and Partnerships](#).

Identify Potential Coalition Members

The next step is to start finding people and organizations who may be interested in joining the coalition. Look for those who share the same goals as the coalition and have demonstrated a commitment to achieving them. This may include local advocacy groups, community leaders, and individuals who have been affected by the issues at hand. It's best to target organizations that work in a similar sector or provide related services. Their enthusiasm and interest will be valuable for sustained engagement and impact. Create a list of potential members with their contact information for recruitment and future communication. When identifying potential members, it's important to consider:

- Their alignment with the coalition's goals and values
- Their influence and network within the community
- Their resources and capabilities in contributing to the coalition
- Their commitment to long-term engagement and advocacy
- Their approach to and philosophy related to serving individuals who have disabilities

Identify the Core Team to Start the Coalition

Starting a new coalition can be a challenging task. To make the process easier and ensure long-term success, it's helpful to create a core team that will assist in managing the initial work. This team will also provide leadership support in the early days of the coalition, help further define the coalition's purpose and goals, and assist with recruitment. Additionally, having a diverse team with individuals and organizations possessing different skills and backgrounds, including leadership, advocacy, communication, and organizational strengths, will lend credibility to the coalition and make it a team effort.

When selecting the core team, various factors, such as the individual's or organization's experience, expertise, and availability, must be considered. By carefully selecting the core team members, the coalition can be guided in the right direction and easily achieve its goals. Potential core team members should have the following attributes.

- Leadership and decision-making abilities
- Expertise in advocacy, law, health care, public health or education
- Capacity for strategic planning and execution
- Commitment to the coalition's long-term success
- Share and/or support the independent living philosophy

It is best to form a core team after developing a draft of the coalition's purpose, goals, and issues to be addressed. Talk to interested individuals and organizations before publicizing the effort and announcing the first meeting. Then, bring them together for a casual conversation to discuss moving forward. During the initial meeting, review and discuss the reason for establishing the coalition, the draft mission and vision of the group, and how the coalition will begin to work toward addressing issues.

Chapter 4: Launching a New Coalition

Once the core team responsible for launching the new coalition has met and started planning, they will draft and refine the purpose statement and goals of the coalition and identify potential members. It's time to start thinking about the first meeting and moving forward. However, before sending out invitations and deciding on snacks, many other important things must be done to ensure a successful gathering. This chapter presents a step-by-step guide to bringing members of the new coalition together for the first time. It also offers tips and suggestions to help maintain momentum in the effort's early days.

Planning for the First Meeting

The first coalition meeting is crucial as it sets the tone for future success. To ensure a successful and welcoming start, several steps need to be taken. These include selecting a meeting location that is easily accessible, streamlining the registration process, providing options for remote access to the meeting, and other relevant considerations.

Identifying a Meeting Location

The first step in organizing a meeting is to choose an appropriate location. Consider a location that is easily accessible and convenient for the attendees. It should be spacious enough to accommodate the expected number of participants and have a welcoming atmosphere. It's best to choose a central location that provides ample parking facilities and is located on at least one public transportation route. This is particularly important as many people with disabilities rely on public transportation for travel.

When planning a meeting, it is vital to consider the room where it will be held. The meeting room must be spacious enough to accommodate tables and chairs, allow people to move around comfortably, and be fully accessible to individuals who use wheelchairs and other mobility devices. The room should also provide space for audiovisual equipment, a sign-in table, and a refreshment table. If necessary, do not hesitate to ask members of the core team or partner organizations to host the event in their meeting space. This is an excellent way to increase collaboration and support for the coalition.

Accessibility is crucial when forming a new coalition involving people with disabilities. It is essential to choose a meeting location that is fully accessible and meets the needs of attendees. This includes the following:

- An accessible path of travel exists from the nearest public transportation stop to the front door of the building
- Offer an ample number of accessible parking spaces, including spaces that can accommodate vehicles with wheelchair lifts
- An accessible path of travel from the parking area to the front door of the building
- Meeting space located on the first floor. If this is not possible, an elevator must be available
- Accessible restrooms
- Meeting room spacious enough to provide ample space for the movement of wheelchairs and other mobility devices

This list includes just some of the things to be considered when determining the location for coalition meetings. The [Accessible Meeting and Event Checklist](#) provided by Cornell University highlights several additional considerations related to accessibility. [Able South Carolina's Civic Engagement Guide also has helpful pointers.](#)

When deciding on a location for a meeting, it is important to consider the needs of people who are deaf or hard of hearing. It will be helpful to find a facility with a loop system, which can transmit audio signals directly to hearing aids or cochlear implants with a telecoil (also known as a 'T' switch). A loop system involves creating a wire that circles a room or area, called an induction loop. This makes participating in the meeting easier for people with hearing difficulties. The loop system takes a sound source, like a microphone used by a speaker, and transmits it as an electromagnetic field within the looped space. Hearing aids within this space can pick up this signal when set to the 'T' (telecoil) setting, providing the user with a clearer sound by reducing background noise. A professional must do the

installation of a loop system. Ideally, it would be done at the time of construction. However, they can be installed at any time. It is important to note that loop systems are different than FM systems. More will be said about addressing and supporting communication access in later paragraphs.

When determining the meeting location for a coalition launch, accessibility is a crucial factor to consider. If the host facility is different from the CIL's building, it is recommended that CIL staff visit the site to make certain it meets accessibility requirements. Being proactive will help ensure that everyone feels welcome and there are no surprises on the day of the meeting.

In addition, organizers need to decide whether they want to offer remote access to coalition meetings. Remote participation can be facilitated through platforms like Zoom, Teams, or other similar tools, providing access to individuals who cannot attend in person. However, it is essential to ensure that remote participation is well-integrated into the in-person component of the meeting and that remote participants can participate effectively. Using digital collaboration tools that work seamlessly can be helpful in this regard. Some examples include:

- Video conferencing with captioning and sign language support
- Support for multiple audio channels to offer other languages if possible
- Collaborative document editing and cloud storage
- Accessible websites and social media platforms for broader engagement

Promotion and Registration

Once the location, date, and time for a meeting have been determined, organizers should start reaching out to encourage people to register and attend. The method chosen for outreach will depend on what works best for the new coalition. Organizers may have a list of partners and or individuals they want to target for participation, or they may want to open participation to anyone in the community. Regardless of the approach, logistics and accessibility must be considered.

It is important to begin outreach and promotional efforts early, at least several weeks in advance. Organizers should decide whether to use a targeted method for inviting individuals to the first meeting or make it open to anyone who wishes to join. This decision will drive the outreach methods chosen.

Organizers must take steps to ensure that the outreach and promotional methods used to promote the coalition are accessible. Electronic materials such as fliers, emails, and social media posts can effectively reach people and organizations, but organizers must take basic steps to make their message accessible. For example,



Disability:IN offers tips for creating accessible social media content in their [Creating Accessible Social Media Content: GAAD Toolkit](#).

During the registration process, organizers can gather important information such as names, phone numbers, organization names, and job titles of registrants. The form should also ask individuals if they want to join an email list to get future updates about the coalition. This information will help organizers build a contact list of individuals and organizations who are interested in the work.

Finally, organizers must offer accommodations that will enable all attendees to fully participate. The registration process is the best way to provide attendees with an opportunity to indicate what accommodation they will need. Adding a section to the form that provides options or asks individuals to write in accommodation requests is ideal. If offering a list of options, the form should include:

- American Sign Language (ASL)
- Digital/electronic materials in accessible format
- Large print
- Braille
- Loop or FM system

It is commonly known that arranging some accommodations such as hiring a sign language interpreter or converting documents to accessible formats may take time. As such, it is recommended to include a statement on registration materials indicating the timeframe for requesting accommodation. For example, some accommodations may require three business days' notice in advance.

Organizers can make it easier to request accommodation by planning. They can save time by identifying organizations in the community that provide commonly requested accommodations such as sign language interpreting, document editing and conversion to accessible formats, and communication access real time communication, (CART) services, as well as establishing relationships with these vendors in advance.

If refreshments will be served, organizers should also ask registrants about any dietary needs. Accommodations for dietary needs could include dairy—or gluten-free, nut-free snacks, etc. Alternatively, organizers could avoid these dietary issues by providing foods that do not cause allergies.

Coalition organizers should continue their outreach and promotional efforts before the first meeting. They can reach out directly to selected organizations or conduct

a social media campaign to increase awareness of the first meeting, increase attendance, and raise the coalition's overall visibility. If using email, organizers should consider sending reminder emails with new or updated content on multiple occasions and making follow-up calls if conducting outreach via phone.

Strategies for a Successful First Meeting

Organizations can take several steps to ensure a successful first meeting. It is important to create an inclusive and welcoming environment. Consider identifying volunteers who can welcome attendees to the meeting as they enter the gathering. Others can support the check-in process and greet individuals in the meeting area. It is particularly important to connect with individuals who may not interact with others, so they feel welcome.

Organizers should encourage open and respectful communication during the meeting. This is a time to build relationships, get to know one another, and discover common interests. Encouraging open discussion and respectful dialogue is important for the coalition's initial meeting and its long-term success.

Organizers should facilitate networking opportunities among members. Allowing time for informal networking before and after the meeting while also including structured activities during the first meeting is vital. Consider structured activities that help individuals get to know one another. Small group activities among individuals at tables followed by report-outs to the larger group can be helpful. Focus on making these activities fun and helpful to the coalition's work. For example, giving each group questions that help them envision and discuss what accessible health programs and services might look like and how they will impact people with disabilities.

Setting the Agenda

It is important that organizers give careful thought to the agenda and structure of the first meeting. Plan the agenda so that the meeting is interactive, focused, timely, and engaging. Consider allocating time for discussions, Q&A sessions, and small breakout groups if the meeting is large.

At the beginning of the first meeting, coalition leaders should make opening remarks to welcome everyone. After that, attendees should have a chance to introduce themselves, their organizations, and their interest in the coalition. This can be done with all attendees participating, but if the meeting is large, it may work better to have attendees make their introduction with others from the same organization together.

Overview

Organizers of a coalition should prepare a presentation that highlights the mission and vision of the coalition. They should also discuss the coalition's objectives and key focus areas, as well as provide an overview of the coalition's structure, leadership plan, and member roles. It's important to emphasize that all members have a voice in shaping the coalition's operations and the roles of its members. Be prepared to discuss how the leadership will be held accountable, the plans for clear and frequent communication, and how members will be given opportunities to voice their concerns.

Review and Discussion of Disability and Challenges with Health Services

The presentation will highlight health-related issues, statistics, and barriers that impact disabled individuals. The main focus of this presentation is to establish the need for the coalition and outline some of the challenges it will be working to address. There will be an opportunity for open discussion, where attendees can share their experiences and observations. This discussion will help create buy-in and mutual trust among the attendees.

The Future of the Coalition

During the coalition meeting, members will discuss both goals and objectives. They will also outline key advocacy areas and strategies for collaboration between member organizations.

Discuss and gather feedback from attendees about logistical issues such as how often meetings will take place, length of meetings, and location. Additionally, talk about establishing communication channels (e.g., email, social media, newsletters). Finally, identify and share information for the individual(s) who will serve as the point of contact for current and future coalition members.

Open Forum

This should be a more informal time for members to ask questions, raise issues, suggest agenda items for future meetings, and provide other input.

Final Remarks

Provide a summary of key points and outline the next steps. Additionally, remind attendees of the date, time, and location of the next meeting and express gratitude for their presence.

Choosing the Right Facilitator

An effective facilitator plays a crucial role in meetings. To ensure that the meeting is productive and within the scheduled time frame, the facilitator should clearly state the purpose of the coalition and oversee all the coalition's business. They should also welcome feedback from other members, respond to challenging questions, and maintain a neutral and guiding presence throughout the meeting. The facilitator should ensure that everyone has equal opportunities to speak and keep discussions on track. They should be prepared to mediate any conflicts and refocus the group on the coalition's goals.

Chapter 5: Ensuring the Long-Term Success of a Coalition

Introduction

Starting a coalition requires a considerable amount of effort and cooperation. The first step is to identify core partners who can help with logistics and planning, followed by holding the initial meeting. However, this is just the beginning of creating and maintaining a successful coalition. It is essential to invest time and effort to ensure its long-term viability and success. The final chapter of this guide provides proven ideas and suggestions that can help coalitions maintain momentum and continue to achieve positive outcomes in the community.

Governance and Leadership Structure

When establishing the governance structure of a coalition, it is essential to consider various approaches, their advantages, and drawbacks. Governance refers to the decision-making processes adopted by the coalition, including who is responsible for decision-making, who provides input, and how decisions are made. This could involve both formal and informal methods.

A formal governance structure typically involves clearly defined roles, responsibilities, and decision-making processes. The coalition may have designated officers or other leadership positions, such as chair, president, vice-chair, secretary, etc. These individuals may be elected by members or appointed through other means. This approach ensures accountability, clarifies tasks, and monitors progress on goals and initiatives. However, it can also lead to bureaucracy and rigidity, reducing flexibility and creativity within the coalition. If not handled correctly, it may also limit input from members, causing frustration and discouragement.



An informal governance structure allows for a more flexible environment where roles and responsibilities can develop naturally based on members' expertise and commitment. This encourages ownership, empowerment, and creativity, leading to greater motivation and innovation. However, without clear guidelines and structure, there may be uncertainty, inconsistency, and conflicts arising from confusing decision-making processes.

One leadership approach is to have elected positions. This allows members to democratically choose individuals to represent and guide the coalition. This approach increases accountability, as leaders are responsible for delivering mandates from coalition members. However, transparency and accountability are essential to prevent a few organizations from taking power and ensure the representation of diverse voices on the leadership team.

Another option is to have rotating leadership roles, where different members assume leadership responsibilities over set periods of time. This promotes inclusivity, diversity, and skill development within the coalition, as members can contribute their expertise and perspectives in leadership roles. However, careful coordination and planning are required to ensure smooth transitions and continuity in decision-making.

Finally, a shared leadership model is another approach where responsibilities are shared among multiple individuals or teams. This approach promotes collaboration, collective decision-making, and shared expertise, using the strengths and talents of various members. Effective coordination and communication are crucial to prevent conflicts or inconsistencies in leadership.

Ultimately, the choice between formal or informal governance structures should align with the coalition's goals, size, and culture. Engaging members in discussions to understand their preferences and concerns is essential to ensure that the chosen approach effectively supports the coalition's work while addressing any potential challenges.

Determining Communication Channels

Effective communication is vital for the success of any coalition. It helps members stay informed, engaged, and connected. To support collaboration and maximize the impact of the coalition's efforts, clear and reliable communication channels must be established. Organizers can choose from a wide range of communication methods such as email, newsletters, social media posts, virtual meetings, telephone, and online collaboration tools. It is essential to choose the methods

that work best for coalition members, taking into consideration factors like the speed and effectiveness of communication, ease of conveying information, the skill of the individuals involved in creating and distributing messages, and the preferences of members.

It is important to carefully consider the information that is shared through these communication channels. General information about the coalition, upcoming meetings, updates on achievements, victories, and challenges, and information on how people can get involved in supporting the coalition's work are all valuable information to share. Be sure to use plain language that all readers can understand. Finally, consider how the coalition can share information in other languages spoken in the community.

Transparency is an important aspect of communication. Sharing relevant information, decisions, and progress updates with all members builds trust and accountability. This empowers members to contribute meaningfully and feel invested in the coalition's mission and achievements.

Regular communication is crucial to maintaining momentum and cohesion within the coalition. The information to be communicated should be concise, clear, and focused to ensure that all members are kept up to date between scheduled meetings.

Strategies for Resource Development

In the initial stages of forming a coalition, the main focus is often on selecting a meeting place and attracting members. However, it is important to consider that additional resources will be necessary to maintain the momentum and ensure growth in the future. These resources might include financial support, strategic partnerships, and other related needs. Therefore, it is crucial for the coalition leaders to plan and think ahead of what resources they will require to ensure long-term success.

Building Partnerships

Resource development requires strategic partnerships with organizations and coalitions. By collaborating with groups that share similar goals or have complementary missions, a coalition can amplify its message and leverage collective strength. These partners may also become allies and supporters who actively participate in the work. To identify potential partners, look for organizations with influence, expertise, and resources that align with the coalition's purpose. Collaborating with these organizations can enhance



credibility and effectiveness, as well as increase reach. To sustain long-term partnerships, establish clear communication channels and mutually beneficial relationships.

Fund Development

Fund development is a crucial tool for many coalitions. It involves raising funds to cover various expenses such as technology for virtual meetings, equipment rental, facilitator payments, office space rent, staffing, and other costs. As the coalition grows and expands, the need for fund development may increase. To raise essential financial support, the coalition can organize fundraising events, campaigns, and appeals to individual donors who are invested in the work of the coalition. However, if a CIL is leading the coalition, it is essential for the organization to consider how these activities might impact broader efforts related to fund development for other initiatives.

To provide greater financial stability, it is important to diversify fund development strategies that appeal to different donors. Combining fund development efforts with grant writing can be an effective way to achieve this.

To maximize success, fund development activities should leverage various platforms and techniques such as crowdfunding platforms, charity events, online donation drives, and direct mail campaigns. These can be very effective when combined with more traditional tools such as email, print media, and direct outreach.

Grant Writing

Grant writing is a crucial strategy for resource development. It involves identifying and applying for grants from government entities, foundations, and corporations, which can provide much-needed funding for coalition initiatives. However, it is important to be strategic and intentional when applying for grant funding.

First and foremost, it is important to ensure that the grant opportunities align with the mission and purpose of the coalition. When reviewing opportunities, consider if the grant fits with the current work of the coalition and future goals, instead of trying to change the coalition's mission to fit the purposes of the grant. This is critical and will help the coalition stay true to its mission.

To develop successful grant proposals, it is important to clearly articulate the coalition's mission, goals, and impact. Each application should be tailored to the



specific requirements of the granting organization and highlight how the coalition addresses pressing needs or challenges in the community. A compelling proposal can greatly increase the chances of receiving the grant. Consult the [Organizational Capacity Building Guide](#) for more information and guidance on submitting successful grant proposals.

To achieve success in resource development, a strategic approach that involves establishing partnerships, fund development, grant writing, and leveraging community assets is important. By implementing these strategies effectively, a coalition can secure the necessary resources to sustain its efforts and make a meaningful impact.

Scheduling and Planning for Coalition Meetings

As a reminder, communication and updates are important, but they cannot replace regular coalition meetings. These meetings are the foundation of a successful coalition. Bringing like-minded people together to discuss and plan action steps towards addressing barriers and community issues is one of the main reasons for creating a coalition.

Organizers should recognize the value of coalition meetings and plan them effectively. A well-structured meeting can ensure that members feel their time is well spent. It is important to develop a well-planned agenda, assign specific portions of the discussion to particular members, allocate time to each item, and consider how to gather input and concerns from members. Leave time for informal conversation, networking, and members to raise issues before the group. Distribute the meeting agenda ahead of time and include notes from previous meetings. Make materials available in accessible formats and allow individuals to request accommodations in the meeting announcement.

When deciding how often and in what format to hold future meetings, consider factors such as members' availability and the need for regular updates. Decide whether arrangements will be in person, online, or through a hybrid model to accommodate schedules and preferences. Check-in with members periodically to ensure that the frequency and structure of meetings work for them. Ask for input and ideas for future meetings. Consider establishing a fixed meeting schedule, such as the first Wednesday of every month at one o'clock. Survey members to find a time and day that works for the majority.

Setting key milestones and timelines is crucial for tracking progress and maintaining momentum. Establish clear and specific goals and objectives for the



coalition's activities and realistic deadlines for achieving them. Communicate these timelines effectively to all members to ensure accountability and alignment toward common goals. Regularly review progress against established milestones and adjust timelines to adapt to changing circumstances or priorities.

For instance, a coalition focusing on disability and health services may aim to improve the accessibility of medical facilities in their community. A goal could be that coalition members will conduct outreach to 50 providers in a calendar year, aiming to train 25 of them on accessibility guidelines and requirements, and that 15 facilities become accessible to persons with disabilities. These are apparent goals and objectives that provide a framework that is easy to track and report to the coalition as progress is made.

Supporting Coalition Members

One effective way to maintain member engagement and participation in a coalition is to ensure tasks and responsibilities are distributed fairly among members. When assigning tasks and coalition roles, consider the interests, skills, comfort level, and availability of each member. Encourage members to take ownership of their responsibilities by aligning tasks with their expertise and passion for the work, if possible. Offer resources and support to help members fulfill their commitments and overcome any challenges they may encounter, such as one-on-one support or training.

To strengthen the coalition and individual members, it is important to identify areas where growth is needed and arrange for training. Conduct surveys to identify areas where members may benefit from additional support or learning opportunities. Some members may have a passion for the work but may lack the knowledge or information needed to be effective advocates. Consider organizing training sessions, workshops, or skill-building activities to enhance members' capacity and effectiveness in fulfilling their roles within the coalition. Ongoing professional development is also crucial to strengthen the skills and abilities of the coalition, and it may be helpful to invite local experts or leaders from nonprofits or businesses working in this field to offer presentations covering topics identified as areas of need.

Sustaining a Coalition through Effective Succession Planning

Coalitions are a powerful tool for driving change and bringing together diverse stakeholders with a common cause. However, to ensure long-term sustainability and impact, enthusiasm and momentum alone are not enough. It is imperative to

plan and anticipate future needs. One critical aspect of this is succession planning, which involves identifying and preparing individuals to take on key roles within the coalition.

Identifying and Cultivating Potential Leaders

Succession planning is a crucial step for any coalition to ensure that they have capable leaders to take over when current leaders step down. Identifying individuals who display the necessary skills and qualities to become future leaders is the starting point for this process. The potential leaders may exhibit leadership qualities through effective communication, strategic thinking, volunteering, and stepping up to lead activities or initiatives, and leading in collaboration and consensus building.

Once a potential leader has been identified, it is important to invest in their development through training and mentoring. Providing opportunities for them to enhance their leadership skills through workshops, seminars, and hands-on learning experiences can empower them to take on these roles with confidence in the future. Mentoring is another effective way to identify and develop leaders since it allows potential leaders to work alongside and receive guidance from experienced leaders.

It cannot be stressed enough how vital it is to focus on succession planning. Coalition leadership will change over time due to various reasons, such as changes in personal or professional lives, new priorities, and competition with other priorities. These changes can create difficulties for coalitions if they are not prepared and actively working to develop new leaders.

Risks and Challenges

Succession planning is crucial for the long-term sustainability of coalitions. However, it too comes with its own challenges. These challenges include resistance to change, maintaining unity and momentum, and more. These challenges can be overcome by adopting a proactive and inclusive approach. It will help reduce the risks of succession planning and prepare for smooth leadership transitions in the future.

One of the most common challenges in succession planning is the reluctance of coalition founders and current leaders to delegate authority to others. To prevent this from happening, coalitions should foster a culture of shared leadership and collaboration from the very beginning. This can be accomplished by emphasizing the importance of collective ownership and accountability within the coalition. By

empowering leaders at all levels and promoting a culture of trust and transparency, coalitions can overcome resistance to change and facilitate smoother transitions.

Ensuring Financial Sustainability

Financial sustainability is a crucial factor in ensuring that coalitions can continue for a long time. Even the most well-developed coalitions may find it difficult to maintain momentum and achieve their objectives without adequate funding. Therefore, effective succession planning should also include plans for ensuring sound financial practices and diversifying funding sources. For solutions and ideas, please refer to the previous section in this guide, which focuses on fund development and grant writing.

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- Guide to Assisting CILs to Increase Organizational Capacity to Better Prepare for Resource Development and Federal Funding Opportunities. Disability and Vaccine Access and Opportunities Center. <https://dvaio.able-sc.org/>



Coalition Building Resource Guide

Additional Resources

1. Coalition building
 - a. [NY Association on Independent Living Coalition Building & Community Organizing Strategies](#)
 - b. [University of Kansas Starting a Coalition](#)
2. How to build a coalition
 - a. [Prevention Institute Developing Effective Coalitions: An Eight Step Guide](#)
 - b. [The Campaign Workshop Coalition Building](#)
3. Disability advocacy coalitions
 - a. [College Student Educators Coalition for Disability](#)
 - b. [HCBS Advocacy Coalition](#)
 - c. [Able SC's Civic Engagement Guide](#)
4. Coalition building strategies
 - a. [University of Kansas Maintaining a Coalition](#)
 - b. [Immunization Coalitions Coalition Building Toolkit](#)
5. Successful coalition building case studies
 - a. [Harvard Business Review Creating High-Impact Coalitions](#)
 - b. [American Journal of Preventative Medicine Case Studies from Community Coalitions](#)
6. Coalition building in non-profit organizations
 - a. [Center for Nonprofit Excellence Action to Impact](#)
 - b. [The Urban Institute Nonprofit Coalition Building](#)
7. Community coalition building techniques
 - a. [Prevention Institute Eight Steps to Effective Coalition Building](#)
 - b. [Home Usability Tips to Building and Sustaining Successful Coalitions](#)
8. Inter-organizational coalitions
 - a. [Association for Neighborhood and Housing Development How to build coalitions that people don't hate](#)
 - b. [National Institute of Health Built to Collaborate](#)
9. Best practices in coalition development
 - a. [Common Social Change Library Five Principles for Building Powerful Coalitions](#)
 - b. [Harvard TH Chan School of Public Health Helpful tips to keep in mind when building and managing a coalition](#)
10. Building effective coalitions in advocacy
 - a. [LinkedIn Secret to Building Strong Coalition Advocacy](#)
 - b. [US Dept. of Justice Considerations for Building Effective Coalitions](#)
11. Coalition building tools and resources
 - a. [Resource Sharing Project Creating relationships to engage and learn](#)
 - b. [Medium The Benefits of Nonprofit Coalition Building](#)
12. Collaborative partnerships and coalitions
 - a. [CDC. Developing Partnerships and Coalitions to Advance Health Equity](#)
 - b. [Rural Health Information Hub Partnerships and Coalitions](#)

13. Leadership in coalition building
 - a. [Coalition Building: Start Here - The Commons \(commonslibrary.org\)](https://commonslibrary.org)
14. Coalition building workshops and training
 - a. [8 Steps to Building and Sustaining Effective Coalitions - CDC TRAIN - an affiliate of the TRAIN Learning Network powered by the Public Health Foundation](#)
 - b. [\(L026\) Coalition Building Concepts | NDPHTN - CDC TRAIN - an affiliate of the TRAIN Learning Network powered by the Public Health Foundation](#)
15. Challenges in coalition building
 - a. [RS00002733.pdf \(fvtc.edu\)](#)
 - b. [Common Difficulties Faced by Coalitions | Ohioline \(osu.edu\)](#)
16. Coalition building for social change
 - a. [Social movement coalitions: Formation, longevity, and success \(ucmerced.edu\)](#)
17. Evaluating coalition effectiveness
 - a. [Evaluating Coalition Progress and Impacts | Ohioline \(osu.edu\)](#)