



# A Guide for Sibling Chapters





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## Background

The purpose of this guidebook is to help nurture and grow sibling chapters throughout the United States. The Sibling Leadership Network (SLN) has helped foster sibling chapters with the vision that every state will have a chapter to connect siblings of people with disabilities. Chapters are the grassroots of the SLN and provide the more personal contacts, connections, and information relevant to specific state and local areas.

This guidebook will provide some basic and general overview to help start and strengthen sibling chapters. Groups may be at different points in the process and certain sections may be more relevant than others. There is also not one right way to develop a sibling chapter, so pull the information that makes sense for your group. This is meant to help your group think about various areas and provide some guidance in the journey.

## Acknowledgments

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## **History of the Sibling Leadership Network**

The founders of the Sibling Leadership Network (SLN) realized that there was a need to communicate the sibling perspective and get the sibling voice to the policy table. When siblings did connect with each other and experience peer support, they saw the need to ensure that siblings across the country had these opportunities. The SLN was created to connect the work happening across the country and provide a stronger collective voice to build awareness of the sibling experience and perspective.

The SLN was founded in 2007 after seeing a need for more of a focus on siblings of people with disabilities. Here are some highlights from over the years:

- 2007: SLN was founded and held its first national conference in Washington, DC in November in conjunction with the Association of University Centers on Disability (AUCD) conference.
- 2008: SLN held its second national conference in October in Columbus, OH which culminated in the creation of a policy Whitepaper published with recommendations for research, advocacy and supports related to siblings.
- 2009: A leadership meeting was held in Washington, DC in November and the first official Board of Directors was created for the SLN.
- 2010: SLN incorporated as a nonprofit organization and also held an International Sibling Conference in Greenwich, CT.
- 2011: A leadership meeting of the SLN Board was held in Nashville, TN where a strategic plan was developed for the future of the organization.
- 2012: The SLN hired the first part-time Executive Director to grow the organization and a virtual leadership meeting of the Board was held in January.
- 2013: The fourth National SLN Conference was held in Pittsburgh, PA in conjunction with the American Association on Intellectual and Developmental Disabilities (AAIDD).
- 2013: Executive Board of SLN met in Chicago to identify emphasis for the next year including Chapter Development and building internal structure of SLN
- 2014: SLN focuses on chapter development, building partnerships, committee work, organizational development, and planning the 2015 Conference
- 2015: The fifth National SLN Conference is held in Louisville, KY in conjunction with the American Association on Intellectual and Developmental Disabilities (AAIDD)

In creating the SLN, the founders learned from other organizations to create policies and structures. SLN looked to Self Advocates Becoming Empowered (SABE), the national organization for people with developmental disabilities, as a model. Like SABE, the SLN created a national board of directors comprised of volunteers from across the country. We also have sibling chapters, like self-advocacy chapters. Self-advocates were, and are, an important part of the leadership of the SLN to ensure that as the SLN grows and develops in a collaborative way with our brothers and sisters with disabilities. The SLN has partnered with self-advocates to ensure we are truly advocating WITH people with disabilities since they are the true experts. This approach models how siblings can learn from each other and work together to improve the system for their entire family.

### **Siblings: What is the SLN definition?**

The term **sibling** refers to the people who have a close sibling or sibling-like relationship with a person with any type of disability (including a physical, intellectual, developmental, cognitive, psychological, learning or other disability). Throughout this guidebook we will just use the term “sibling” instead of writing out the full “sibling of people with disabilities” each time.

A **sibling supporter** is anyone who is supportive of the importance of the sibling experience and is important to the Network. Sibling supporters can include people with disabilities other family members, friends, professionals, and anyone who believes in the mission of the SLN.

“**Sib-in-laws**” are important supporters for our sibling networks. Sib-in-laws are the people who choose to date, partner with and/or marry someone who has a sibling with a disability. Siblings know that sib-in-laws are very important in our lives and often provide support to us individually as well as sometimes to our brothers and sisters with disabilities and our whole families.

***Once a sibling, always a sibling.*** Therefore, we warmly welcome siblings whose brother or sister with a disability has passed away. We have many members who have joined the SLN long after their brother or sister with disabilities died. They retain their sibling perspective and are valuable to our groups.

SLN leaders have had deep discussion about our mission and values. We debated about whether to focus only on siblings of people with developmental disabilities but decided to include siblings of people with any disability. We welcome those that are drawn to our mission and values. We rely on people from across the country that share their time and talents to make the organization what it is today.

The sibling movement is strong and building momentum. The SLN has been a vehicle to bring together the movement and support agents of change. The future of the SLN and the sibling movement is in all of our hands.

*The **mission** of the SLN is to provide siblings of individuals with disabilities the information, support, and tools to advocate with their brothers and sisters and to promote the issues important to them and their entire families.*

## **Core Values of the SLN**

*We believe:*

- Individuals with disabilities have the same rights as all members of society to dignity, respect and the opportunity to grow and to be productive members of their communities.
- Siblings of individuals with disabilities can have a powerful, positive impact on their siblings' experiences, and are uniquely positioned to help ensure their present and future care in partnership with service organizations and government.
- In promoting the rights of our brothers and sisters, and of all individuals with disabilities, we are committed to advocating for policies and services that meet their needs.
- Siblings can be of great support to one another to enhance both our lives and the lives of our siblings.

## Join the SLN: Who are the SLN members?

First, you should join the SLN as an individual so you get information about the activities of the organization. The SLN is dedicated to advancing causes important to the millions of siblings of people who have disabilities, such as future planning, employment, housing, accessibility, and others. The more members we have, the greater impact we will have. By joining, you will receive information and updates about the activities of the SLN including events, conferences, social gatherings, policy and advocacy efforts, and research related to siblings and our families. Also, encourage other people you know that may benefit from the SLN to join as well! The SLN is for siblings of individuals with disabilities as well as sibling supporters.

### Who should join the SLN?

- ***Siblings of people with disabilities.*** By uniting, we can support each other and be stronger together.
- ***People with disabilities.*** The self-advocacy movement serves as a model for us to learn how we can get involved in advocacy with our brothers and sisters.
- ***Parents and family members.*** Connections through the SLN can provide a unique perspective for families.
- ***Professionals.*** Many professionals can provide important support to siblings and partner with them throughout their lives.
- ***Sibling supporters.*** Anyone who is a friend or colleague to siblings and their families is welcome.



### Why should you join the SLN?

- ***Stronger together***—become connected to siblings and sibling supporters nationwide. The SLN is dedicated to advancing causes important to the millions of siblings of people who have disabilities. The more members we have, the greater impact we will have.
- ***Information is power***—all members receive information and updates about our activities as well as initiatives, policy decisions and sibling related events that are important to brothers and sisters. Keep up to date on conferences and events, initiatives, policy decisions, and more.
- ***Chapter connections***—get information about how to connect with or create a state or local sibling chapter of the SLN.
- ***Siblings matter***—as our membership increases, so does SLN’s impact. The more members we have, the stronger our voice in promoting support for people with disabilities and their families.

**It is free and easy to join, just sign up at [siblingleadership.org/get-involved/join-sln/](https://siblingleadership.org/get-involved/join-sln/)**

### Join SibNet too!

If you are a sibling of an individual with a disability, please also join SibNet.

**SibNet** is the first and largest online community for adult brothers and sisters from around the world. SibNet is co-sponsored by the Sibling Support Project and the SLN. This online network of adult siblings provides a space for sibs to connect and share information with each other from their perspective.

Join SibNet at [https://www.siblingsupport.org/connect-with-others-sibs/meeting\\_other\\_sibs\\_online/sibnet](https://www.siblingsupport.org/connect-with-others-sibs/meeting_other_sibs_online/sibnet).

## **How do I Start a Sibling Chapter of the SLN?**

The main purposes of sibling chapters are peer support and the information sharing. This section provides some areas to think through when starting a sibling chapter.

If you are thinking of creating a chapter of the SLN please reach out to the SLN and let us know what you are doing and how we can help! Email [info@siblingleadership.org](mailto:info@siblingleadership.org)

### **Process for becoming a chapter of the SLN**

There are certain steps to starting a chapter that have been identified by the national SLN. See the handout “How to Start an Affiliate Chapter” for more details on these steps. Once you are ready to submit information to the SLN in order to become an official chapter, you will also be required to complete an SLN Affiliate Chapter Applications/Agreement. Please contact [info@siblingleadership.org](mailto:info@siblingleadership.org) to obtain these documents.

### **New Sibling Chapters**

Sibling chapters are the grassroots of the national SLN. They provide the state and local connections for siblings to get peer support and information. Each chapter has its own feel and flavor. One main purpose of sibling chapters is to provide a judgment free atmosphere for siblings to meet each other and share their sibling experiences. A judgment free zone allows siblings to share stories that they may not be able to share with other groups. This can include feelings of anger or jealousy about their sibling with a disability, or frustrations with their families or providers. Sibling chapters provide a space where others will listen to the concerns of each members without judging their thoughts and feelings.

### **Where are the other siblings? How do I find them?**

Finding siblings can be the most difficult part of starting a chapter. Though there are established networks of people with disabilities and families who receive services, information does not always reach siblings. Many chapters have to do initial work to create a network of siblings of people with disabilities. You can learn from existing chapters and reach out to organizations in your area, such as agencies that serve people with disabilities, to ask them if there are siblings that are part of their networks. Start close to home. Are your parents involved with any groups that bring together families? Where does your brother or sister with disabilities get support or services?

### **Gather Information**

Gathering information is important to help you learn about siblings’ needs and to see what other resources may exist for siblings.

### **Understand the Needs and Perspectives of Siblings**

As you start developing a chapter, it’s important to understand the diverse needs and perspectives of siblings. These needs can be as diverse as the people in your community.

### ***What do YOU need?***

As a sibling, it can be difficult to think about your own needs but this is a great time to reflect. Ask yourself before asking others and think of a few things that you, as a sibling, want or need. Identifying your own needs and sharing them with other siblings may also help them to articulate what supports they need or desire.

***What are the needs of siblings within your local and state area?*** Every state and local area may have different needs. For instance, one state may have more funding than another making advocacy efforts look different. One state may need to advocate for more funding in general while another state may advocate for specific programs.

### **What are some ways you could gather information to get a better sense of siblings' needs so you can focus the purpose of your sibling chapter?**

- Look at the information and resources for siblings on the SLN website
- Review some of the research about siblings of people with disabilities (see the research section of the SLN website)
- Meet with a group of siblings in your area (either in person or on the phone) and ask people to share what they perceive as their needs. They are bound to be different depending on the person's stage in life, family experience, and more.
- Survey siblings in your state or area to find out about or access their needs.
- Join SibNet and read through what siblings have on their mind.
- Meet with organizations or providers who serve people with disabilities and their families. They may know siblings or have an understanding of the community needs.

### **Are there other similar organizations serving siblings?**

Thankfully, nearly every community has at least one organization that provides services to people with disabilities and their families. However, there are no agencies that view siblings of those with disabilities as their main clientele. Disability organizations can provide a starting point for building a chapter by building upon current services and approaches. By reaching out to these organizations, you are doing that work. This is what makes the SLN, and your new chapter, so important to siblings. No one needs to reinvent the wheel.

**Do any organizations in your community or region provide services and supports to siblings of those with disabilities?** If there are, that's great! This will help give you a lay of the land. This information will be useful as you develop your chapter to get a sense of some potential organizations to work with as you build and grow the chapter. If you are unsure about what is already in place for siblings search the internet and make contact with possible supportive agencies. Examples of organizations that may be doing work with siblings include:

- The Arc
- UCEDDs (University Center for Excellence in Developmental Disabilities)
- Developmental Disabilities Councils
- Respite Groups
- NAMI (National Association of Mental Illness)
- Places that host Sibshops
- Partners in Policy Making
- Direct Service Providers
- Centers for Independent Living
- National Alliance for Caregivers

## Strategies for Reaching Siblings

### **Connect with other SLN state chapters**

When starting anything new, connecting with someone who has already been through the process can be very useful. Thankfully, SLN already has chapters that have been through the process you are going through. To get in touch with any of the SLN chapters contact: [info@siblingleadership.org](mailto:info@siblingleadership.org) or visit <http://siblingleadership.org/about/sibling-leadership-network-state-chapters/> for SLN chapter locations and information

**Use social media** to find other siblings. SibNet on Facebook is a great place to start with a post looking for siblings in your state. Make use of Twitter and the use of Hashtags to distinguish tweets related to siblings by using common tags such as #siblings, #sib, #sibleadership. Meetup has been successfully used to connect with other siblings, though be aware this is not a free service.

**Attending local conferences** and Sibshop trainings are two great ways to find other siblings. You can find Sibshop trainings listed on the Sibling Support Project's website at [www.siblingsupport.org](http://www.siblingsupport.org). If you can't find a training in your state look for the closest one to you, some siblings may be willing to travel to attend and meet other siblings.

**Connect with professionals** to spread the word about the SLN and your chapter. Some examples are: advocacy or provider organizations for people with disabilities, health care professionals, school professionals, special needs lawyers and financial planners, and similar professionals. These professionals can share information about your chapter with their clients and offer your chapter as a support resource.

**Additional Resources:** For how to effectively use Hashtags:  
[www.business2community.com/social-media/effectively-use-hashtags-maximum-engagement-0960602](http://www.business2community.com/social-media/effectively-use-hashtags-maximum-engagement-0960602)



## **Benefits of Becoming a Chapter**

### **Benefits**

There are a number of benefits to becoming a chapter of the SLN. The benefits include the following:

- Siblings matter – SLN’s impact gets larger with every new chapter and member. The more chapters and members we have, the stronger our voice is when promoting support for people with disabilities.
- Become part of a larger national sibling movement – the SLN is leading the national movement. There is power in numbers: the more connection and coordination at the state and national level, the better support can be provided to siblings throughout the lifespan.
- Receive financial support when possible – the SLN will try to provide funding to our chapters. For example, with the first grant SLN received through Autism NOW, funds were designated for chapters to receive if they led a webinar related to siblings.
- Provide a voice to the national direction of the Sibling Leadership Network – the perspective and voice of the chapter representatives helps inform the direction of the national SLN. Chapter representatives are elected from the Chapter Committee to serve on the national Board and ensure the chapters’ needs are understood and addressed. In this way, chapters are helping to set the strategic direction of the national organization.
- Connect to other chapters – learn from each other, share information and materials. The SLN facilitates connections with chapters by hosting conference calls for our chapters to discuss ways they have gotten started, ideas to reach out to siblings and sibling supporters, places they have found support and funding, successes and challenges they have had. Materials are shared through our SLN Google apps site that can be used as examples and templates so other groups don’t have to start from scratch. For example, materials include chapter brochures, membership forms, state sibling conference materials, organizational structures and bylaws, outreach materials, etc.

## **Naming Your Group**

Naming your chapter is important to help brand your group as an official entity. Think about what type of name makes sense so the public can easily understand the work you are doing as a chapter. Take a look at the variety of names of other SLN chapters. Discuss it as a group and identify a name that fits.

## What to do at the first meeting?

Decide where to hold your first meeting. Sibling chapter meetings have been held in homes, restaurants, library community rooms, churches and coffee shops. If you choose a public spot make sure it is conversation friendly, has ample parking or public transportation available, and is physically accessible.

Invite all the siblings you have found from your search. Use emails, social media and announcements from supportive agencies to advertise your meeting. Occasionally other family members are interested in joining a sibling group but sibling chapter meetings should promote the sibling perspective and to allow siblings to feel comfortable in sharing their own experience. It can be very helpful to have a sibling from an already existing chapter attend, if at all possible. If you can't find a sibling from an existing chapter to attend in person, try to find someone who can call or Skype in to your meeting.

The first meeting is often an informal meet and greet session. It is helpful to agree that what is talked about at the meeting stays at the meeting. A good icebreaker is to simply go around the room and have siblings introduce themselves and say something about their sibling experience. It is useful to have a short agenda and a time limit for introductions to keep the meeting on track.

Allow time to discuss when and where the next meeting will take place. Identify who may be willing to help with the next steps. Be sure to gather the contact information from all those attending and encourage them to promote the next meeting. Something as informal as a sign up sheet could help capture the contact information such as names, email addresses, and phone numbers. It can be helpful to have someone take notes at the meeting to keep track of what happened. At the next meeting, you may want to create a more formal agenda to keep the meeting focused. After the meeting, send out a summary of what was covered at the meeting and include reminders to individuals who volunteered for any tasks.

*“Set a consistent conference call day and time, this makes scheduling month-to-month a breeze. Not everyone can attend each month, but they will all know it’s happening.”*

*-Jacqueline, California Sibling Leadership Network member*

## **Building on the First Meeting**

### **Communications**

To build on your first meeting you need to develop a good communications system. Figuring out a process to capture who is a part of your group, as well as communicating to the group, is a key part of building the chapter. It is important to create an **internal contact list**. Collect names, phone numbers, and email addresses to develop your list. Closed Facebook pages, Meetups and a listserv can also be used for internal communications. A free **email listserv** can be set up through popular Internet providers like Gmail and Yahoo.

External communications help get the word out about your chapter and can also help you grow the chapter. A good place to start is creating your website (see more details later). Social media is a very important way to promote your chapter. Facebook, Twitter, LinkedIn and Google+ currently have the most users and have been called the social media big four. It is helpful to have one or two people in charge of your website and social media. Additionally newsletters and blogs can help create awareness and grow your group. Often other related organizations are willing to share links to your information with their networks.

*“Ask outside, objective, third-party peers for feedback on websites, social media pages and posts, as if they were members of the general public and rating the ease of use and navigation of your various outlets.”*

-Julie, California Sibling Leadership Network member

As your chapter grows and you begin to get more members, it can be helpful to create a logo, website, and other things that will help build your group. The idea of making these may seem overwhelming, but do not worry. Other chapters have created these, often for little to no cost.

### **Get a Conference Call phone line**

In order to hold meetings by phone, your chapter may need a conference call line. There are free services such as freeconferencecall.com that can give your group a phone number to use. Note that each person that calls the number pays for individual phone charges.

### **Create a logo**

A logo is a way to brand, promote and professionalize your chapter. The logo can be used on your business cards, letterhead, and materials distributed by the SLN and your chapter. Below is more information on how to create a logo. Also, check out the SLN website to see examples of other chapter logos.

### **Create a social media presence:**

Create a Facebook group or page for your organization, get a Twitter, LinkedIn and Google+ account. These are the big four. Also, you may want to get an Instagram or other accounts to help spread the word about your chapter.

### **Create a website**

You also may want to create social media pages for your chapter. Please see the communications section for more information on this. At first, a personal website for your chapter may not be necessary but as your chapter grows, a website is a great tool for your chapter to get out information to current and prospective members. There are resources out there to create a website for little or no cost. For example, Weebly and WordPress.

### **Using document sharing tools**

Another great tool for your chapter is a document sharing program such as Google drive or Dropbox. These allow members within your group to share and edit documents without having to email copies back and forth. You can also use the cloud to store and share documents as long as all of your members (or the ones that need access) are able to access these tools via the Internet.

### **Adopt the SLN Values**

Every chapter has core elements while also having a unique feel and flavor. All chapters agree to uphold and support the mission and values of the SLN. See the SLN's mission and values on page 6 as well as the SLN website at [www.siblingleadership.org/about/](http://www.siblingleadership.org/about/). Please contact the national SLN at [info@siblingleadership.com](mailto:info@siblingleadership.com) to obtain an affiliation agreement which explains the core elements.

#### **Additional Resources**

How to create a logo:

<http://www.entrepreneur.com/article/71902>

<http://www.creativebloq.com/graphic-design/pro-guide-logo-design-21221>

<http://www.logogarden.com/>

How to create free letterhead: <http://www.wikihow.com/Make-a-Letterhead>

Business cards: [http://www.vistaprint.com/?no\\_redirect=1&xnav=logo](http://www.vistaprint.com/?no_redirect=1&xnav=logo)

Creating a website: <https://www.yola.com/pricing> <http://www.weebly.com/>

Which social media accounts matter: <https://blog.kissmetrics.com/which-social-accounts-matter/>

Document sharing options: <http://www.computerworld.com/article/2505487/web-apps/10-file-sharing-options-dropbox-google-drive-and-more.html>

## Organizational Structure

In the beginning, your chapter may not have any formal structure. This is to be expected, so do not worry! As your chapter evolves, the formal structure of your chapter will evolve as well. The national SLN has a sophisticated structure that involves a board of directors and many positions underneath the board. However, this is not the same throughout the SLN chapters. Every chapter is different and can create a structure that works for them.

Some chapters just have a few people as the key leaders that get people together and move things along. Others have created a formal Board of Directors where they elect their leaders. Many chapters start out with an informal structure and slowly evolve to a more formal structure. Keep in mind that for the first three years of its existence, the SLN did not have a formal Board. Organizations take time to evolve and there is no requirement to have a formal structure in order to be a sibling chapter. Please see the section below on chapter leadership and formal roles for more information.

### **Pick a Representative**

One important part of your organizational structure is determining who will represent your chapter on the SLN's Chapter Committee as well as attending quarterly conference calls and sharing information. The chapter representative must be a sibling of an individual with disabilities and join the SLN by signing up for free at [www.siblingleadership.org/join-sln/](http://www.siblingleadership.org/join-sln/)

### **Submit the following information to the SLN:**

- SLN Affiliate Chapter Application/Agreement
- Please include background information including the name of your group, how long you have been meeting/in existence, the number of people who are part of your group, and any activities you have done or are planning to do.
- Chapter information for the SLN website including a brief description, logo (if you have one), and link to your website (if you have one).

### **Mission Statement**

When starting and developing your chapter, creating a mission statement will help focus and communicate the purpose of your chapter. An example of a mission statement is the national SLN's:

*The mission of the Sibling Leadership Network is to provide siblings of individuals with disabilities the information, support and tools to advocate with their brothers and sisters and to promote the issues important to them and their entire families.*

To see more examples, you can visit other SLN chapter websites and see their mission statements.

**Appendix A** shows you how to create your own mission statement.

## Promoting the SLN

An important element of being an SLN chapter is promoting the national SLN.

This includes:

- Encouraging members to sign up with the SLN on the join us page at [www.siblingleadership.org/join-sln/](http://www.siblingleadership.org/join-sln/)
- Participating in SLN Board Committees
- Indicating on your chapter materials (including website, brochures, and membership materials) that your organization is a chapter of the SLN. Please use the SLN logo and link to the SLN website for people to learn more about the national network.
- Share information about the SLN at chapter events.

### Additional Resources

Formal/informal structures and their pros and cons:

[http://www.ehow.com/info\\_8101157\\_formal-vs-informal-organizational-structures.html](http://www.ehow.com/info_8101157_formal-vs-informal-organizational-structures.html)

The national SLN has developed a formal Board structure. Feel free to take a look at this as one example. Your chapter could create a similar type of structure or a different structure. Decide what works best for your chapter now. Also, be open to things changing as your organization grows over time.

To see the National SLN's board of directors please visit:

<http://siblingleadership.org/about/who-we-are/>

To see a list of the National SLN's committees please visit:

<http://siblingleadership.org/get-involved/sln-committees/>



## Planning Your Chapter's Goals

In order to determine what your chapter will do, it is important to think through and plan for the future. Initially, your goals may be as simple as meeting more siblings or planning a social event. Thinking about goals can start a conversation between members in those initial meetings. Not every chapter has formal goals and objectives right away. Eventually, goals and objectives, action plans, and evaluations will help you and your chapter really focus on what you would like to accomplish and what could be done better.

As your chapter grows, your goals and objectives may become larger with a broader audience. For example, one common chapter goal is to *educate others*. This can be done in a variety of ways including hosting a state or local conference. The conference could be on any topic related to siblings of individuals with disabilities. Some examples for conference topics including:

- Future planning (starting the conversation in families about planning for the future as parents age, how to create a person-centered plan and get supports and services, finding special needs lawyers and financial planners)
- Balancing your own needs with your family's needs
- Sharing sibling stories and experiences (such as through a panel of siblings)—this is useful to siblings to hear other people's experiences as well as sibling supporters to learn more about the experiences of sibs.

### **Goals and Objectives**

Goals and objectives can be helpful when developing your chapter. These goals and objectives will change as they are completed and new goals will arise along with new focus areas. To begin, identify two or three goals that your chapter wants to accomplish.

*TIP: "Create objective, measurable tasks and goals for your team. Distinguish between intermediate outcomes and ultimate outcomes. Set yourself and others up for success so you feel rewarded for your time and efforts."*

**Appendix B** shows you definitions and examples of goals and action steps.

### **Action Plans**

An action plan is a detailed list of tasks to be done in order to achieve an objective. These are explicit tasks such as "make 100 copies of flyer and hand out at workshop".

**Appendix C** has a sample goal, a sample objective to achieve that goal, and an action plan (a list of example tasks) to achieve that objective. There are multiple tasks for every objective, and multiple objectives for every goal.

## **Evaluation**

You have now created your mission statement, at least one goal, your objectives to achieve that goal, and developed an action plan for every objective. Now, did you achieve your goal, and how will you know when you do? Is there something your chapter could have done better? These questions are answered during a thorough evaluation. This part of the process involves gathering information and interpreting that information with your group.

### **Additional Resources**

Definition of goal: <http://dictionary.reference.com/browse/goal>

Difference between goals and objectives and how to write them:

<http://tulane.edu/publichealth/mch/tp/upload/Tips-for-writing-goals-and-objectives.pdf>

Everything about evaluations:

<http://managementhelp.org/evaluation/program-evaluation-guide.htm>

## **Growing Chapter Leadership**

As your chapter grows, you will most likely experience organizational growing pains. Often as more people become involved, there is a greater diversity of opinions. It is useful and important to have diverse perspectives and listen to different voices in the group, but conflict may occur that the chapter leadership will need to resolve. There is also a need to ensure everyone is respectful to each other in the way they communicate. See more information on conflict resolution later in this Guide.

### **Formal roles**

As your chapter grows and you begin to develop a formal structure, you may have specific roles that need to be filled by dedicated members of your chapter. Every chapter is different, so your roles will be specific to your chapter. For example, you may want to create a Leadership Team, Steering Committee, or Board of Directors. This could include positions such as Chair/President, Vice Chair/Vice President, Treasurer, and Secretary.

The National SLN uses an Executive Director and Board of Directors leadership structure. The Board of Directors consists of formal roles filled by members of the SLN. The Board of Directors with their titles and descriptions can be found here:

<http://siblingleadership.org/about/who-we-are/>.

### **Committees**

Committees are a great way to engage your members in the work of the organization. These committees can be developed for many reasons. Mainly, they are formed to accomplish specific tasks or to focus on important areas for the work of the chapter. It can be a committee on outreach, fundraising or advocacy. The national SLN list and description of committees can serve as an example on the website at <http://siblingleadership.org/get-involved/sln-committees/>

## **Decision Making**

One of the most important decisions your chapter has to make is how it will make decisions. There are many different ways chapters can make decisions and no one way is the right way, or the best way. Also, the decision making process does not have to be the same for every decision made.

Here are some of the options:

- Spontaneous Agreement
- One person decides
- Compromise
- Multi-voting
- Majority voting
- Consensus building

## **Conflict Resolution**

As a chapter, you will run into conflicts along the way between members of your chapter and also conflicts between your chapter and outsiders. These conflicts are part of the process of growing an organization and often lead to a healthier, more cohesive chapter later on in the process. One important role of your chapter leadership is to facilitate discussion and to help resolve conflicts. Many people believe that conflict is a sign of an unhealthy group, but conflict is often a sign of healthy growth toward a challenging place.

### **Additional Resources**

How to facilitate a group: <http://brown.edu/about/administration/sheridan-center/teaching-learning/effective-classroom-practices/discussions-seminars/facilitating>

Conflict Resolution: <http://www.forbes.com/sites/mikemyatt/2012/02/22/5-keys-to-dealing-with-workplace-conflict/>  
<http://smallbusiness.chron.com/5-conflict-management-strategies-16131.html>  
<http://www.helpguide.org/articles/relationships/conflict-resolution-skills.htm>

Pros, cons, and uses for each of the decision-making options:

<http://volunteermaine.org/blog/making-group-decisions-%E2%80%93-six-options>

## **Financial Management and Funding**

Your chapter does not need to raise a large sum of money in order to be successful. In fact, your chapter of the SLN can raise as little or as much as you want or need. The goals of your chapter will help determine how much money is necessary. For instance, you will not need funding for meeting space if you meet at a coffee shop or at people's homes.

Your chapter needs to decide how much time and energy they would like to commit to fundraising or filling out paperwork for grants, non-profit status, or becoming a corporation. While fundraising is necessary to achieve some goals, it can also take away from the initial purpose of your chapter. When thinking about funding, you must always keep the purpose of your chapter in mind.

For instance, some chapters have reached out to college students who may be willing to offer their services such as graphic design and grant-writing, as an internship. This can save your chapter time and money.

If you have arrived at the conclusion that your chapter would like to become one of the following: Non-profit, tax-exempt, incorporated, or a 501(c)3 tax exempt organization, please see **Appendix D**.

### **Additional Resources:**

Website about starting a non-profit with many links: <http://grantspace.org/tools/knowledge-base/Nonprofit-Management/Establishment/starting-a-nonprofit>

A map with links to all 50 states and the way to start a non-profit in all of them: <http://foundationcenter.org/gainknowledge/map/start-up-map.html>

### **Budgeting**

As a new chapter, you need to remember to *not make your budget more complicated than it needs to be*. Since most of the chapters are small with relatively small income, there doesn't need to be any more budgeting than a table showing your income and another table showing your expenditures. When you grow, your budget should grow alongside you. It can be helpful to have someone in your chapter have expertise in finance to provide guidance with budgeting.

When your chapter is operational and donations (big or small) start coming in, you need to be able to keep track of how much money is coming in and how much is going out. More importantly, you will need to identify what the money is being spent on. A budget can be a useful tool to inform your leadership team or Board about how the organization is doing financially and determine which financial goals are important to focus on.

## **Types of funding**

After you have decided the general direction of your chapter, including making a budget, it is important to know the types of funding that are available your chapter. There are a lot of funding sources, however each of them falls under the umbrella of either restricted or unrestricted funds. Unrestricted funds are any funds that are raised but not for a specific purpose. These usually go towards the operating costs of your chapter. For instance, any donations collected that the donor does not designate for a specific purpose or program are unrestricted. However, if the donor designates their donation for a specific purpose, the funds become restricted and can only be used on that. When funds can only be used for a specific program, or reason, then it is a restricted fund.

**Appendix E** is a list of specific funding sources as well as their definitions. These include: in-kind, donations, gifts, sponsorships, grants, and member dues and fees.

### **Additional resources:**

On how to make a budget please visit:

<http://money.cnn.com/magazines/moneymag/money101/lesson2/index.htm>

Sample outline of a budget: [http://financialplan.about.com/library/n\\_budget.htm](http://financialplan.about.com/library/n_budget.htm)

Another way to make a budget: <https://www.snpo.org/samples/V150446.pdf>

Nonprofit Accounting basics: <http://www.nonprofitaccountingbasics.org/>

## **Conclusion**

We hope that this guide has given you some things to think about that will help you develop your sibling chapter. Know that you are not alone and the national SLN is always a call or email away. Thank you for your interest and dedication to bring siblings together and create a chapter of the SLN.



# APPENDICES

## Appendix A: How to Create Your Own Mission Statement

Here are some guidelines on how to create a mission statement for your chapter.

A mission statement should be:

- One sentence
- Broad; allowing for many goals
- Outcome focused; state what your chapter wants to achieve
- Done with many people from your chapter
- Approved by at least a majority of your chapter; preferably a consensus

## Appendix B: Goals and Objectives

### **Goals**

#### Definition:

Goals come from your mission statement and should be developed as a group. They can be long term or short term and are general statements of your chapter's intentions.

#### Examples:

- Bring siblings, and sibling supporters, together and share information
- Provide information to policy makers and legislators about sibling issues
- Increase communication and support among siblings and sibling supporters
- Inform other siblings and sibling supporters of the support available
- Increase awareness of the Sibling experience

### **Objectives**

#### Definition:

Objectives are the steps needed to achieve any given goal. There will be multiple objectives for every goal. Just like the goals, these should be developed as a group.

#### Examples:

- Create a contact list of all organizations that serve individuals with disabilities in the area.
- Notify all organizations that serve individuals with disabilities that the [insert the name of your chapter of the SLN] exists
- Create informational handouts for chapter meetings.
- Host a conference for siblings and sibling supporters
- Host social gatherings for siblings and sibling supporters – inclusive of their siblings with disabilities or without

## Appendix C: Sample Goal with Objectives and Action Plan

Here is an example of a goal with objectives and an action plan. While there are typically multiple objectives for every goal, for the purpose of this exercise only one objective will be listed. Remember, there are multiple objectives for every goal, and multiple actions for every objective.

**Goal:** Increase awareness of the Sibling experience

**Objective(s):**

- Develop an informational brief for the general public so they can learn more about the SLN and the issues faced by siblings

**Action(s):**

- Include time in the next chapter meeting for discussion
- Find siblings volunteers and create a task force with this objective
- Develop a list of the issues faced by siblings
- Draft the informational brief
- Distribute the draft to the chapter members for feedback
- Make changes and edits
- Task force presentation to the chapter members for last comments, changes
- Send brief out for printing
- Identify methods of distributing the brief
- Develop a list of agencies and businesses that could benefit from this information
- Develop a list of public places or events to hand out the briefs
- Share brief through networks

## Appendix D: Financial Management and Funding

### **Becoming a corporation**

In order to apply and receive non-profit and tax-exempt status, your chapter needs to become a corporation. In order to do this, you will need to file articles of incorporation with your Secretary of State or other state agency.

Find your state here: <http://www.irs.gov/Businesses/Small-Businesses-&Self-Employed/State-Links-1>

### **Non-profit and tax-exempt**

Non-profit status is given by the state where the organization is operating while tax exempt status is given by the federal government. While they are not the same thing, they do go hand in hand. Here are some general facts about the two along with other resources:

- Most states have their own process of granting **non-profit** status so be sure to check with your Department of State.
- There are 28 types of nonprofit organizations that are exempt from some federal income taxes (**tax-exempt**)
- Non-profit status must be obtained before tax-exempt status can be requested from the IRS.
- Visit <http://www.irs.gov/Charities-&Non-Profits/State-Nonprofit-Incorporation-Forms-and-Information> for contact information for your state.
- Visit <http://www.irs.gov/pub/irs-pdf/p557.pdf> for information on all of the 501(c) options available.
- **WARNING:** If you gain non-profit status, you must file an *annual* 990 form with the IRS and your organization will have an *annual* audit. Failure to do so will result in a fine and potentially loss of your non-profit status.

### **501(c)3 status**

501(c)3 status is often synonymous with non-profit status. However, 501(c)3 is only one type of non-profit, tax-exempt status which has many benefits:

- This status allows an organization to receive tax deductible donations.
- Grant opportunities, which will be discussed later, are typically only open to organizations that have this status from the IRS.
- For information on how to become a 501(c)3 recognized organization visit: <http://www.irs.gov/Charities-&Non-Profits/Application-for-Recognition-of-Exemption>
- For a step by step process visit here: <http://www.irs.gov/Charities-&Non-Profits/Application-Process>

## Appendix E: Types of Funding

### **In-kind**

The term “in-kind donation” is used for donations that are not cash; such as services or products. Great places to look for in-kind donations are organizations within your area that serve individuals with disabilities and/or their families. In-kind donations are given with the expectation that they will get something in return, such as advertising.

#### **Examples of in-kind donations are:**

- Providing room for meeting
- Providing free space for events you hold
- Providing food for events
- Providing logistical support for events such as have them handle the registration
- Consulting services (an accountant helping with the budget)
- Chapter supplies
- Advertising within their organization

#### **Examples of these organizations are:**

- UCEDDs (University Center for Excellence in Developmental Disabilities)
- The Arc
- Developmental Disabilities Council
- NAMI (National Association of Mental Illness)
- Partners in Policy Making
- Direct Service Providers
- Centers for Independent Living

### **Donations or Gifts**

The terms “donation” and “gift” often mean the same thing which is typically money. However, it can also be property that can be converted to cash. Examples of this are stocks, bonds, cars, real estate, or anything else that is given to your chapter. This is different than an in-kind donation because in-kind donations are loans, while regular donations and gifts are not.

### **Sponsorships**

The term “sponsorship” refers to funds given to support specific events or programs. For instance, a hospital may sponsor a walk against cancer. The sponsor gets the positive publicity and may also have a stake in the fundraiser. If your chapter is looking to host a conference or any size event, sponsorships are a valuable option as they can often negate costs related to the event.

### **Grants**

The term “grant” refers to restricted funds given to an organization for a particular purpose. Grants are usually given by the government or other large institutions. While grants can be a great source of funding, they are often for specific purposes and given to 501(c)3 organizations and time consuming. It is recommended to use an outline such as “The Common Grant Application Format” or follow the basic guidelines for preparing a grant which can be found here: <https://www.cfda.gov/?s=generalinfo&mode=list&tab=list&tabmode=list&static=grants>

### **Dues and Fees of members**

Some chapters may receive at least a portion of their funding by required dues and/or fees from their members. Dues are a set dollar amount that every chapter member must contribute in order to remain a member. Dues are usually paid every year. Fees are one time contributions for a specific project or function. For instance, your chapter may have fees in order to host a conference.