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**A GUIDE FOR SIBLING CHAPTERS**

**ARC**

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If you are having technical issues type your issues in the chat box and we will take care of them. Thank you for joining today.

Good afternoon and welcome to the webinar entitled to leadership network how to start a state sibling chapter. We are delighted you are able to join us today. Before we begin our presentation I would like to go over a few housekeeping rules first. All participants are currently in a listen only mode. There will be an opportunity to ask questions following the presentation, however, at any time if you need assistance post a question on the right‑hand side of your screen and we will be happy to assist you.

This webinar is being recorded and a link to the recording, PowerPoint slides and any handouts for the presentation will be sent out to all attendees following the webinar. The webinar is also been caption today. If you need or want captioning go to the webpage listed on the screen in front of you. We have also put the link into the chat box you can easily copy and paste it into your web browser. We have one final request before we begin. You will receive a session evaluation immediately following the webinar.

Please take five minutes to complete and submit this to us. It is very important for us to have a good understanding of how you plan to use the information today. Once again, thank you so much for joining us and I will now turn it over to Robin who is with individual family support to get started.

>>: Hello, this is Robin, the ARC Senior executive officer and thank you for joining us for the ARC family support training webinar entitled Sibling Leadership Network presents how to start a state sibling chapter. The Arc hosts Family Support Research and Training Center webinars as part of our work as a proud partner of the Family Support Research and Training Center at the University of Illinois at Chicago. The Family Support Research and Training Center works to define the state of the science in family support; generate new knowledge in critical policy areas, including self-direction, managed care, and culturally competent peer-to-peer family interventions; and generate and implement a vision for policy and practice in family support.

We are proud to host this webinar today with another partner on the SSRT, the sibling leadership network. This is a national nonprofit dedicated to providing support and information and the siblings of those with disabilities across.

Currently there are 22 state chapters have sibling leadership network and we want to have a chapter in every state and country. These are with the organization and our personal contacts. As a project partner for the SS RTC the leadership network has developed a guide for sibling chapters that shows you how to nurture and grow sibling chapter's. Today's webinar will provide foundational information on how to start and grow sibling chapters in your state. We are pleased to have three speakers on the call who can't speak from experience on issue.

Our first speaker, Katie Arnold, is the Executive Director of the Sibling Leadership Network (SLN). Katie also works at the Institute on Disability and Human Development at the University of Illinois at Chicago as the Director of Community Education. Katie has been involved in the SLN since the organization’s inception in 2007.

Our second speaker, Amy Halm, is the Project Manager of the Sibling Leadership Network (SLN). Amy is a Licensed Clinical Social Worker and has been a Board member of the Supporting Illinois Brothers and Sisters (SIBS) chapter for many years.

Our third speaker today is Barbara Sapharas. Barbara is a co-founding member of the Ohio sibling chapter, Ohio SIBS.

I will turn things over to Katie to get things started.

>>: Thank you Robin and Jenny and thank you to ARC for hosting this webinar. I am Katie Arnold the director of the sibling leadership network and, as Robin mentioned, we will be presenting how to start a state sibling chapter. I will start out by providing a brief overview as context and then Amy, project manager will go over foundational aspects of starting a chapter. I'm really excited we have a guest presenter, Barbara, a leader in the movement who has been the past chair of the board and cofounding member of Ohio SIBS.

As Robin mention and before I dive into the topic I want to acknowledge the support research and training center at UIC for human development and the family support training research and training center is a collaboration of researchers and organizations that are focused on both synthesizing and generating knowledge about the needs and experiences of families who provide support to children and adults with disabilities across the life course. The SLN is excited to be a partner in this initiative increasing support to siblings. I encourage you to check out the website and join the SR TC listserv to get updates about family support training and opportunities.

The sibling leadership network is a national nonprofit whose mission is to provide siblings of individuals with disabilities, information support and tools to advocate with brothers and sisters and promote issues important to them and their entire family.

We created the organization in 2007 from sine need to bring together those with disabilities that was happening across the country. The purpose was to provide a strong reflective voice to build awareness of the sibling experience and perspective. The SLN has three focused areas, research, policy and advocacy and support and information. We now have over 5000 siblings and sibling supporters as part of the national network from across the country and even around the world. I encourage you to join the network if you have not already as it is free and easy and you can sign up at the website sibling leadership .org.

You should join the SLN? We welcome siblings with those with any type of disability and we tend to draw the most members as siblings of those with intellectual and developmental disabilities. By uniting we can support each other and be stronger together. Sibling supporters are an important part of our network and participate in the work we do. Sibling supporters include anyone who believes it is important to support siblings.

People with disabilities are an important part of our network and serve on our board and committees. 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 can get more information about the sibling experience to help them learn how to better support siblings and many professionals provide important support to siblings and partner with them throughout their lives.

We encourage professionals to join the network and share information with the families they work with.

Our core values are central to the work we do. We believe individuals with disabilities have the same rights as all members of society to dignity, respect and the opportunity to grow and be productive members of their community. We really focus on equality and enhancing mutual relationships between people with and without disabilities.

The need for our group stems from the stigma discrimination and oppression of those with disabilities as a marginalized group. Siblings of individuals with disabilities have a powerful and positive impact on their sibling’s experiences and are uniquely positioned to help ensure that present and future care in partnership with service organizations and government.

This highlights the value of the sibling goal. We have an important place in our families to help make positive change benefited lives of our brothers and sisters with disabilities, ourselves as siblings and I whole family. And 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. Much of our work is mobilizing simulates and creating a movement to get more siblings in advocacy. This is to get the voice of the policy table. This is enhancing our lives and the lives of our siblings. We know there is a real power and peer support in connecting siblings to create communities is a critical part of our work.

Most of you watching and listening today probably know about the experience of being a sibling to someone with a disability. Siblings are often each other's first playmates and friends as well as tormentor. Ourselves help prepare us for the world in many ways as we learn how to fight and make up, confided cap for one another. The relationship changes over time siblings have the longest relationship of our lives with each other. We will be there for each other 20 plus years longer than our parents and the sibling experience is often overlooked and forgotten. Traditional service and support structures focus on the role parents play and the lives of their children with disabilities well less attention has been given to the role the siblings play.

H sibling has a unique experience. Each child within a family has a different perception. There often are similarities within the difference. Supporting siblings is important to the SLN and state sibling play a role in carrying this out. I will turn it over to Amy, the project manager to tell you more about starting a chapter at the SLN.

>>: Thank you Katie and thank you to Jenny and Robin as I am pleased to be here with you today. I am a sibling myself and I live in Illinois and have been a member of the Board of Directors for my states chapter supporting Illinois brothers and sisters for six years.

Currently the SLN has 23 state chapters and this includes our newest chapter of Mississippi who just joined the network this week. We are so excited to welcome Mississippi. Our state chapters are they grass roots of the SLN as that is where siblings connect with each other, provide support locally and form a personal relationship. These personal connections are the best part of my experience with the state chapter. I have formed genuine friendships with a small group of siblings and fell they really get me. Sometimes better than my friends even though the only thing in common is our experience as siblings of those with disabilities.

The SLN has found each state chapter has their own flavor and personality. From the national perspective we love to see the diversity of events and activities on the ground in each state. SLN has a vision to have state chapters in all 50 states and we are very glad each of you are with us today because we hope you can help us accomplish this goal.

You may be wondering what are the benefits of becoming a state chapter? Siblings matter collectively the voice of siblings is amplified as we grow and are able to provide more support with those with disabilities. By becoming a state chapter you become part of the national sibling movement and the sibling movement is growing nationally and SLN is building more awareness at the sibling experience and connecting experience for siblings across the country. The Mark ordination as state and national level, the better we can support siblings throughout the lifespan.

By becoming a chapter of the SLN you are becoming something bigger that will help your chapter as a launches.

Opportunities to receive financial export support and collaboration. We went to help the chapters develop and grow and we generally enjoy the opportunity to partner with states and help her see grants that was support siblings and Chris they chapters. Currently the SLN is collaborating was they chapters and partners in New York and North Carolina on exciting projects that have directly impacted siblings. We recently finished a partnership with the Pennsylvania Chapter creating and implementing an innovative and effective sibling Ambassador program to expand their states chapter exponentially across the state.

We are looking at some exciting potential products in other states as well. The SLN has grant writing and project management experience as well as content expertise and collaborative relationships with large organizations, we really embrace the opportunity to be partners with state chapters on grants. Providing direction to sibling leadership network, the perspective and voice is critical to the direction of the national SLN. We have chapter representatives on the board and they help ensure the chapters needs are incorporated into the work we do.

Connecting to other state chapters, three chapter meetings and national conferences, state chapter representatives enjoy learning from each other and sharing information and material. The SLN facilitates those chapters hosting conference calls for the chapters to discuss ways they have gotten started, I'd is to reach out to siblings, places they have found support and funding, success and challenges they have had.

We also have time at the conference where the chapters to connect with each other. At our last conference the Wisconsin chapter got together and it was the first time for many of them to meet in person since much state work is done over the phone to reach all areas of the state. Becoming connected to local peers in a judgment free zone, we hear all the time that when siblings come together they feel like they are understood and don't have to explain themselves. By having a group specifically devoted to needs and interests of siblings we feel heard and connected. Provide connections for state and local siblings, the power of sibling support is almost indescribable. I imagine some of you in attendance today are siblings who have enjoyed meeting and other sibling and want to share the experience with others.

Siblings can act as friends, peers and confidants at the state level. Some siblings want to be connected on an emotional level and other times they are looking for facts and information. Siblings often say the most valuable information they have received about system navigation for future planning or policy information comes from there sibling connections.

Let's talk about the important components of becoming a chapter. The SLN has an affiliate chapter that outlines the guidelines for state chapters. It includes a degree agreeing to uphold the mission, purpose and core values. Katie share this with you earlier. And agreement to support those with any type of disability. Your group should have a group in the state that has been together for more than six months or has three members and has a plan for future activities. I really want to highlight this component as I know we have gotten enthusiastic chapters putting in their application before all requirements are met. We have found that this length of time minimum number of core members and roadmap for future events are really critical to the success of the state chapters.

Commitment to join this page, this is quick and easy and is a great way to promote and stay connected. Designate a sibling representative and alternate to attend quarterly chapter committee meetings and these occur by phone and serve as a liaison to share information between state chapters and SLN national network. We have heard from current chapters these meetings are interesting and informative and give great ideas to use in their own state. Finally, promote SLN by joining and participating in committees, sharing information, using SLN logo and responding to occasional request for information from the SLN.

The first step is really finding other siblings. Before I began talking about how to reach other siblings I want to acknowledge there may be people attending right now that you want to connect with. We have people from more than 20 states he registered for this webinar and we may have more than that as we don't have everyone's estate recorded. You may be wondering if anyone else from your status on this webinar today and may be able to help you organize the state chapter. If you are thinking this and want to reach out for connections I offer to suggestions, one possibility is to e‑mail me and I will help get you connected or at the end of the presentation is my e‑mail address and I'm happy to be in contact that way. You can type your name, e‑mail and state and to the chat box to the host and I would be happy to connect interested participants over the next few days. This would make us happy to have more chapter submitting application for state chapters about six months from now.

Onto how to reach siblings. When a strategy is to connect with other state chapters. I included this bullet today because in preparation for the webinar I reached out to our current chapters and asked them for advice on what they thought I should include. The chapter wraps are lovely and wonderful and helpful and responded right away with great suggestions that I had not thought of. As a result today, you are learning a lot from their advice. I encourage you to do the same and on the website you find state chapter contact information and if a nearby state has a chapter you may fill free to ask if you can attend one of their meetings. For example, many SLN members attend the conference in Ohio even if coming from another state. That is how our SIBS chapter got started after they attended the conference and brought the information back to her state.

You can also use social media, Facebook and Twitter and the sibling leadership network has a Facebook page and a group and a twitter account. On Facebook is a community for those around the world and is hosted by the sibling support project in partnership with the SLN. This is a closed group for siblings of people with disabilities. You could post in the forums and look for other siblings who live in your state. Additionally, you could attend local conferences and related fields and search for siblings there for attend the training. For those who are not familiar these are great events providing young brothers and sisters and children and teens with the lively and recreational setting.

You have the organization serving people with disabilities and you can think of more than I can because you know the agencies in your region and some may work for them. There are state and local arcs and the state developmental counsel and university centers for excellence in DD, partners and policymaking groups, self-advocacy organizations, providers, special needs lawyers and financial planners and healthcare professionals.

These professionals know siblings interested in connecting and may be interested in using your chapter as a resource for their services. Also, attending the national SLN conference to meet siblings from your state.

I cannot encourage you strongly enough to consider joining us for the SLN 2017 national conference in Hartford Connecticut on June 24 and 25th. It will be wonderful. We are expecting 150 siblings to learn from speakers, connect with fellas siblings and celebrate the tenth anniversary of the SLN. This is a great chance to meet other siblings. Our conference is targeted to siblings we welcome sibling supporters and professionals to attend as well. The SLN conference occurs in collaboration with AAI DD national conference and if you happen to be interested in and tending you can join our conference by arriving two days earlier.

Registration for conference is not open yet, but is coming soon and we will begin registration March 7 and if you would like to get more information about the conference and registration this is another great reason to join our website and Facebook page for the sibling leadership network to get the updates. It is important to acknowledge siblings are really busy people who often juggle multiple caregiving roles. You may be familiar with the sandwich generation referring to people caring for both aging parents and their and children.

Siblings are referred to as the club sandwich generation due to the multiple caregiving responsibilities that they often juggle for their aging parents, their children and the extra layer at their brothers and sisters with disabilities. This can be overwhelming and may be too big to take a bite out of as is shown in this photo with a little girl. I share this slide with you because while being a club sandwich and a ration member makes a person the perfect candidate for support through a state sibling chapter it makes it very challenging for siblings to find time to volunteer, attend and organize sibling events.

Chapter leaders say this is a hard hurdle to clear and siblings want to come, but it is hard to find the time. Several chapters have share they have addressed this by providing meetings virtually and providing different events to meet the needs of different schedules and interest. And recent communication with chapter representatives, they told me to share on the webinar telling new chapters to just keep trying even if there is a small turnout at first, stick with it and more siblings will show up as you grow.

When you have people interest you can hold the first meeting and there are things to consider. You want to decide on a location and it could be a home, restaurant, library, copy shop, try to make this physically accessible and conversation friendly. You can use e‑mail and social media to invite siblings.

Occasionally other family members are interested in joining a sibling group, but sibling chapter meeting should promote the sibling perspective and allows siblings to fill comfortable speaking openly.

This is a great way to meet and greet and we encourage you to be an formal and establish a general guideline of confidential conversation. A good icebreaker for meetings is to have sibling share something about their experience and may be a favorite memory or something you have taught or learned from your sibling. This gives the opportunity to share their siblings with other people that they think really get it. You may consider bringing NA speaker from another state to the meeting even if this happens phase time or Skype. This was suggested by our Pennsylvania chapter representatives and she said doing this helps to have ideas from another state, but help siblings see they are greater than something part of something greater.

Take time to develop next steps for the next meeting and make sure that you have contact information for those that attend. I will tell you that sometimes in my own chapter in Illinois we are so great at socializing and having informal conversations that we realize at the end of the meeting we forgot to ask people's names and phone numbers.

Building on the first meeting, it is important to think about internal and external communication. You want to collect names, phone numbers and e‑mail addresses to develop a list you can use going forward. Close to Facebook pages, meet ups and listserv can be used as internal communication. Many states use a free conference call line or Google hangouts to communicate. On the topic of internal communication I went to share a suggestion from a chapter representative at SIBS New York who suggested chapters keep a manual whether written or electronic, the documents, how that got started and information at website passwords and membership members from year‑to‑year. During times of leadership transition this written record prevents history and operating instructions of getting lost.

It is important to consider external communication. You create a website or Facebook or twitter profile and organizations will share your links in their newsletters and they are happy to provide information about other siblings.

Think of the needs of siblings in your state and this may be different state to state. For example, some states, hopefully it is one of years may have well‑funded services and advocacy efforts look different in your state than those struggling to fund specific programs. It is helpful to get a sense of sibling needs in your area to plan activities. This can be done through informal conversation, focus groups or surveys. Each state chapter has its own flavor and a lot of groups have more social and casual events were siblings make connections and some chapters prefer a more formal organizational style with agendas and speakers.

Some smaller chapters have told us they are searching for or enjoy having partnerships with established organizations in the area. This may provide resources and opportunities. Other chapters have said that this relationship can be challenging because they fill it may jeopardize their own identity as a sibling group. Establishing meetings is important and I know our Colorado Chapter suggested consistent meetings and consistent messaging about meetings in order to be effective.

>>: This is Katie, if I can interject and share a few thoughts. Just to put this into context and terms of four key things chapters often to. The first is get to siblings together and as Amy talked about the social gatherings that are so important. Some of our chapters have had a Valentine's Day breakfast, SIBS in the city gathering. Often that is the first priority of chapters to have siblings get together to really connect socially and share their personal experiences and stories. The second key thing is supporting siblings throughout the lifespan where chapters choose to host shops as was mentioned or mentor other siblings and provide information at future planning resources and training. The third key thing is educate other people about the sibling experience. May be presenting for parent groups or professionals and give them a better sense about what the sibling needs are and doing webinars and having conferences or events. The fourth area is advocacy and getting siblings and advocates together to try to make policy changes and states and having the power of pairing stories with statistics. Those are four key areas of focus chapters often do. At the first meeting and as you develop your communication internally and externally, those are things to keep in mind for what the chapter wants to focus on.

>>: You will need to create a name and logo as that is brand, professionalize and it can be used on business cards, letterhead or other promotional material. You can look on the website to see examples and get ideas of other chapter logos and names. We found developing a name and logo can be a great creative and collaborative way to bring the group together to work on a tangible task.

Talking about chapter structure as they really are different state to state and can be customized to fit your needs. When developing your chapter, creating a mission statement will help focus and communicate the purpose of your chapter. Mistake chapters have mission statements that are one sentence that is brought and states what they want to achieve. It should be something your chapter approved seven supports and we encourage you to look at the national SLN mission and make sure yours aligns with the national mission.

Regarding goals and objectives, in order to determine what your chapter will do, it's important to think through and plan for the future. This may be as simple as meeting more siblings or creating a social event. Thinking about goals can start a conversation between members and those initial meetings and on every chapter has formal goals and objectives right away. Goals and objectives and action plans will help you and your chapter really focus on what you want to accomplish and what could be done better.

As your chapter goals they may become larger with a broader audience. For example, a common chapter goal is to educate others as Katie said and this can be done NA variety of ways including hosting a state or local conference.

State chapters think about roles and responsibilities. In the beginning, your chapter may not have any formal structure and this is to be expected said do not worry about this as your chapter involves the structure of your chapter will evolve as well. Some chapters have a few key leaders to get people together and move things along and others have created a board of directors or a steering committee. Some elect their leaders while some smaller chapters of positions mutually agreed upon many chapter start with an informal structure and evolve to a more formal structure. Keep in mind for the first three years of existence the SLNB did not have a formal board of directors. Organizations take time to evolve and there is no requirement in order to be a sibling chapter. I do want to share that having a defined role helps with expectations as opposed to just a philosophy of we will see you when you can make it to a meeting and having those roles help people plan what they should do to pre‑ prepare for the organization.

However it is you choose to organize say chapters say to have strong leadership is really critical to success. To the extent you are able it is helpful to match members natural interests and strengths with your chapter's needs. To provide an example from my own chapter I am very loyal to my end state chapter and I would do a lot of things to help them out, but I am not interested in being the treasure as this does not match with my interest and strengths and I would be looking for reasons to not show up at meetings. I have tried to match my on strengths and needs with what the strengths and needs are for my organization.

You may consider regional leaders as well. Our Pennsylvania chapter realized that having regional representatives was the key to reaching across the state. Wisconsin SIBS had three areas at the state to get through collaboration and relationship building and SIBS New York is trying to get borough representative so they can meet phase to phase closer to home. As you get close to submitting your affiliation agreement it's important to determine who will represent your chapter on the SLN chapter committee as well as attending quarterly conference calls and sharing information. The chapter representative must be a sibling of an individual with a disability. We ask each state has an alternate in case the representative cannot make it to a meeting.

The finances of a chapter, your chapter does not need to raise a large sum of money in order to be successful. Your fact your chapter can raise as much or little as you want. Goals of the chapter determine how much money is necessary. Princes, you don't need funding for meeting space if you meet at a local spotlight coffee shop or people's homes. Your chapter needs to decide how much time and energy they want to commit to fundraising or filling out paperwork for grants, nonprofit status or becoming a corporation.

Fundraising is important to but can't take away from your chapter and takes away from volunteers time. State chapters like New Jersey use college interns to help with grant proposals and website design and this is a great way to save money and get a lot of work completed.

You will want to consider budgeting. As a new chapter you keep the budget is simple and must chapters are small with relatively small income there does not need to be any more budgeting than a table showing income and expenditures. When you grow your budget should grow alongside of you and it can be helpful to have someone in the chapter with expertise in finance to provide guidance with budgeting. Of course, if you're getting donations it's important to track and thank the donors.

Types of funding, after you decide the general direction of the chapter including making a budget it's important to know types of funding available for the chapter. There are a lot of funding sources, however, each falls and the umbrella of restricted or unrestricted funds. And restricted is any that are raised, been off for a specific purpose and they get where the operating cost of the chapter. Any donations collected the donor does not designate for specific purpose are and restricted, if the donor designates donation for a specific purpose it becomes restricted and can be used for that purpose only. We are told by some a larger budget chapters that and restricted funds have been very helpful moving forward.

A question we hear from chapters issued we become a nonprofit, tax‑exempt, Inc. or five O one C three organization? There is not a right or wrong answer, a handful of current chapters are nonprofit organizations and two chapters have part‑time paid staff. Some siblings work in organizations allowing them to use a bit of their work time to help them build their chapter and the rest of the chapters are volunteer run. to set a process for tax‑exempt requires patience and follow‑through. I've heard from several is better to not rush into this process as it may be a goal that you work toward.

I will give a couple of basics and know that this information is available for you and writing at the conclusion of the webinar. In order to apply and receive nonprofit and tax‑exempt status the chapter needs to be a corporation and to do this you need to file articles of incorporation with the secretary of state or other state agencies. Nonprofit status is given by the state where the organization is operating while tax‑exempt is given by the federal government. They are not the same thing, but they do go hand‑in‑hand and there are a few things to keep in mind. Misstates have their and process for granting nonprofit status and you want to be sure to check with your and Department of State. Nonprofit status must be obtained before tax‑exempt status can be requested and I went to share that if you gain nonprofit status you must file an annual 990 form with the IRS and the organization will have an annual audit. These are important to keep in mind.

 five O one C three status is one type of nonprofit tax‑exempt status having benefits and this can receive tax deduction and this is open to organizations that have the status from the IRS.

The SLN has created a guide for sibling chapters containing a large amount of information I have shared today. Please feel free to download the information and the website is listed here and you can find us on the state chapters page and then here is the SLN chapter guide there.

I know I have presented a lot of information and we will have time for questions at the end of the webinar, however, it is my pleasure to introduce Barbara who was previously the SIBS network and founding member of the Ohio chapter. Barbara has dedicated her time and talent to improving the lives of people with disabilities and their families in her state of Ohio and nationally.

Thank you.

>>: Hi and thank you everyone. Thank you for the opportunity to talk and share about Ohio's SIBS and are continuing growth and evolution. our founder really is Doctor Thomas fish, Tom was the director of family and employment services at the center in Ohio State University and is one of our two university centers for excellence in Ohio.

For decades he provided support groups for skull age siblings and he realized that he was now seen siblings as students at Ohio State and realized the needs of adult the siblings was much different and the needs of those for school‑age children.

In 2001 he organized a statewide adult sibling conference and I was working in this field and a professional publication I saw this a blurb about an adult sibling conference. I had two brothers with disabilities and when was that the seminal disabilities and one with an acquired. Why have I never heard about this? I attended a conference in Columbus and went to the Cleveland area and I am two or three hours from Columbus. As you have heard already, the first time being NA room with siblings and realizing you are not the only one and people do get it. We did not have to explain things.

I bet Tom Fishman every person and that room and learned our stories and learn a little bit about as. After the conference Tom connected with some of us and said did you like the conference, did it help and would you be interested in helping plan the next one? Somehow, to discuss the need for adult siblings support. Our meetings were very casual. Tom would call and ask what do you think about this or do you know anybody and a couple of times he called and said can you make it to Columbus for a meeting? This group evolved into an advisory committee and we had a chair, regular meetings and we had a secretary. We had documentation of all meetings. The focus at that time was how do we continue the signature event of an annual conference? This is 2017 and we will be holding our 17th annual conference. Tom was very deliberate in the way that he pulled SIBS together as he tried to get brothers and sisters to be part of this advisory group as we know from past experience we see a lot more sisters and brothers and activities.

He also tried to pull in people from throughout Ohio. Targeting specifically the Cleveland and Columbus and Cincinnati areas and all parts of the state. We met to plan the conference and we also were open and receptive to possibilities. A small group in the Cleveland area wanted to meet on their own and we fully supported that. That group we met just to talk, we met at restaurants, a couple of times we actually had brothers and sisters night to where we went out to a gaming place where we could play video games and eat and hang out with our brothers and sisters.

We also looked at possibilities of sharing about the sibling perspective and how to engage siblings. We all recognized and less you are the guardian siblings are really not included. We made presentations for organizations, advocacy groups, conferences, meetings and almost anywhere we could. We realized we wanted to become a nonprofit and were receiving support, all kinds of support with the work of students, financial support from Ohio State University and we wanted to become our own entity. And September 2010 we acquired the nonprofit status. We became a nonprofit. We did not get the federal tax‑exempt status for quite a while. There is a gap between the two.

In the spring of 2012 we applied in 2011 for a grant from our counsel and received a grant for five years specifically targeted to hire a part‑time executive director.

We also, that spring, held our first transition weekend where we had students in transition attend a two night, three‑day overnight camp with their siblings or a couple of times there were cousins for the weekend to talk about the transition process from student to adult life. We were able to have groups where the students could talk and also we had targeted conversations where siblings were able to share their concern. The one thing we learned was that siblings really knew what their brothers and sisters really had passion for and wanted to do as adults. Also they knew how to best support them. I worked in the field for years and it was a moment where I thought we really do no more than we give ourselves credit for.

In 2013 the Council Oxford as the opportunity to manage and coordinate an advocacy day at our state house and we did that for two years. At the end of 2013, September or October are developmental of developmental disabilities director John Martin identified he was going to pull together a strategic planning leadership group and advocates or people receiving support and providers to do strategic planning for the department and the state.

At the time, when the initial information went out we had siblings perspective that was not identified and a board member approached Director Martin and Ohio was been included as one of the four advocacy groups on that strategic planning leadership group and that gave us a seat at the table. We had a sibling or I was part of that group and we were able to bring the sibling perspective in addition to the family and the parent perspective to the table.

As a result of that participation, Ohio SIBS has been included in several statewide workgroups looking at rules and laws that affect our brothers and sisters and the people we love.

In 2016, we received a grant from department at the development of disabilities to organize, loss of audio, this was held in Columbus and this was a three‑hour drive and four siblings who are caregivers that provided or presented a challenge to get away.

I wanted to share some things we have learned and some things we still need to consider. Amy and Katie have identified these. This is just reiterating some of what you have heard. One thing is we need commitment and leadership and we had that initially with the vision from Tom and the support to move forward and several siblings throughout the 17 years have committed a lot and taken great leadership roles.

We learned we wanted to engage siblings from all parts of the state because we wanted to be seen as a statewide organization. We fill it is important to continue our signature a events at the conference and I just want to say to just start. Start with whatever you have and whatever you can, just start. Be open and responsive and flexible to whatever may come your way. We did not know when we started we would be at the table revising rules and reviewing rules. We did not know we would have a transition weekend. We did not know any of that.

And we talked about having a mission and we have felt that has been critical. As you grow through time sometimes you have to look at her mission and say do we really want to do this and does the support our mission? We also learned we had to ask to be included initially as we were not included as an advocacy group. Now we are.

That was because we had a board member who asked. We also learn to start small and grow. The process is ongoing and evolution all and you won't know the answer of how things will be a less you move forward and do it.

Also, be patient with yourself. You won't have all of the answers and be open to learning as you move forward. The other thing we had to do is we had to identify our priorities based on our resources. We have a part‑time executive director, but a lot of the work has to be done by the volunteers. Sometimes we had to look at the opportunity and two we have the resources to take this on? Some things to consider and remember is we are challenged and we want to stay free from the service system. We know that many people with developmental disabilities in Ohio do not receive services from the system.

I have seen statistics nationally and that is pretty true for many states. Most of the people are not served by the service system. Some siblings attending the conference has said that is great, but my brother or sister does not receive services so what about me? We have learned that we want to stay clear or conflict free from the service system. Some ways to do that is to look at other places to hold meetings and you have heard some of that. Libraries are a great place, rec centers, community centers are great as well if you have someone who lives in the area.

Another thing to remember is to engage the working board and let them know there is going to be worked. Katie or Amy said that we have to have clear expectations for the board members and also for anybody that we contract with whether you hire a consultant or someone to do the IT work or set up a webpage, there has to be clear expectations any way to follow through. You need a vision and a sustainability plan. As you have heard, Ohio SIBS has received many through grants and that has been great. It has supported us to have activities or events, but we have not been able to use that money for other needs. We have to look at unencumbered funds and how we raise funds we can use the way we see fit for supports for the organization.

And other thing to think about is diversity. Beyond the gender and race we need to look at disability diversity, geographic diversity and generational diversity. At our Ohio steps conference we have siblings that a 10 from three generations and our oldest attendee was in her 70s and our youngest was 16. That is three generations. The concerns and need for support do differ.

The other thing is like at what gifts the siblings bring. Nonprofits are always told to click what knowledge do they have and what resources can they bring to the table with people who they know who can donate, what they can donate themselves. I hope this has been helpful and just start as this, everything I have been from every gathering with siblings have had the opportunity to meet each other tell them how powerful this is to be NA room with other siblings and realize you are not the only one and to not have to explain everything as people use the expression of they get it.

I wish you luck and you just need to start and enjoy.

Thank you.

>>: Thank you Barbara. Can people hear me?

Thank you so much for the presentation. We are going to move to questions and answers and we have to that were asked. The first comes from someone in Maine who has been trying to start in SLN chapter and has not had much success and they have been gathering contact information and a large and rural state and trying to close state groups and have been tossing out other suggestions and they are trying to do a webinar for siblings or focus on the siblings and the more urban area and expand after a chapter is established. It feels like they are chasing their tail with recruiting and getting people on board. They were asking for suggestions from the panel on ways is how they can get this going.

I think of the things that Barb has shared and without knowing all details of what is going on I like the idea of getting started as sometimes it is a small group and as you enjoy you have the small group and you enjoy it and it progresses and more people join in. If you have any other ideas I would be happy to connect after the webinar to learn more specifics about the situation and trying to provide any advice.

>>: I think that is a great question and points that this is a process and a can be a while to bring siblings together and so I really appreciate this person's persistence and commitment to try to keep working on it and we would love to connect more personally about some strategies that we can help with more specifically in your state. Feel free to reach out to us and I would be happy to come and do a webinar and come to your state and other ways and maybe see about sending a people to the national conference as well if that is possible.

>>: Thank you, a second question who is hitting at the issue related to recruiting people from different generations as we do siblings shops connecting with Hank siblings and we are struggling to really reach out and connect with other generations of siblings. We were wondering if you had any suggestions. Social media has it been so important for us to really expand our network in different states and nationally. This is tapping into that and tapping into the previous and current networks that we have in seen if there are siblings from your state that happened to be on said net also using different forms of gatherings even over the phone like in New York State we have been starting SIB chats. We know people are so busy and cannot get together and person and we have been having different topics where people can call in and listen to a topic and be able to get information and have a discussion about that. Thinking of different formats to reach out to those older siblings.

>>: One of the things that we did in Ohio is we try to present to conferences where we knew the service coordinators attended. May be people from agencies in order to get the word out about Ohio and the conference because we had something that we can bring them to. Also the website and the Facebook page just to connect and say please share this with your families as there are older siblings who are the caregivers and are taking care of their brothers and sisters. That was a population that we reached in that way.

>>: Thank you. Since it is just now 1:00 o'clock I went to handed over to Robin to wrap up the presentation and thank you so much Katie, Barbara and Amy for your thoughts today.

>>: Thank you everyone for participating with us today. Participants will receive an e‑mail with a couple of things in it in addition to the reporting and the slides from today's presentation. One is a survey and we would really appreciate your spending a few minutes giving feedback. The second is also a survey and you can see on the screen a fire for the family of individual needs for disability support survey and we are working with the RTC a community at Minnesota to try to broadly survey caregivers with intellectual disabilities and as our last speakers and many siblings fall into that category. If you can fill out the survey we would greatly appreciate it and were trying to get as broad and deep responses we can. If you are having parents or others who are caregivers or you are in touch with caregivers we greatly appreciate your sharing that. Thank you to our colleagues from the sibling leadership network for this very rich presentation and thank you for joining. Have a good rest of the afternoon.