Toward Equal Access: A Model for Lay Advocacy Programs
That Serve People who are Deaf or Hard of Hearing

By

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About the Author

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Melissa is not deaf or hard of hearing herself but works alongside this population to remove communication and attitudinal barriers. She is passionate about the program she oversees and has spoken at national and state conferences on a variety of topics including accessibility, empowerment, and equal opportunity for people who are deaf or hard of hearing.

Melissa earned a Bachelor of Arts in Sociology from the University of Mary Hardin-Baylor and an Associates of Applied Science in Sign Language Interpreting from Collin College. She also holds a professional certification as a BEI Advanced sign language interpreter. Melissa's interests include playing the piano, serving in her church and community, camping with her husband, Stanley, of 22 years, and spending time at the lake with family and friends. She can be reached at melissabell@twc.com.

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Abstract

This research focuses on lay advocacy programs housed in or contracted by state government agencies that specialize in serving persons who are deaf or hard of hearing. Efforts are needed to formalize and advance these programs to maximize their effectiveness. The purpose of this research is to compile components that comprise an ideal model for lay advocacy programs serving the target population. First, a preliminary model was developed using scholarly and practical literature that revealed five components: a defined scope, adequate funding and administrative support, qualified staff, engaging and collaborating with the community, and program evaluation. Next, advocacy program directors from state agencies around the country gave input via survey about the structure and makeup of their programs, followed by focused interviews to evaluate and refine the components of the model. The data gathered showed the model could be refined by the addition of subcomponents to identify the demographic within the target population to serve and determining the program's philosophies. A new component emerged: technology infrastructure. Entities can refer to this model when creating, administering, evaluating, or enhancing lay advocacy programs for persons who are deaf or hard of hearing. The study showed that almost every state with a dedicated state agency serving the target population provides advocacy-related services. A recommendation was made for these programs to form a network across the country for sharing information, resources, and tools to maximize existing resources. In addition, efforts must continue to formalize the profession, including establishing certification, ethical standards, and training programs for advocates.

Key words: advocacy, deaf and hard of hearing, state government, model program

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CHAPTER 1: INTRODUCTION

"Ears are not important. It's what's between them that counts," declared Fred Schreiber (as cited in Nomeland & Nomeland, 2012, p. 199), former Executive Director of the National Association of the Deaf. He would agree that the general population's reliance on, even obsession with, sound and spoken language hinders their ability to accept and respect those who use entirely different methods to communicate and obtain information.

A young man called my office, upset after leaving a restaurant where the manager told him, "You're deaf. You can't work here." The man had applied for a dishwasher position in the kitchen and went for an interview. When he arrived, the manager realized he did not hear and told him he would not be able to work there. As a lay (non-attorney) advocate for people who are deaf or hard of hearing, that kind of discrimination was all too familiar. I thought about my own supervisor who was deaf and had a law degree. If she could work as an attorney, I felt the man who applied to wash dishes for a living should be given a chance.

There is much work to do to level the playing field for people who are deaf or hard of hearing so they can have the same access and opportunities as everyone else. The 11.5 million people in the United States who reported having a "hearing difficulty" on the U.S. Census Bureau's American Community Survey in 2018 should be able to live free of discrimination. Many have made great strides to overcome barriers, such as the couple in Figure 1.1.

Figure 1.1. Vladimir and Inna Giterman are Deaf.
They not only wash dishes at Crepe Crazy in Austin, TX,
they own the restaurant.
Source: www.pec.coop/news/2018/crepe-crazy

United Nations Special Rapporteur on Minority Issues, Fernand de Varennes, issued a statement on the 2019 International Day of Signed Languages that said, in part, that countries "should undertake concrete legislative, institutional and policy measures to ensure [people who are deaf] are recognised as users of fully-fledged minority languages and that their rights as members of linguistic minorities are protected and promoted without discrimination…." ("States should recognise", 2019). Advocacy programs all over the globe exist to fulfill this mission and promote justice for people who are deaf and hard of hearing.

In this introduction, a case will be made for the need to develop a model for lay advocacy programs that serve people who are deaf or hard of hearing. Barriers exist to accessing basic information and communication that hinder opportunities that others who are not deaf or hard of hearing take for granted. Advocacy is a vital element to removing these barriers. For entities that provide lay advocacy services to this population, no set of best practices exists, and advocates have a wide range of knowledge and skills without standardized, recognized training programs available. The goal of this research is to contribute to efforts to formalize and advance lay advocacy programs serving people who are deaf or hard of hearing.

Defining Deaf or Hard of Hearing

The Hearing Loss Association of America explains that "typically, people who use residual hearing, amplification and/or hearing assistive technology and who do not use sign language as a primary mode of communication, consider themselves hard of hearing" (2020, para. 25). Deaf scholars Paddon and Humphries helped set the standard on identifying others in this population by using "the lowercase 'deaf' when referring to the audiological condition of not hearing, and the uppercase 'Deaf' when referring to a particular group of deaf people who share a language, American Sign Language (ASL), and a culture" (1988, p. 2). The term "hearing

impaired" is viewed as a negative, offensive term to many, as it labels people as inferior or as damaged goods (Bryan & Emery, 2014). Although persons who are d/Deaf or hard of hearing can be worlds apart in their identities and perceptions of their communication methods, they have one thing in common: the need for access to information and effective communication, which is often denied by the greater world around them.

Barriers and Discrimination

Discrimination is part of the everyday reality of a person who does not hear or who has limited hearing. A communication barrier exists because of the larger world in which they live that relies heavily on sound and spoken language to communicate. Technology, communication access services, and communication strategies are used regularly to overcome barriers. Hearing aids, cochlear implants, assistive technology with sound notifications, and smartphones apps are examples of technology used to aid in communication. Examples of communication access services include sign language interpreters and real-time captioning services. Communication strategies may involve lipreading, gesturing, and writing notes to exchange information.

Another type of barrier exists that has proven to be the most challenging: an attitudinal barrier. Hearing people have historically made determinations for the non-hearing population that prevent them from having equal access and equal opportunity in aspects of life ranging from employment to education to recreational activities. They may deny employment or workplace accommodations to persons who are hard of hearing who require alternate means of conducting business over the telephone. If hired, they may be informed they could not be promoted without adequate hearing ability. Deaf people have been told they are not fit to raise children because they do not hear. Some believe deaf people should not drive because they feel it is unsafe.

This mindset is called "audism," the "overt, covert, and aversive practices of discrimination" (Eckert & Rowley, 2013) among people who hear and feel themselves superior to those who do not hear. Audistic attitudes have a negative impact on the healthy social and emotional development, social integration, and academic and career success of this population (National Deaf Center, 2019). A statement made by a leader in the National Federation of the Blind also applies to persons who are deaf or hard of hearing: "We have come to understand… that society's low expectations are the true obstacle between us and our full potential" (Paré & Cazares, 2019, p. 572).

People who do not hear are marginalized in many areas of life (Mousley & Chaudoir, 2018) by the greater society that is largely oblivious to the needs of people who communicate differently. Their human and civil rights go ignored or are outright denied. These ongoing injustices create the demand for statutes to promote equality, entities to enforce the laws, and advocacy programs to educate hearing people on the rights of this population and the value they add to society.

Access to Communication and Information

Being able to effectively communicate with others leads to developing positive relationships, a strengthened identity, and overall well-being. It facilitates the development of complex linguistic and social skills and allows meaningful participation in education and workplace environments (National Deaf Center, 2020). Conversely, the opposite occurs when there are barriers to accessing information and when there is a lack of effective communication. Having full access to information can also result in greater independence for a person who is deaf or hard of hearing. Knowing when someone is at the door, being alerted to smoke in the building, and getting the latest information about a pandemic on the news are some examples of

information deaf or hard of hearing people need but sometimes lack because of discrimination that occurs when they are denied requests for aids and services needed to overcome barriers.

The collective efforts of people who are deaf or hard of hearing through the years have led to major breakthroughs toward equal access and equal opportunity in the areas of education, employment, access to healthcare and community services, and more (Barnartt & Scotch, 2001). One such success, a movement called Deaf President Now, which will be discussed in the next chapter, helped inspire the Americans with Disabilities Act of 1990. Entities are now required to provide reasonable accommodations for employees and auxiliary aids and services for the people they serve to ensure effective communication (Americans with Disabilities Act of 1990). Significant barriers remain, however, like those mentioned above, despite ongoing efforts to promote accessibility, equality, respect, and dignity (Pereira & Fortes, 2010; Punch, 2016; Tijsseling, 2015).

Advocacy Efforts

Addressing the communication access needs of this population is often accomplished on an individual level through self-advocacy, which centers around people who are deaf or hard of hearing expressing their needs for communication access and educating the world around them about their civil rights. In addition, people become active in advocacy initiatives through formal and informal approaches, such as working in disability rights organizations or volunteering in grassroots efforts, which are independent activities to promote equal access and equal opportunity in their communities, schools, and workplaces (Deaf Grassroots Movement, 2020). These concepts will be explored further in Chapter 2.

For the purpose of this research, advocacy is defined simply as speaking up for the rights of people who are being treated unfairly (Flynn, 2013). It is based on the values of equity, social

justice, and inclusion (Forbat & Atkinson, 2005), and the reason advocacy initiatives exist is to

"champion the rights of individuals or communities through direct intervention or through

empowerment" (Gibelman & Kraft, 1996, p. 45). Advocacy activities can be conducted in both

the community and through the legal system, "including informal or formal advocacy,

representative or self-advocacy, and systemic or individual advocacy" (Flynn, 2013, p. 492).

The ultimate goal is for this population to have the same access and opportunities

everyone else has. Ideal outcomes include families and healthcare providers identifying children

early to address their communication and language acquisition needs, entities providing sign

language interpreters and captioning services when needed, and employers hiring and promoting

qualified employees at the same rate as their hearing peers. In an ideal world, hearing people

would overcome audism and value persons who are deaf or hard of hearing as a natural part of

diversity.

Public and private entities across the country serve this population and provide advocacy

services, teaching people who are deaf and hard of hearing how to diplomatically request what

they need for effective communication. They inform people of their rights and responsibilities

under federal and state laws that prohibit discrimination. These advocates also consult with

businesses on how to become accessible, addressing concepts such as effective communication

strategies, cultural competence, workplace accommodations, and sign language interpreters and

captioning services (National Association of the Deaf, 2020).

Although advocacy efforts are central to achieving equal access and equal opportunity

(National Association of the Deaf, 2020), programs that provide these services tend to work in

isolation from each other and rarely network with similar programs for support and resource

sharing. They often operate independently and may be missing important elements to providing

high quality services. Despite decades-old federal legislation and an American culture becoming

increasingly more inclusive (U.S. Embassy, 2020), injustice is an ongoing occurrence this

population faces (Hamill, 2018). Advocacy will continue to be in demand on all levels, both

formal and informal, and both wide-scale and small-scale to protect the rights of people who are

deaf or hard of hearing.

The Need for an Advocacy Program Model

Research is scarce on the topic of ideal components for lay advocacy programs serving

people who are deaf or hard of hearing, and literature searches do not reveal a model for

effective services focusing on this population. Also, a best practices guide does not exist for

entities currently administering an advocacy program or would like to implement one. Gathering

this information and developing a model advocacy program could be foundational to a

government agency or other entity looking to begin a new program or enhance existing

services. It involves identifying best practices and compiling essential, ideal components of an

effective program.

Lay advocacy programs differ from other professional advocacy services in that lay

advocates are not attorneys. They are knowledgeable and skilled individuals who act as liaisons

between the target population and entities that serve, employ, and interact with them. Becoming

a lay advocate typically requires no formal training, education, or experience (Howey, 2019).

There is no agency regulates lay advocates or the programs that direct their activities at this time.

The closest formal lay advocates are a small group that work in K-12 special education, and most

scholarly literature on the topic of advocacy for persons who are deaf or hard of hearing centers

around K-12 education.

Examples of organizations that house advocacy programs include those administered by the National Association of the Deaf, Hearing Loss Association of America, the federally mandated and federally funded protection and advocacy systems, state agencies that serve people who are deaf and hard of hearing, non-profit organizations, and for-profit businesses that contract with government agencies. These programs have achieved great success toward equal access and equal opportunity in their communities and on the national and global scale. Their efforts encompass a variety of issues: correcting and preventing wrongful convictions among inmates who are deaf (HEARD, 2020), ensuring students have technology and supports they need in school (Disability Rights Texas, 2020), supporting text to 9-1-1 capability (Hearing Loss Association of America, 2020), developing a model hospital policy to ensure effective communication with people who are deaf or hard of hearing (National Association of the Deaf, 2020), and much more. Analyzing these programs as well as programs housed in state agencies to identify the components that make them effective could be highly beneficial to those who are newer to the field or who wish to evaluate their program's impact. Without this shared information, programs miss the opportunity to benefit from learning how others have optimized their programs.

Many people who are deaf are proud to identify themselves as members of the Deaf community (Maxwell-McCaw, Leigh, & Marcus, 2000). They consider themselves members of a linguistic and cultural minority (Lane, 2005), belonging to Deaf culture and making valuable contributions to society. Instead of "hearing loss," they emphasize "Deaf gain" (Bauman & Murray, 2014) and envision a world not where they will someday be cured of deafness but where society will accept them as equals, part of the larger, diverse global population. Advocacy plays a vital role in that journey, and those providing the services will need to continue honing their

practice. It is likely that lay advocacy will develop into an official profession with formal

training, agreed-upon minimum qualifications for advocates, a code of ethics, and a set of best

practices. Creating a model for lay advocacy programs is a step in that direction.

Research Purpose

The purpose of this research is to compile components that comprise an ideal model for

lay advocacy programs serving people who are deaf or hard of hearing. First, a preliminary

model or "practical ideal type framework" (Shields & Tajalli, 2006) was developed using

scholarly and practical literature. Next, advocacy program directors housed in state agencies

around the country gave input via survey about the structure and makeup of their programs. The

survey was followed by focused interviews with these directors to evaluate and refine the

components of the ideal model. Entities can refer to this model when creating, administering,

evaluating, or enhancing lay advocacy programs for persons who are deaf or hard of hearing.

CHAPTER 2: LITERATURE REVIEW

Components of an Effective Lay Advocacy Program

The purpose of this chapter is to present a summary of literature for five ideal categories that make up a healthy, well-rounded advocacy program that seeks to improve access and opportunities for the target population. Since a set of best practices does not yet exist for this type of program, administrators and program staff have had to rely on their experience and conventional wisdom to produce their outputs. The literature review synthesizes important research on the topic and justifies the categories of the practical ideal type framework (Shields & Rangarajan, 2013). Categories include a defined scope, adequate funding and administrative support, qualified staff, community engagement and collaboration, and program evaluation.
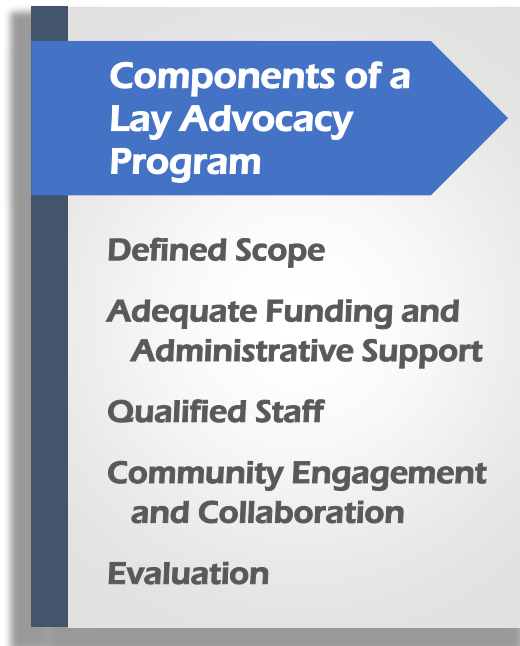
Components of a Lay Advocacy Program

Defined Scope

Adequate Funding and Administrative Support

Qualified Staff

Community Engagement and Collaboration

Evaluation

No matter the program's composition, its mission should be in line with the core values shared by persons who are deaf or hard of hearing. These include having effective communication, access, increased opportunities for education and employment, and social justice (National Deaf Center, 2017). Authors Gournaris, Hamerdinger, and Williams (2010) explain that there is no one-size-fits-all model for mental health programs serving people who are deaf. In the same way, there is no one, standardized approach for advocacy programs. They vary in scope, funding sources, values and philosophies, administrative support, and other factors (Kimberlin, 2010). As the remainder of this chapter discusses, programs must define who they

are and who they will serve, what they will do, and what methods they will employ to carry out

the work to fulfill their mission.

Component 1: Defined Scope

Edwin Osgood Grover said in 1909, "I am only one, but still I am one. I cannot do

everything, but still I can do something. I will not refuse to do something that I can do."

Defining the scope of the "something" lay advocacy programs

Defined Scope

can do is foundational for entities that provide the services.

Sometimes the program's funding or a state's statute

determines the advocacy focus. Other times the program is at liberty to determine their own

course of direction. Drawing boundaries to clarify the focus and type of advocacy to be provided

is imperative, since no advocate or program has expertise in all areas. Once defined, it is also

necessary to communicate the scope clearly and regularly with staff, clients, stakeholders, and

the public.

Donaldson's (2008) comprehensive article on the topic of developing an advocacy

program within a human services agency contains many concepts that also apply to lay advocacy

programs serving people who are deaf or hard of hearing. They may be housed in a non-profit

organization, government agency, or contracted entity. First, the agency's advocacy activities

should be "written into the mission statement, vision statement, and core values of the agency"

(p. 48). The author urges agencies to practice advocacy only in their areas of expertise, rather

than be pulled into a realm that is outside their scope of practice, and they should refer to other

entities when asked to be part of advocacy activities outside their level of competency.

1.1 Advocacy Focus

It is important for an entity to define and communicate the focus of its advocacy efforts. The scope may be somewhat broad, such as promoting equal access and equal opportunity for persons who are deaf or hard of hearing. Some programs may choose to concentrate their efforts on one or two areas, such as employment, access to healthcare, early intervention, language acquisition, affordable hearing aids, or other. To illustrate, the non-profit organization Hands and Voices houses the Advocacy, Support, and Training (ASTra) program that focuses on K-12 educational needs for families of children who are deaf or hard of hearing. Another non-profit organization, Helping Educate to Advance the Rights of the Deaf (HEARD), promotes equal access to the legal system. The National Association of the Deaf Law and Advocacy Center focuses on legislative and public policy issues and encourages its members to take action on a local level.

There are multiple types of advocacy services that can be provided. They range from promoting self-advocacy in individuals to lobbying on a state or national scale to persuade lawmakers to pass laws to protect the rights of people. Kimberlin (2010) cautions against narrowing the concept of advocacy only to lobbying and explains that advocacy can encompass a wide range of activities including public education, research on community needs, and monitoring policy implementation. She explains that the "targets" for advocacy can be broad, as well, and may include state legislatures, businesses, and the general public. Each advocacy program is unique, and the leadership, with input from the people it serves, can determine which type it will practice. Five common types of advocacy described in this chapter are self-advocacy, individual, systems, legislative, and grassroots advocacy.

1.2 Self-advocacy

Teaching self-advocacy skills to children who are deaf or hard of hearing is crucial for maximizing self-determination and self-sufficiency as they grow older. There are four components of self-advocacy that are emphasized for students, as Figure 2.1 points out: knowledge of self, knowledge of rights, communication skills, and leadership (Luckner & Becker, 2013). The Deaf Self-Advocacy Training (DSAT) curriculum teaches these skills and is "of, by, and

Figure 2.1. Poster promoting self-advocacy. Source: www.nationaldeafcenter.org

for" people who are deaf, a peer-led training (National Consortium of Interpreter Education Centers, 2012, para. 7). It contains modules on the topics of self-esteem and self-determination, the role of sign language interpreters and the Code of Professional Conduct they follow, how to control attitudes and behaviors, and how to utilize resources when needed. Lay advocacy programs may choose to focus all or some of their attention to the efforts of promoting self-advocacy skills to do as the Chinese proverb says: Teach people how to "fish" so they can "eat for a lifetime."

1.3 Individual Advocacy

Individual advocacy is a type of advocacy where a third party intervenes on behalf of person who is experiencing discrimination when trying to access employment, healthcare, legal services, social services, education, etc. (National Black Deaf Advocates, 2020). A scenario involving individual advocacy could begin with a person who is denied a sign language

interpreter when he or she requests the service to be able to communicate effectively with a business, a common experience among persons who are deaf. When that occurs, the deaf person can contact an advocacy organization in their community to intercede. The advocate may reach out to the business and reiterate the deaf person's request for an interpreter and offer information about the Americans with Disabilities Act or other applicable laws that may require the business to provide an interpreter for accessibility. Advocates are often trained on interpersonal skills and diplomacy to avoid damaging the relationship between the business and the individual who is deaf or hard of hearing. Since they tend to have some level of training and expertise in civil rights laws and navigating complex systems, they are often successful at convincing businesses to make their services accessible.

1.4 Systems Advocacy

Systems advocacy involves efforts to educate and influence entire systems to become more accessible to persons who are deaf or hard of hearing by implementing or changing policies and practices (National Black Deaf Advocates, 2020). For instance, a person who is hard of hearing may contact an advocate when having difficulty convincing his or her employer to add captions to safety training videos he or she is required to watch. The advocate may reach out to the employer's corporate office to discuss the matter with the human resources department and explain the employee's right to reasonable accommodations under federal and state laws. The advocate may suggest that the business come into compliance and create an accessible workplace by adding captions to *all* their videos so that employees who are deaf or hard of hearing in all their branch locations can have access, both now and in the future. This is a system-wide approach that can make a positive impact on a large number of people, generating long-lasting effects.

1.5 Legislative Advocacy

Some advocacy programs incorporate legislative efforts in their scope and are involved in

a variety of stages throughout the legislative process (Kimberlin, 2010). They engage in

lobbying activities by meeting with their state or national representatives to educate them about

the needs of persons who are deaf or hard of hearing and to asking them to sponsor bills that

protect the rights of this population. Lay advocates testify in public hearings and rally support

for their causes. Federal and state statutes are a highly effective tool used by advocates to

persuade entities to become accessible. Penalties for noncompliance with the laws are a

motivating factor, however some advocacy programs may be prohibited from lobbying,

especially if their funding comes from the government (Kimberlin, 2010; Donaldson, 2008). In

those cases, they may rely on their stakeholders to develop relationships with lawmakers to

influence them to pass laws.

1.6 Grassroots Advocacy

Lay advocacy programs may choose to participate in grassroots efforts. According to

Pimsler, et al. (2019), "'Grassroots' refers to a reliance on local-level collective action to induce

structural change at broader regional, state, or national levels. Grassroots advocacy is, in essence,

about capacity building – nurturing personal relationships with influencers in local governments,

institutions, or community organizations" (p. 79). This can be one of the most empowering,

confidence-building approaches to advocacy. People come together to work toward a common

goal, and the *group* leads the efforts, rather than the government or other system.

In 1988, a movement based in grassroots advocacy, Deaf President Now, took place at

Gallaudet University in Washington, DC, the world's only four-year, liberal arts university for

deaf students in the United States. In the 124-year history of the university, Gallaudet presidents

Figure 2.2. Students protesting Gallaudet University's new president, 1988. Source: www.deafsense.com

had all been hearing, not deaf. Students received national attention when they shut down the campus for eight days to non-violently protest the appointment of the next hearing president, which included a rally at the capitol, pictured in Figure 2.2. The protest ended with the appointment of I. King Jordan, the university's first deaf president (Gallaudet University, 2020). There have been three presidents at Gallaudet University since then, all deaf.

The students' grassroots advocacy became a turning point in the recognition of the equal status of people who are deaf (Higgins & Lieberman, 2016). Two years after the movement, the Americans with Disabilities Act passed, prohibiting discrimination against people with disabilities and people who are deaf or hard of hearing (Gallaudet University, 2020). The drive to ensure equality, representation, and access continues today in organizations like Deaf Grassroots Movement, whose mission is to "push... activists to engage in nonviolent direct action, including civil betterment, to end the jobs/education discrimination, to shatter the communication barrier and to provide equality for all" (Deaf Grassroots Movement, 2020).

These five types of advocacy are among the common approaches used by lay advocacy programs. They may use one or more of these in their scope of services, depending on their funding source, community needs, staff expertise, and leadership philosophy.

Component 2: Adequate Funding and Administrative Support

The second component of a healthy, well-rounded advocacy program that improves

access and opportunities for people who are deaf or hard of hearing centers around funding and

administrative support. Carrying out activities related to

advocacy would not be possible without adequate financing

and without management that places advocacy as a priority in

their organization. Advocacy programs may be housed in various types of entities, such as

government agencies and non-profit organizations, and funding sources may come from

government grants and contracts, donations, special events, and sales (Child & Gronberg, 2007).

One of the ideal characteristics for advocacy programs Donaldson identified is having "a

diversified funding portfolio to minimize dependence on one or two funders" (2008). In case

one funding source becomes unavailable, others are in place to continue supporting the work.

Obtaining and maintaining funding is a challenge for many organizations, however. Government

funding is often limited, grants from private foundations are typically small, and donations are

many times restrictive on how the funds are used (Kimberlin, 2010). Advocacy programs often

have no choice but to operate on a small budget and work within the confines of their financial

limitations.

Support, leadership, and vision from administrators is key to a successful advocacy

program (Donaldson, 2008; Gibelman & Kraft, 1996) because both financial and personnel

resources are being committed. Board of director members may participate in advocacy efforts

themselves to influence public policymakers (Saidel & Harlin, 1998). Additional research by

Suchy (2019) found advocacy efforts to be more successful when higher-ups were supportive.

She described one entity that demonstrated support by sending a member of the board for

Funding and Administrative Support

training to better understand the advocates' role, updating the association's bylaws to include

advocate committee functions, and even adding advocacy into the association's mission

statement. This is important for staff morale and sends a signal to donors or supporters that the

leadership is committed to success.

Component 3: Qualified Staff

The third component of an advocacy program centers around selecting and training the

staff hired to provide direct advocacy services to people who are deaf or hard of hearing. As

Qualified Staff mentioned in the introductory chapter, there is no set standard

for advocates related to the education and experience they

must possess to work in their field. There is no licensing

board for advocates, and formalized training to become an advocate for people who are deaf or

hard of hearing does not yet exist (Howey, 2019). As Heitin stated, "This means that there is no

agreed-upon standardized set of skills that would qualify one as an advocate" (2013, p. 45).

However, Heitin went on to explain that advocates can receive training and sometimes earn

certificates from professional groups or private professionals. They most often receive on-the-

job training and otherwise learn by trial and error. Research uncovered literature on some of the

desirable attributes and qualifications an advocate possesses and touched on hiring and

professional development aspects of employing advocates, discussed in the next section.

3.1 Attributes and Qualifications

Special Education Advocate members of the Council of Parent Attorneys and Advocates

(COPAA) follow a Voluntary Code of Ethics, which creates an expectation that advocates will

provide "competent assistance." These consist of having "knowledge, skill, thoroughness, and

preparation reasonably necessary for the assistance required under the circumstances" (Council

of Parent Attorneys and Advocates, 2020, para. 7). Having strong interpersonal skills is also an

attribute vital to successful advocacy outcomes. Literature searches revealed other desirable

attributes of lay advocates that serve a variety of target groups. These also apply to advocates

serving people who are deaf or hard of hearing:

- being respectful of personal autonomy of the people they serve, independent from the

  advocate's own vested interests, and mindful that advocacy services are to be directed

  and operated by the people they serve (Flynn, 2013);

- listening and helping people explore options, supporting them to obtain information so

  their decisions can be better informed (Barnes & Brandon, 2002); and

- being informed, convicted, articulate, courageous, and persistent…and therefore effective

  (Myers, 2019).

Regarding minimum qualifications for an advocate, the National Association of the Deaf

sets appropriately high standards for the Education Advocates they train. Advocates are deaf or

hard of hearing themselves, and most have a Master's degree in deaf education and experience in

teaching or working with students who are deaf and hard of hearing (Hlibok, 2019). Chapter 4

lists additional minimum qualifications state governments establish for advocates serving this

population based on surveys and focused interviews involving advocacy program directors from

around the country.

3.2 Hiring and Professional Development

Donaldson emphasized the importance of hiring staff to carry out the activities of the

advocacy program on a full-time basis. A line item in the entity's budget should be dedicated to

this to ensure advocacy efforts are given a high priority (2008). Assigning these duties to other

employees who already have a full workload or who may have little interest in advocacy is not

advised (Gibelman & Kraft, 1996). Advocacy activities may get lost in the flurry of other, pressing responsibilities the organization places on the employee.

Building capacity is necessary to improve the skills needed to conduct effective advocacy (Kimberlin, 2010), including participating in professional development to gain specialized knowledge and skill. This can be accomplished by attending conferences (Figure 2.3), trainings, team meetings, and supporting other advocates on a one-on-one basis or in groups (Forbat & Atkinson, 2005). The Special Education Advocates

Figure 2.3. National Association of the Deaf Conference attendees, 2018
Source: National Association of the Deaf Facebook

with COPAA mentioned above complete continuing education courses annually (Council of Parent Attorneys and Advocates, 2020). National Association of the Deaf Education Advocates attend online trainings and at least one in-person training each year. Topics may include updates on relevant legislation, provisions specific to deaf and hard of hearing children, ways to develop and apply negotiating skills, and more (Hlibok, 2019). Professional development through ongoing education from experts and support from peers is a key component providing high quality services that lead to successful outcomes.

Component 4: Community Engagement and Collaboration

The next ideal component of an effective lay advocacy programs is engaging the community and collaborating with other entities for maximum, effective results. Efforts such as

Community Engagement and Collaboration

maintaining an active social media and online presence or other avenues to inform the public of the program's activities

and successes can enhance the community's understanding of the issues the program addresses. This can lead to greater participation in donations and recruiting volunteer or other support (501 Commons, 2020). Donaldson recommends utilizing a communications officer to implement a strategy for communicating with the public and for developing relationships with the local media (2008).

Collaboration is the second part of this component. Building coalitions with like-minded entities and pooling resources of its staff or members can lead to powerful outcomes. In small communities where resources are scarce, one entity may have the *staff* with expertise to carry out an advocacy effort. Another may have the *technology* needed to create videos and advertise on social media. Another may have *funding* to contribute. Working together can lead to greater success than any one entity working alone. Collaborating is also a way to mentor a new program so it can learn from more experienced advocacy programs (Donaldson, 2008).

Component 5: Program Evaluation

The final essential component of a healthy, thriving lay advocacy program is evaluation. Collecting input from both internal and external sources is part of a sound performance management practice that can be useful for accountability and service improvement (Hestness, 2010). It aids entities in ensuring the program is accomplishing its mission and making the impacts it intends to make. At the same time, regular opportunities for review and reflection can inspire the program to celebrate its achievements as well as identify, acknowledge and learn from its mistakes.

Program Evaluation

Staff, stakeholders, clients, and the community can all provide feedback that provides justification needed to modify activities where needed, make plans for future work, grow in new

areas, and more (Wilson-Grau, 2018). Programs can gather data from surveys, town hall

meetings, and community advisory groups (Kinney, 2010) for a qualitative approach.

Quantitative performance measurement data can also be collected to track the number of clients

served, for example, which can also be useful tool in evaluating the advocacy program.

Conceptual Framework

The five categories discussed in this chapter contain ideal components that make up a

model lay advocacy program: a defined scope, adequate funding and administrative support,

qualified staff, community engagement and collaboration, and program evaluation. Table 2.1

summarizes the model or conceptual framework and ties it to the literature review conducted.

The main categories are then narrowed to incorporate specific components that leaders can

consider when creating, administering, evaluating, or enhancing advocacy programs that serve

persons who are deaf or hard of hearing. The next chapter describes the methodology used to

evaluate and refine these ideal components that make up a model lay advocacy program.

Table 2.1

Conceptual Framework

Title: Toward Equal Access: A Model for Lay Advocacy Programs That Serve People who are Deaf or Hard of Hearing **Purpose:** The purpose of this research is to compile components that comprise an ideal model for lay advocacy programs serving people who are deaf or hard of hearing. First, a preliminary model or "practical ideal type framework" (Shields & Tajalli, 2006) was developed using scholarly and practical literature. Next, advocacy program directors housed in state agencies around the country gave input via survey about the structure and makeup of their programs. The survey was followed by focused interviews with these directors to evaluate and refine the components of the ideal model. Entities can refer to this model when creating, administering, evaluating, or enhancing lay advocacy programs for persons who are deaf or hard of hearing.

Essential Components	Supporting Literature
1. Defined scope	
1.1 Advocacy focus	Kimberlin, 2010
1.2 Self-advocacy	Luckner & Becker, 2013; National Consortium of Interpreter Education Centers, 2012
1.3 Individual advocacy	National Black Deaf Advocates, 2020
1.4 Systems advocacy	National Black Deaf Advocates, 2020
1.5 Legislative advocacy	Kimberlin, 2010; Donaldson, 2008
1.6 Grassroots efforts	Pimsler, et al., 2019; Gallaudet University, 2020; Higgins & Lieberman, 2016, Deaf Grassroots Movement, 2020
2. Adequate funding and administrative support	
2.1 Sources of funding	Kimberlin, 2010; Donaldson, 2008, Child & Gronberg, 2007
2.2 Oversight	Suchy, 2019, Donaldson, 2008; Gibelman & Kraft, 1996; Saidel & Harlan, 1998
3. Qualified staff	
3.1 Attributes and qualifications	Howey, 2019; Heitin, 2013; Council on Parent Attorneys and Advocates, 2020; Flynn, 2013; Barnes & Brandon, 2002; Myers, 2019; Hlibok, 2019
3.2 Hiring and professional development	Donaldson, 2008; Gibelman & Kraft, 1996; Kimberlin, 2010; Forbat & Atkinson, 2005; Council on Parent Attorneys and Advocates, 2020; Hlibok, 2019
4. Community engagement and collaboration	
4.1 Sharing successes	501 Commons, 2020; Donaldson, 2008
4.2 Collaboration	Donaldson, 2008
5. Program evaluation	Hestness, 2010; Wilson-Grau, 2018; Kinney, 2010

CHAPTER 3: METHODOLOGY

This chapter describes the methodology used to refine components that make up the preliminary ideal model for lay advocacy programs serving people who are deaf or hard of hearing presented in Chapter 2. Components were derived from scholarly and practical literature and informed by the researcher's experience. The model was refined by collecting data and gaining insights from people who administer these types of programs across the country through survey and follow-up focused interviews. A final, suggested framework emerged based on the research. Included in this chapter is a table that operationalizes the conceptual framework, a description of the participants and methods for collecting data, strengths and weaknesses of the methods, and human subject protection information.

Research Participants

Participants in the research to aid in refining components of the preliminary model included directors of state agencies or managers of advocacy programs that are housed within or contracted by state agencies serving people who are deaf or hard of hearing across the United States. They were selected because they oversee the type of program this research aims to analyze and are highly familiar with the components of their programs. The National Association of State Agencies of the Deaf and Hard of Hearing lists 38 states with state government agencies in the United States dedicated to serving people who are deaf or hard of hearing (NASADHH, 2020). Through the research process, an additional state with a dedicated agency was revealed (Georgia). The entire population of 39 states was included in the research, illustrated in Figure 3.1. Some agencies are stand-alone agencies such as Commissions for the Deaf or Hard of Hearing while others are part of a larger state agency such as Health and Human Services or Vocational Rehabilitation Services.
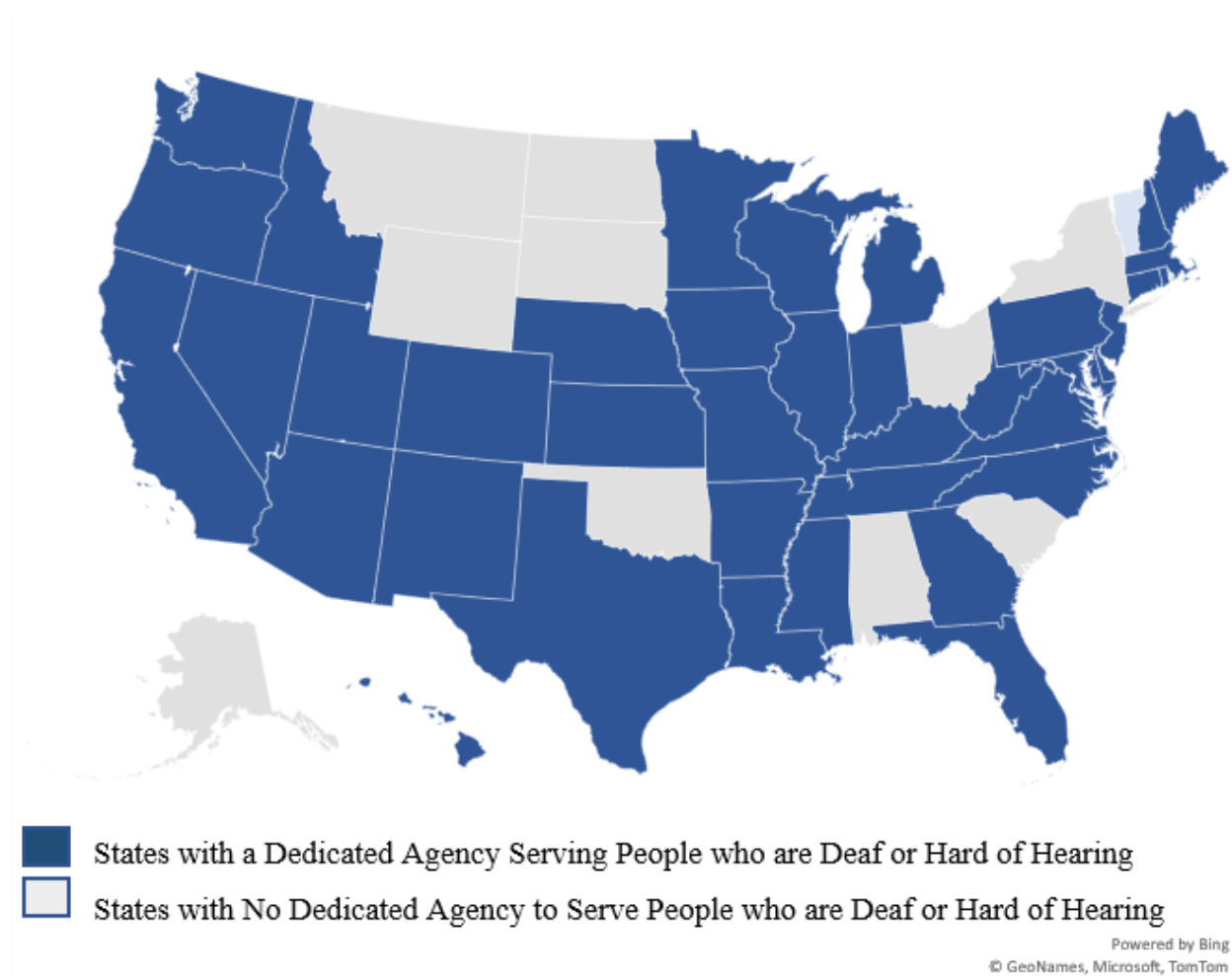
Figure 3.1. States with dedicated state government agencies serving people who are deaf or hard of hearing

Methods of Data Collection

Data collection methods included survey and follow-up focused interviews. Since surveys can be used to gather information as well as perceptions (Ballou, 2008), it was determined that it would be an appropriate research method. In the survey, respondents were asked specific questions about their experiences, opinions, and characteristics of the programs they oversee (Fowler, 2013).

The purpose of the survey was twofold. First, it identified which of the 39 states that have a dedicated state agency to serve people who are deaf or hard of hearing include advocacy in their array of services. Second, for the states that provide advocacy-related services, it

captured information about the structure and makeup of their programs. This data was useful for comparing the states and their programs to identify trends that would either validate or invalidate information initially compiled for the preliminary model.

According to Shields and Rangarajan (2013), survey research is one of the most common modes of data collection for descriptive information being collected. The survey utilized in this research has a descriptive, quantitative component when gathering basic information about advocacy programs housed in state agencies throughout the country. There is also a qualitative element to the survey when respondents are asked about challenges or barriers they face to incorporating the ideal components of an effective lay advocacy program. Johnson (2014) observed that qualitative approaches are often combined with quantitative research to describe and measure a particular phenomenon.

The survey contained various types of questions and utilized a combination of both open-ended and closed-ended questions. Those that were closed-ended resulted in standardized responses relatively simple to summarize. The open-ended questions allowed respondents to express their views more fully and provide insightful information (Johnson, 2014). Questions with a "yes or no" response narrowed down the group of states to those that provide advocacy-related services. A five-point Likert-type scale was used to elicit responses regarding the types of advocacy services they provide. Demographic information was also gathered to discover which states responded to the survey.

The second method of data collection was follow-up focused interviews. O'Rourke (2008, p. 386) describes this method as a "formal, standardized conversation between a person asking questions (the interviewer) and a person giving answers to those questions (the respondent)." She went on to explain that the respondents are selected because they belong to a

population of interest. The directors of the state agencies or managers of advocacy programs

who responded to the survey were the "population of interest" invited to participate in a follow-

up focused interview for this research.

The purpose of the interview was to gather more in-depth information and further

evaluate the preliminary model and its components. It contained questions to elicit additional

data about the programs they oversee that align with ideal components from the preliminary

model. Directors were also asked to consider whether they agree or disagree with the

components contained in the preliminary model and if there were others they felt were essential

for an effective lay advocacy program.

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Operationalizing the Conceptual Framework

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Table 3.1 shows how the conceptual framework introduced in Chapter 2 is

operationalized to collect data from state agencies about their advocacy programs and their

insights about ideal components of a program. Included are each of the five components from

the preliminary model and the corresponding questions asked in the survey and interviews.

Table 3.1

Operationalization Table

Essential Components	Method	Questions
Introduction	Survey	- What is the name of your state agency? - In which U.S. state are you located? - Does your agency provide advocacy-related services for people who are deaf or hard of hearing? Yes or No (Note: For the purpose of this research, advocacy is defined as speaking up for the rights of people who are being treated unfairly. Services may include teaching/promoting self-advocacy skills. Advocacy services may be

		provided by employees, volunteers, or contractors of your agency.) - If Yes, please indicate "Yes" and continue the survey. - If No, what are the primary reasons your agency does not provide advocacy-related services? Check all that apply: lack of funding, lack of interest/demand, lack of administrative support, lack of qualified advocates, other (please specify). - If No, where do you refer people who are deaf or hard of hearing in your state for advocacy services?
Demographics	Survey	Approximately how many people who are deaf or hard of hearing are served annually through your advocacy program? Please indicate if the number represents unique individuals or is duplicative where the same person may be served more than once in a year.
1. Defined scope	Follow-up focused interview	- Are your program's advocacy activities reflected in your agency's mission statement, vision statement, and core values? - What led your entity to choose the advocacy focus and types of advocacy it provides? - Do you feel it is important for advocacy programs to define and communicate the focus of their entity's advocacy efforts? Why or why not?
1.1 Advocacy focus	Survey	- In which settings does your advocacy program promote equal access and equal opportunity for people who are deaf or hard of hearing? Check all that apply: K-12 educational, post-secondary educational, employment, legal, medical, community, other (please specify). - In what other realms does the advocacy program provide services? Check all that apply: Social Security benefits advocacy, guardianship/mental competency advocacy, hearing aid legislation, other (please specify).

On a scale from 1-5, how much of your advocacy efforts is focused on each of these types of advocacy? 1 = none, 2 = very little, 3 = some focus, 4 = large majority, 5 = all		
1.2 Self-advocacy	Survey	**Self-advocacy**: teaching people to speak up for their own rights and needs
1.3 Individual advocacy	Survey	**Individual advocacy**: intervening on a person's behalf to address discriminatory actions against the person
1.4 Systems advocacy	Survey	**Systems advocacy**: working with large systems such as healthcare, education, legal, and other to improve access to persons who are deaf or hard of hearing
1.5 Legislative advocacy	Survey	**Legislative advocacy**: supporting the passage of new laws that protect the rights of people who are deaf or hard of hearing
1.6 Grassroots efforts	Survey	**Grassroots efforts**: a bottom-up approach to advocacy that may include rallying individuals from the community to approach lawmakers and leaders to address the needs of people who are deaf or hard of hearing
1.7 Policies and procedures	Follow-up focused interview	Does your program have policies and procedures that detail the focus and type of advocacy provided? If so, may I have a copy for my research?
2. Adequate funding and administrative support	Follow-up focused interview	Do you consider funding and administrative support to be key components of an advocacy program? Why or why not?
2.1 Sources of funding	Survey	Please enter the percentage of funding your agency receives for your advocacy program/services from the following funding sources: federal government, state government, grants, private donations, fundraising events, fees for services provided, other (please specify).
	Follow-up focused interview	Are there ideal sources of funding for advocacy programs?

2.2 Oversight	Survey	Briefly describe what kinds of meaningful support upper management provides to the advocacy program/services provided.
3. Qualified staff	Follow-up focused interview	Do you consider qualified staffing to be a key component of an advocacy program? Why or why not?
	Survey	- What is the staffing makeup of your advocacy program? Please indicate the number of persons for the following: full-time advocates, number of part-time advocates, administrative support, other (please specify). - Do the advocates perform other roles in your agency besides advocate? If so, what percent of their time is spent on advocacy activities?
3.1 Minimum competencies	Survey	- What are the minimum competencies for the advocates you hire? - If you are able to share a sample job description for your program's advocates? If so, please email to mbb110@txstate.edu.
3.2 Staff development	Survey	Do advocates receive ongoing training in their role? - If Yes, what training formats are used? Check all that apply: conferences, in-person seminars, webinars, team meetings, mentoring, other (please specify). - If No, what are the challenges or barriers to advocates receiving ongoing training?
4. Community engagement and collaboration	Follow-up focused interview	Do you consider community engagement to be a key component of an advocacy program? Why or why not?
	Survey	Does the advocacy program engage stakeholders and the public to inform them of your program's activities? - If Yes, what format(s) do you use to engage stakeholders and the public? Check all that apply: agency website, social media, other media (television, newspaper, radio, etc.),

		newsletter (mailed), electronic newsletter, vlogs, other (please specify). - If No, what challenges or barriers have you faced in engaging stakeholders and the public to inform them of your program's activities?
4.1 Sharing successes	Survey	Does your program communicate success stories with the public? - If Yes, what format(s) do you use to communicate success stories with the public? Check all that apply: agency website, social media, other media (television, newspaper, radio, etc.), newsletter (mailed), electronic newsletter, vlogs, other (please specify). - If No, what challenges or barriers have you faced in sharing success stories with the public?
4.2 Collaborations	Survey	Does your program collaborate with other organizations to pool resources, share information, host outreach events, etc.? - If Yes, please elaborate briefly on the advantages of collaborating with other organizations to pool resources, share information, host outreach events, etc. - If No, what challenges or barriers do you face in collaborating with other organizations?
5. Program evaluation	Follow-up focused interview	Do you consider program evaluation to be a key component of an advocacy program? Why or why not?
5.1 Client feedback	Survey	Do you gather feedback from **clients** to evaluate the effectiveness of your advocacy program? - If Yes, what format(s) do you use to gather feedback from clients? Check all that apply: surveys, town hall meetings, informal conversations, other (please specify). - If No, what challenges or barriers do you face in gathering feedback from clients?

5.2 Stakeholder/ community input	Survey	Do you gather feedback from **stakeholders** and the **community** to evaluate the effectiveness of your advocacy program? - If Yes, what format(s) do you use to gather feedback from clients? Check all that apply: surveys, town hall meetings, informal conversations, other (please specify). - If No, what challenges or barriers do you face in gathering feedback from stakeholders and the community?
5.3 In-house reflection	Survey	Do you gather feedback from **program staff** and **those providing direct services** to evaluate the effectiveness of your advocacy program? - If Yes, what format(s) do you use to gather feedback from program staff and those providing direct services? Check all that apply: staff meetings, surveys, informal conversations, other (please specify). - If No, what challenges or barriers do you face in gathering feedback from program staff and those providing direct services?
6. Other	Follow-up focused interview	- Besides the five components included in this survey (defined scope, funding and administrative support, qualified staff, community engagement, and program evaluation), are there others you feel make up an effective advocacy program? - What resources or tools does your program need to provide the most effective advocacy services to people who are deaf or hard of hearing?

Strengths and Weaknesses

As Johnson states, "All research approaches have strengths and limitations within the particular situation" (2014, p. 12). Both methods of collecting data used in this research proved to have both strengths and weaknesses. The survey was an opportunity to quickly and easily gather preliminary information to discover which states provide advocacy-related services to people who are deaf or hard of hearing. It allowed the researcher to identify which states to invite to participate in a follow-up focused interview. The survey was also an efficient tool to facilitate the collection of quantitative data useful for gaining an understanding of how advocacy programs around the country compare in terms of their components and structure.

Among the weaknesses of the survey method is the large amount of quantitative data collected. Although it shows how programs are made up, it does not indicate whether they are effective or not. This is a key element to the research. Also, surveys require a certain amount of time to complete, 15 minutes or less in this case. Because they are sent in an impersonal manner, email, recipients may not see completing it as a priority among their other pressing duties. There is little incentive to complete a survey, and there is no guarantee that state agencies will respond.

The other method of collecting data, the follow-up focused interview, had its own benefits. It provided an opportunity to build on the survey and collect more in-depth information about advocacy programs across the country. It also allowed the researcher to establish a rapport with respondents for a more personal approach so that they perhaps felt more comfortable providing their opinions about components that make up an ideal lay advocacy program. The qualitative data gathered brought balance to the statistics produced by the survey. This was useful in determining components that lead to an effective program.

The focused interview shares one of the same weaknesses as the survey: the time it takes to participate. Participants were informed that it would take approximately 30 minutes, which is more time than some could invest. The survey asked respondents if they would agree to participating in a follow-up interview. This potentially narrowed the group of respondents, and it was not guaranteed that all who completed the survey would agree to the interview.

Research Procedure

Gathering data for the research began with the survey containing questions found in Table 3.1. A link to the online survey in Qualtrics was distributed via email to the 39 directors of state agencies or departments within state agencies that provide dedicated services to persons who are deaf or hard of hearing. The researcher collected their email addresses from their agencies' websites. Participants were asked to complete the survey within two weeks, and a reminder was sent 7 days after the initial email to those who had not yet submitted the survey. After another 7 days, a reminder call was made to those who had not yet participated via telephone or videophone, which is videoconferencing technology for persons who are deaf and use sign language to communicate.

The last question of the survey asked participants if the researcher could contact them to ask additional questions, the follow-up focused interview. Those who agreed were asked to provide their name and contact information so the researcher could set up an appointment. Interviews were conducted via videophone or a videoconferencing platform in the preferred language of the respondent: either American Sign Language or spoken English. An email was sent to each interviewee afterwards to thank them for their time and contribution to the research.

Human Subjects Protection

To protect the rights of research participants, the research project was submitted to the Institutional Review Board (IRB) at Texas State University, IRB #7439. Their mission is "to protect the rights and welfare of human research subjects conducted or supported by Texas State University" (Texas State University, 2020). Some of the information the Board reviewed included the potential risks, how research participants would be recruited, and how the data would be collected. The project was approved prior to disseminating the survey and conducting interviews.

It was determined that the research poses no foreseeable risks. The Informed Consent document uploaded to the survey assured respondents that participation was voluntary and that any identifiable information would remain confidential. Raw data from survey responses and interviews will be stored on a Texas State University protected computer hard drive on the Texas State University server and will be destroyed three years after collection. Survey and interview results were reported in aggregate format so no personal information was disclosed about the respondents. Participants did not receive compensation for participating in the study.

Chapter Summary

The Methodology chapter described the research participants, survey and interview methods of collecting data, and the process used to collect data to refine components that make up the preliminary ideal model for lay advocacy programs serving people who are deaf or hard of hearing. The next chapter will compile the findings and describe additional input provided by research participants to modify the model. Once completed, entities will be able to use the model to create, administer, evaluate, and enhance advocacy programs, tailoring it to their unique needs.

CHAPTER 4: RESULTS

In this chapter, the results of the survey and follow-up focused interviews are reported, analyzed, and discussed. Figures and tables display the quantitative data compiled from the states that provide advocacy services for each of the five identified key components of an effective advocacy program. Comments are included to highlight the meaningful results, and summaries of the qualitative components of the survey and interviews give a broader perspective of the insights provided by respondents. The chapter concludes with an overall summary of the data collected in the research process.

The purpose of the survey was first to determine which states provide advocacy-related services of any kind to people who are deaf or hard of hearing. Among those that provide advocacy, the survey gathered information about the five key components the researcher identified from scholarly and practical literature and that was informed by the researcher's experience. The follow-up interview provided additional information about their programs' structure, their perspective about the preliminary model's five key components, and insight into any other components they believe make an effective advocacy program.

Eighteen (46%) of the 39 states with government agencies dedicated to serving people who are deaf or hard of hearing responded to the survey, and 10 (26%) participated in a follow-up interview, as detailed in Table 4.1. Two states (California and Tennessee) responded only on behalf of the portion of the state they serve because their entities (along with others in their states) are contracted by the state government and assigned a specific geographical area to cover.

Table 4.1

States that Participated in the Research

California	Colorado*	Delaware	Florida	Hawaii*	Iowa*
Kansas*	Maine*	Maryland*	Minnesota*	Mississippi	Nebraska*
New Mexico*	Rhode Island	Tennessee*	Texas	Virginia	Wisconsin

Note. Asterisks indicate states that participated in both the survey and follow-up interview.

States and Advocacy Programs

The first determination to be made through the research was which of the 39 states with dedicated state agencies serving persons who are deaf or hard of hearing offer some type of advocacy in their array of services, whether provided by employees, contractors, or volunteers. Out of the 18 states that participated in the survey, 15 (83%) indicated they do and three (17%) do not. The states that did not respond were reminded to participate two to three times via email and telephone/videophone call. After the allotted time passed, the researcher reviewed the websites for the remaining 21 agencies to ascertain if they offered advocacy services. Three of the websites did not mention advocacy, so the researcher contacted those agencies by telephone or videophone to inquire. The purpose was to gather complete information to ensure the data on the map in Figure 4.1 accurately reflects which states offer advocacy services to this population.
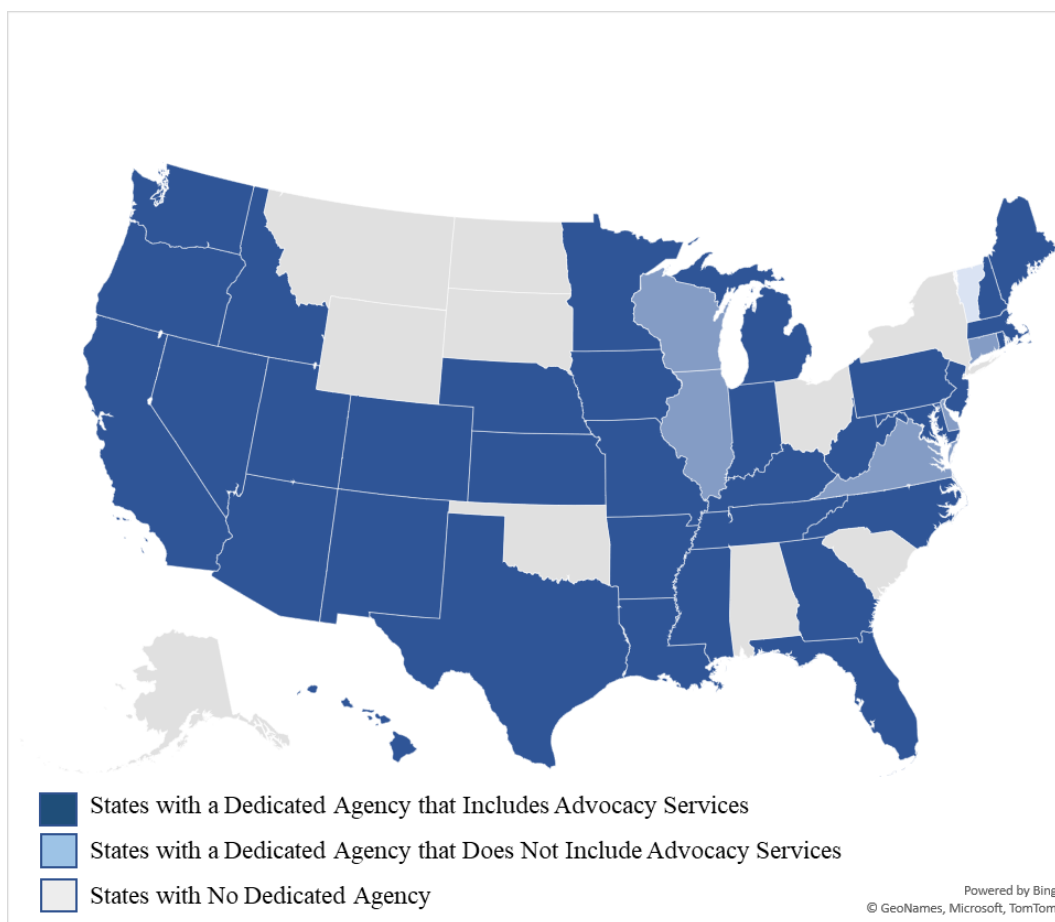
Figure 4.1. States that do or do not offer advocacy services for people who are
      deaf or hard of hearing

The compiled data for the 39 states that have dedicated government agencies serving

people who are deaf or hard of hearing revealed that 34 states (87%) provide advocacy-related

services and five (13%) do not: Connecticut, Delaware, Illinois, and Virginia, and Wisconsin.

Advocacy is not included in their array of services for a variety of reasons. One of the directors

explained in the survey, "As a state agency, we cannot 'advocate,' but we can provide

'individualized assistance' where deaf or hard of hearing constituents face access barriers to state

government services." Another stated that advocacy is not within their scope of work and that

they cannot provide that type of service. A third director explained that their agency has very

little legal authorization to advocate. Instead of advocacy, these agencies provide various other

services to persons who are deaf or hard of hearing to promote communication access and

independence. For advocacy needs that come to their attention, they stated that they refer people

to other entities to assist: federal or state agencies that enforce civil rights laws, non-profit

organizations that provide advocacy services, or their State Protection and Advocacy Agency, for

example.

The remainder of the results chapter focuses solely on the states that provide advocacy-

related services and that chose to participate in the research. Four of these states (27%) contract

with other entities to provide advocacy services: California, Maine, Tennessee, and Texas.

Maine uses an especially noteworthy model for their advocacy services. Their state government

contracts with Disability Rights Maine, the State Protection and Advocacy agency, which is

categorized as a formal (not lay) advocacy entity. This is unique from all other states that

participated in the research, which utilize lay advocates. As mentioned in Chapter 4, some states

that do not have advocacy programs at all refer to their state's Protection and Advocacy

agencies. In Maine, the advocates work under the supervision of attorneys and are required to

comply with the same code of ethics as the attorneys. Their agency of approximately 40 staff

serves the broader population of persons with disability but includes a Deaf Advocacy and

Communication Access program comprised of staff who are Deaf themselves.

<div align="center">**Number of Persons Served**</div>

The number of people served annually by state government agencies through their

advocacy programs varies widely, depending on what type of advocacy they provide, the size of

their state's population, the number of staff providing the service, and other factors. Among the

states that participated in the survey, the number of people served annually ranges from 200

unique individuals (Florida) to 5,000 (Minnesota) to 1.2 million (Maryland). Some states'

numbers are duplicative, meaning an individual who receives advocacy services may return for additional advocacy services in the same year and would be counted among the total number of people served. These figures range from 250 (Maine) to 5,200 (Texas) to 26,000 (California).

Advocacy in the Mission Statement

The article by Donaldson (2008) used throughout the literature review to piece together components of an effective advocacy program suggested that the agency's advocacy activities should be written into their mission and vision statements as well as core values. All 10 (100%) of the states interviewed incorporated advocacy into their mission and vision statements. The following are examples of mission statements from states that participated in the follow-up interview, gathered from their agency websites:

Kansas:	The mission of the Kansas Commission for the Deaf and Hard of Hearing (KCDHH) is to advocate for and facilitate equal access to quality, coordinated and comprehensive services that enhance the life of Kansans who are deaf and hard of hearing (Kansas Commission for the Deaf and Hard of Hearing, 2020).
Tennessee:	Our comprehensive programs seek to break the cycle of inequality and better the lives of individuals by bridging communication barriers, making connections, and educating the public (Tennessee Council for the Deaf, Deaf-Blind and Hard of Hearing, 2020).

Examples of vision statements:

Colorado:	We envision a barrier-free Colorado (Colorado Commission for the Deaf, Hard of Hearing, And Deafblind, 2020).
Maryland:	All Maryland citizens who are Deaf or hard of hearing will have equal and full access to resources, services, and opportunities for participation in all aspects of community life (Maryland Governor's Office of The Deaf and Hard of Hearing, 2020).

Key Component 1: Defined Scope

As indicated in Chapter 2, defining and communicating the scope of services provided is

foundational for an advocacy program. Both the focus and type(s) of advocacy must be

determined so staff, clients, stakeholders, and the public are aware and can set appropriate

expectations. Survey respondents indicated the focus of advocacy in their programs, compiled in

Tables 4.2 and 4.3.

Table 4.2

Advocacy Focus – Promoting Equal Access and Equal Opportunity

Settings	States	No. of States (N= 15)	Percentage of States
Educational, K-12	CA, CO, FL, HI, IA, KS, MD, ME, MN, MS, NE, NM, TN, TX	14	93
Educational, post-secondary	CA, FL, HI, IA, KS, MD, ME, MN, MS, NE, NM, TN, TX	13	87
Employment	CA, FL, HI, IA, KS, MD, ME, MN, MS, NE, NM, RI, TN, TX	14	93
Legal	CA, FL, HI, IA, KS, MD, ME, MN, MS, NE, NM, RI, TN, TX	14	93
Medical	CA, CO, FL, HI, IA, KS, MD, ME, MN, MS, NE, NM, RI, TN, TX	15	100
Community	CA, CO, FL, HI, IA, KS, MD, ME, MN, MS, NE, NM, RI, TN, TX	15	100
Other	HI, IA, KS, MD, ME, MS, NE, NM, TN	9	60

Nine states indicated they provide advocacy in additional settings to promote equal

access and equal opportunity. Five listed focusing advocacy efforts on government entities such

as state and local government agencies, police, correctional facilities/prisons, emergency

management, public meetings and press conferences, and the US Citizenship and Immigration

Services. Two states advocate in the area of communication-related services such as telephone

relay services and text-to-911. Other areas listed may be incorporated into the "medical"

category, such as first responders and mental/behavioral health while others may be part of the

"community" category, such as small business, housing, homeless and domestic violence

shelters, and non-profit organizations.

Table 4.3

Advocacy Focus – Other Realms

Settings	States	No. of States (N= 15)	Percentage of States
Social Security benefits advocacy	CA, KS, MN, NM	4	27
Guardianship/mental competency advocacy	CA, ME, MN, NM	4	27
Hearing aid legislation	CA, FL, HI, KS, MD, ME, NE, NM, RI	9	60
Other	CA, CO, HI, KS, ME, MS, TN	7	47

Note. Responses in the "Other" category included the regulation of sign language interpreters/ interpreter licensing, Early Hearing Detection & Intervention, Language Equality and Acquisition for Deaf Kids (LEAD-K) legislation, and any other legislative bill that directly impacts persons who are deaf or hard of hearing.

Advocacy Type

This research study focused on five types of advocacy that entities could provide:

promoting self-advocacy, individual advocacy, systems advocacy, legislative advocacy, and

grassroots advocacy. Those who responded to the survey indicated which type(s) their programs

provide and how much efforts are focused on them, ranging from "none" to "all." States that

have at least "some focus" are listed in Table 4.4. A result to note is that all 15 states (100%)

engage in promoting and teaching self-advocacy skills to persons who are deaf or hard of hearing

so they can gain skills to express their own needs and resolve conflict.

Table 4.4

Advocacy Types

Types	States	No. of States (N= 15)	Percentage of States
Self-advocacy	CA, CO, FL, HI, IA, KS, MD, ME, MN, MS, NE, NM, RI, TN, TX	15	100
Individual	CA, FL, HI, KS, ME, MN, MS, NE, NM, RI, TN, TX	12	80
Systems	CA, FL, HI, IA, KS, MD, ME, MN, MS, NE, NM, RI, TN, TX	14	93
Legislative	CA, FL, HI, IA, KS, MD, MS, NE, NM, RI	10	67
Grassroots	FL, HI, IA, KS, ME, MN, MS, NE, NM, RI	10	67

The researcher discovered through the surveys and interviews that while most states provide direct services to people who are deaf or hard of hearing for their individual needs, a few do not. Instead, their sole focus is on systems advocacy to ensure state agencies within their state government are fully accessible to this population. As one director explained, "We are a policy coordinating office advocating for better policies and programs." These state agencies may consult with sister agencies within their state on policies regarding the use of sign language interpreters, real-time captioning services, captioning online videos, etc. and promote services that are linguistically accessible and culturally appropriate for this population. When asked of all interviewees what led their state agencies to select the areas of focus and types of advocacy they or their contractors provide, there were two main answers: their governing statute requires a certain focus, or they respond to the citizens' demand for advocacy in the settings where the services are needed.

Nine out of 10 interview respondents (90%) agreed that defining and communicating the scope of an entity's advocacy efforts is a key component of an effective advocacy program. They provided a variety of supporting perspectives. From the public point of view, open and transparent government is imperative. From the client perspective, persons receiving services

know what to expect in regard to limits in the types of services provided so they don't see a lack

of services as a deliberate rejection. For programs with a very broad scope, communicating with

their clients would give them reassurance that they could contact the agency for their needs and

that the agency intends to meet their needs. From the agency staff point of view, defining the

scope allows them to focus on the outcome and keep the end in mind when providing services.

One director explained that defining the scope allows administrators to set benchmarks to assess

the progress the staff are making and determine future goals. The director who did not feel

strongly about setting a defined scope explained that the agency needs to be fluid in terms of

what assistance it provides as new issues emerge. He explained his agency does have

boundaries. If they are not able to assist, they refer to other entities for continuity of services.

Key Component 2: Adequate Funding and Administrative Support

Advocacy programs require an appropriate amount of funding as well as support from

upper management if they are to provide services that enhance the lives of persons who are deaf

or hard of hearing by promoting social justice and "levelling the playing field" for this

population. Survey results showed that state funds is the source of the vast majority of funding

for advocacy programs housed in state agencies. Table 4.5 displays the percentage of each type

of funding received for all states that participated in the survey combined.

Table 4.5

Funding Sources

Funding Source	Percentage
Federal government	1
State government	97
Grants	1
Private donations	0
Fundraising events	0
Fees for services provided	1
Other	0

Part of the research centered around ideal sources of funding. Although none of the

directors specifically named other sources of funding as more ideal than what they receive,

several stated the need for additional funds to expand their program because, as some stated,

funding creates capacity and provides the resources to meet the needs of the people they serve.

One director wished to add direct services by providing individual advocacy in addition to the

systems advocacy in their state. Another cited a severe disparity of services available to this

population because of a lack of adequate funding. One director stated their agency did not focus

as much on the amount of funding as much as how they used it, being creative and doing "more

with less."

All interview respondents (100%) agreed that adequate funding and administrative

support are key components of an effective advocacy program, and they provided insights

regarding the support their advocacy program receives from upper management. One explained

that administration must have the will to make advocacy a priority because having their support

turns into funding. Another explained that their advocacy efforts are successful because their

state's administration provides the authority they need. When providing systems advocacy to

other state agencies, agency leaders respond positively to the advocates because they are under

the authority of the state's leadership. One director asserted that having administrative support is

more important than having a large amount of funding because having the necessary support and

approvals in place allows the advocacy program to be able to meet the needs of the people it

serves.

Key Component 3: Qualified Staff

All advocacy program directors interviewed (100%) gave a resounding "yes" when asked

if having qualified staff was key to an effective advocacy program. One who has extensive

advocacy in his own background said, "Yes. But looking back, how do you get your start?" He acknowledged that he gained experience not through a training program or other formal means but rather through trial and error because his management allowed him the flexibility to try his own approaches in the early days of his career.

Most directors emphasized the critical importance of hiring advocates who are deaf or hard of hearing themselves. Some described the difficulty in accomplishing that because of the small pool of qualified applicants. Two directors mentioned the importance of advocates being from the local area or at least belonging to the same ethnic group as they serve. Otherwise, it is difficult for advocates to build rapport with clients. Several cited a certain minimum education level, such as an Associate's or Bachelor's degree, though some placed a higher value on knowledge, skills, and abilities, and some would accept experience in exchange for education.

Survey and interview respondents listed some of the specific minimum qualifications required of their advocates:

- deaf or hard of hearing or (in one state) a person who represents a demographic of the deaf or hard of hearing community: audiologist, agencies serving the deaf or hard of hearing community, parent of a child who is Deaf, etc.

- fluency in ASL or (in one state) willingness to learn sign language

- experience ranging from 2 to 5 years

- knowledge, skill, and ability in the area of advocacy including the Americans with Disabilities Act

- knowledge of state programs or other systems in which they are advocating

- strong personal self-advocacy skills

- excellent interpersonal communication skills

Table 4.6 shows the number of staff dedicated to advocacy or administrative duties among survey respondents. The states that have at least some of their staff dedicated to advocacy 100% of the time are labelled in the table as "full-time advocates." Those that perform other duties besides advocacy are listed as "part-time advocates." The survey revealed the percentage of time they spend on other duties ranges from 10% to 95%. In addition to advocates and administrative support, one state also uses volunteer advocates.

Table 4.6

Staffing Makeup

Staffing	States (Number of Staff)	Total
Full-time advocates	FL (1), HI (1), KS (1), MD (3), ME (3), MN (14), NM (4), TN (1), TX (11)	39
Part-time advocates	CA (10), IA (1), MD (1), MN (6), MS (1), NE (5), TN (6)	30
Administrative support	CA (3), CO (3), KS (1), ME (3), MN (2), MS (1), RI (2), TN (1)	16
Other	KS	-

Note: The survey indicated Kansas also uses an unspecified number of volunteers as advocates.

The literature reviewed showed that building capacity through professional development is vital to increasing an advocate's skill and knowledge. Table 4.7 reports the findings of which formats states across the country are using to train their advocates. Two states indicated the question was not applicable to them. One director explained their barrier or challenge to providing ongoing training: a lack of people knowledgeable in the field of advocacy for people who are deaf.

Table 4.7

Training Formats Utilized to Train Advocates

Training Formats	States	No. of States (N= 15)	Percentage of States
Conferences	CA, FL, HI, IA, MD, ME, MN, NE, NM, TN, TX	11	73
In-person seminars	CA, FL, IA, MD, ME, MN, NE, NM, TN, TX	10	67
Webinars	CA, FL, HI, IA, MD, ME, MN, NE, NM, TN, TX	11	73
Team meetings	CA, IA, KS, MD, ME, MN, NE, NM, TN, TX	10	67
Mentoring	CA, FL, KS, MD, ME, MN, NE, NM, TN, TX	10	67
Other	FL, KS	2	13

Note. Responses in the "other" category included "presenters at the Quarterly Council Meetings" and a Hard of Hearing Summit.

Key Component 4: Community Engagement and Collaboration

States with dedicated state government agencies serving people who are deaf or hard of hearing employ a variety of methods to engage their stakeholders and the public to inform them of their program's activities and successes. This is one of the key components of an effective advocacy program, according to the literature review. Tables 4.8 and 4.9 show the formats used.

Table 4.8

Formats Used to Engage Stakeholders and the Public

Format	States	No. of States (N= 15)	Percentage of States
Agency website	CA, CO, FL, HI, IA, MD, ME, MN, MS, NE, NM, RI, TN, TX	14	93
Social media	CA, CO, FL, HI, IA, KS, MD, ME, MN, NE, RI, TN	12	80
Other media (television, newspaper, radio, etc.)	MD, MS, NE, RI, TN	5	33
Newsletter (mailed)	FL, KS, NE, RI, TN	5	33
Electronic newsletter	CA, CO, FL, MD, ME, MN, NE, RI, TN	9	60
Vlogs	CA, CO, HI, IA, MD, MN, NE, NM, RI, TN	10	67
Other	CA, FL, HI, KS, ME, MN, MS, NE, NM, TX	10	67

Note. Responses in the "Other" category included townhall meetings, public meetings and events, written agency reports, mass emails, advisory committee, and marketing materials.

Table 4.9

Formats Used to Inform the Public of Success Stories

Format	States	No. of States (N= 15)	Percentage of States
Agency website	CA, CO, FL, HI, IA, MD, ME, MN, NE, NM, RI	11	73
Social media	CA, CO, FL, HI, IA, MD, ME, MN, NE, RI	10	67
Other media (television, newspaper, radio, etc.)	CA, FL, HI, MD, ME, MS, NE, RI, TN	9	60
Newsletter (mailed)	NE, RI	2	13
Electronic newsletter	CA, CO, FL, MD, MN, NE, RI, TX	8	53
Vlogs	CA, CO, HI, MD, MN, NE, RI	7	47
Other	CA, HI, IA, MN, MS, NM, TN	7	47

The other methods used to communicate success stories to the public are similar to the other methods for engaging stakeholders and the public, listed after Table 4.8. One director explained that they do not communicate success stories because of privacy and confidentiality

concerns. However, they stated that they communicated some success stories at their Commissioners meeting, which is open for the public to attend.

All states that have an advocacy program serving people who are deaf or hard of hearing (100%) reported collaborating with other entities to pool resources, share information, host outreach events, etc. One director noted that because there are not enough support services available to this population, it is critical for entities to share resources with each other. Another explained that their office contributes their expertise in serving this population when collaborating with entities on efforts to serve a larger population, such as people with disabilities. Directors elaborated on other advantages of collaborating, which included:

- leveraging and maximizing each other's services, decreasing duplication, being more efficient with collective resources

- reaching more consumers, developing capacity of other providers

- helping to offset costs of marketing at community events

- networking and helping grow the next group of advocates

All directors that participated in a follow-up interview (100%) agreed that community engagement and collaboration are key to a healthy, effective advocacy program. One noted a missed opportunity in his state because of the lack of collaboration between state agencies and non-profit organizations. Additional comments respondents made regarding reaching out to stakeholders and the public regarding their activities and successes as well as collaborating with others included:

- More visibility in the community leads to the state agency being held more accountable.

- Engagement brings community buy-in. Building rapport with the Deaf community is crucial so they feel comfortable reaching out to the agency for assistance.

- Collaborating with entities not familiar with serving people who are deaf or hard of hearing helps develop relationships so they can learn the importance of breaking down communication barriers by addressing attitudinal barriers and their lack of knowledge in that area.

- Good, *not competitive,* collaboration with stakeholders, such as the state's association of the deaf, is healthy.

- Collaboration brings multiple perspectives represents the entire spectrum of experiences.

- Collaboration leads to returns by trading referrals to each other's programs, which improves outcomes for the population it serves.

Key Component 5: Program Evaluation

The literature review revealed that gathering input from internal and external sources to evaluate a program's effectiveness is part of sound performance management practices. All survey respondents (100%) use some type of method to collect feedback from at least one of three categories: clients who receive services, stakeholders and the public, and the staff that provide advocacy services directly. Table 4.10 highlights the formats used to gather client feedback from by states that responded to the survey. Table 4.11 shows which formats are used to collect feedback from stakeholders and the public. Finally, Table 4.12 highlights formats used to collect input from staff and those providing direct services when evaluating the advocacy program's effectiveness.

Table 4.10

Formats Utilized to Gather Feedback from Clients

Format	States	No. of States (N= 15)	Percentage of States
Surveys	CA, CO, FL, ME, MN, NE, RI, TN, TX	9	60
Town hall meetings	CA, CO, HI, IA, KS, MD, MN, NE, RI, TX	10	67
Informal conversations	CA, CO, FL, IA, KS, ME, MN, MS, NE, NM, RI, TN, TX	13	87
Other	HI, IA, MN, MS	4	27

Note. Responses in the "Other" category included regular formal public meetings, input from clients communicated via council or advisory groups and commissioners, and one state's email address dedicated to client feedback and messages.

Table 4.11

Formats Utilized to Gather Feedback from Stakeholders and the Public

Format	States	No. of States (N= 15)	Percentage of States
Surveys	CA, CO, FL, KS, NE, RI	6	40
Town hall meetings	CA, CO, HI, IA, KS, MD, MS, NE, RI, TX	10	67
Informal conversations	CA, CO, FL, IA, KS, MD, MS, NE, NM, RI, TX	11	73
Other	FL, HI, IA, ME, MS	5	33

Additional formats states use to gather feedback from stakeholders and the public are similar to those used with clients, listed after Table 4.10. One director explained they do not gather feedback from stakeholders and the community because they prefer to keep their focus on clients, a human-services approach, since stakeholders may have competing or conflicting needs.

Table 4.12

Formats Utilized to Gather Feedback from Staff/Service Providers

Format	States	No. of States (N= 15)	Percentage of States
Staff meetings	CA, FL, HI, IA, MD, ME, MN, MS, NE, NM, RI	11	73
Surveys	KS, NE, RI	3	20
Informal conversations	CA, HI, IA, KS, MD, ME, MN, MS, NE, NM, RI, TX	12	80
Other	MN, TX	2	13

Note. Responses in the "Other" category included one-on-one meetings and meetings with both contract supervisors and specialists providing direct services.

All interview participants (100%) stated they consider program evaluation to be a key component of an advocacy program. They shared their insights, summarized here:

- Metrics and measures are not very effective because they are all numbers. Accountability comes with community feedback via townhall meetings and one-on-one meetings.

- The Deaf community is small and tight knit. They will give honest feedback whether it is elicited or not.

- Staff reviewing cases together can ensure quality services are provided and be a means to determine how to improve services.

Other Components

To fulfil the purpose of this research and refine ideal components that make up a model lay advocacy program, interview participants were asked if there were other key components they would add besides the five discussed thus far. They were also asked what resources or tools their programs need to provide the most effective advocacy services to people who are deaf or hard of hearing. While some items mentioned may fit under one of the components already

established, the insights based on the experience of the persons interviewed is worth noting. Key

components of an effective advocacy program they shared include:

- hiring staff members who are Deaf themselves, including people making decisions for the

  program (qualified staff)

- serving the entire demographic and not assuming the program serves only people who are

  Deaf (defined scope)

- building trust with the population served and getting to know them so they can address

  their needs appropriately (community engagement)

- non-attorney advocates following the same ethical standards as attorneys, including

  advocating for the client's expressed wishes, not their best interest (defined scope)

- utilizing the Deaf Self-Advocacy Training curriculum (mentioned in Chapter 2) in

  schools and in the community (defined scope)

- having the right leadership. According to one director, "Good people, good processes,

  and good decision-making will lead to good outcomes." (administrative support)

- developing specialization within advocacy in the areas of domestic violence, mental

  health, and more (defined scope)

- investing in technology infrastructure that would allow staff to shift easily between

  working in the office, remotely, or in the field (new component)

- having a good sense of humor. Advocacy work is difficult, and it sometimes takes time

  to see results, especially with systems advocacy. As one director stated, "People don't

  call because they're having a great day. They're calling because there's an issue." It is

  important to have a balance and celebrate successes to avoid staff becoming discouraged,

  losing their passion, and becoming ineffective.

Chapter Summary

Results of the survey and follow-up focused interviews show that almost every state with a dedicated state agency serving people who are deaf or hard of hearing provides advocacy-related services, and they make it known prominently in their agencies' mission and vision statements. The data collected paints a picture of the structure and makeup of their programs. Directors or managers of advocacy programs interviewed agreed that the five components identified in the preliminary model are key to an effective program. Several reiterated or gave input on additional components. The implications of these results will be discussed in the Conclusion chapter.

CHAPTER 5: CONCLUSION

In this study, a preliminary model for a lay advocacy program was compiled, then refined by input from states that either house advocacy programs in their government agencies or contract with other entities that provide services to people who are deaf or hard of hearing. This chapter discusses the implications of the survey and follow-up interview findings and is organized into sections for research contributions, important findings, recommendations, study limitations, and suggestions for future research.

Contributions to Research

The goal of this research is to contribute to efforts to formalize and advance lay advocacy programs serving people who are deaf or hard of hearing. Advocacy is a vital element to removing barriers for this population, so it must be effective if it is to influence positive change so that this population enjoys the same access and opportunities everyone else has. The researcher set out to determine what components make up existing advocacy programs based in state governments around the countries so other states could compare and learn from each other.

The components identified in the preliminary model for a lay advocacy program along with other components that program directors contributed are not unique to lay advocacy programs serving people who are deaf or hard of hearing. All government and non-profit programs must define their scope, have adequate funding and administrative support, hire qualified staff, engage and collaborate with the community, and evaluate their program for effectiveness. The key is to modify these components to fit this highly specialized service and to implement them in a way that maximizes the impact of the program.

State agencies and other entities can benefit from the research by referring to the refined model when creating, administering, evaluating, or enhancing lay advocacy programs for persons

who are deaf or hard of hearing. Administrators who oversee programs that currently exist can

review the model's components to identify areas of strength and areas that could benefit from

improvement. They can observe how their program's structure and makeup compares to other

states. For any state or entity that is considering developing a new advocacy program serving

this population, the information presented in the research introduces them to approaches other

states are using, which could be useful in creating their own. The model is broad enough that

entities can tailor it to fit their program's parameters.

Key Findings

As the survey data was submitted and compiled, patterns began to emerge to show which

methods and approaches states use to administer their lay advocacy programs. The early

literature review process uncovered numerous recommendations for advocacy programs. The

key findings center around how the components that make up lay advocacy programs around the

country align or do not align with the components in the preliminary model.

The survey results showed that states that participated in the survey reflect several of the

literature's recommendations in their programs: incorporating advocacy in their mission and

vision statements, defining and communicating their scope of services (or intentionally not doing

so to remain flexible), having the support, leadership, and vision they need from the

administrators in their agency, providing professional development to build the advocates'

knowledge, skills, and abilities, and engaging the community and collaborating with other

entities.

Though the literature surrounding well-rounded advocacy programs suggests having a

diversified funding portfolio, the survey data revealed this is not the case for any of the states

that participated in the research. Almost 100% of their funding comes from state government.

This is likely beyond the program's control due to the way their state government is established. The literature may have intended that recommendation more for non-profit organizations than government agencies.

Another recommendation from the literature is to hire staff dedicated 100% to advocacy activities. This helps ensure advocacy remains a high priority for the agency and does not become an afterthought that may suffer due to other pressing agency needs. The survey findings show there are more advocates that provide advocacy on a full-time basis than not (57%), but a large number of advocates (43%) are assigned other roles in their organizations and perform the advocacy function only as a part of their duties.

All states that participated in the survey reported engaging in performance management activities surrounding program evaluation, which comes highly recommended in the literature. The key finding is regarding the primary method of collecting input about their programs: informal conversations. This method is used in 87% of states when gathering feedback from clients, followed by town hall meetings utilized by 67% of states. When gathering input from stakeholders and the public, 73% of states rely on informal conversations, followed by 67% that host town hall meetings. Informal conversations are used in 80% of participating states to collect input about the program from staff and those providing direct advocacy services. Other methods of collecting input, such as surveys, public meetings, staff meetings, and others are utilized at a much lower rate.

Refining the Model

The preliminary model was comprised of five key components: a defined scope, adequate funding and administrative support, qualified staff, community engagement and collaboration, and program evaluation. Directors of advocacy programs confirmed these are key

components. Ninety percent of directors agreed that defining the scope was a key component, and 100% of directors agreed that the other four components were key to an effective advocacy program.

Additional components and subcomponents emerged as the researcher dialogued with directors around the country. The first key component in the preliminary model, defined scope, encompasses the program's focus (whether on communication access, education, legislation, or other) and the type of advocacy provided (individual advocacy, systems advocacy, or other). As a result of the research, two additional subcomponents were added. One relates to the demographic to be served within the population of people who are deaf or hard of hearing. Will the program primarily serve people who are Deaf and use American Sign Language (ASL) to communicate? Will they focus primarily on students and youth? Will they promote their services to the entire deaf and hard of hearing population? This must be determined and communicated.

The other subcomponent to be added to scope relates to defining the program's philosophies. The advocacy program must establish and communicate how they approach advocacy, such as whether they will take a more reactive role in confronting entities after discrimination has occurred or a more proactive role by reaching out to entities to promote policies and bring awareness of the needs of this population. Programs may either emphasize empowering clients they serve to advocate for themselves or take on that activity on behalf of the client. They may prefer to assist clients in filing complaints against entities that discriminate, or they may choose an educational role to solve problems and implement change. As Maine's philosophy dictates, some may advocate solely for the client's expressed wishes where others may advocate for what they feel is in the client's best interests.

A new component to be added to the model based on conversations with advocacy program directors is technology infrastructure. Agencies investing in devices necessary for advocates to move easily between their office, working from home, and meeting clients in the community is crucial to providing highly effective services. They may require smartphones, laptops, videophones, webcams, a Virtual Private Network (VPN), or other technology to carry out their job functions.

Recommendations

Through the course of collecting data from both the survey and follow-up interviews, insight into the trends and common approaches used by lay advocacy programs around the country were revealed. This led to recommendations for both existing advocacy programs and entities that wish to create an advocacy program serving people who are deaf or hard of hearing. They center around three approaches: maximizing existing resources, building capacity, and formalizing lay advocacy programs.

Maximize Existing Resources

Programs that maximize their existing resources generate greater outcomes for the people they serve. The following are recommendations on how they can enhance their services utilizing currently available resources:

- Advocates should network with other advocates. The number of advocates in state agencies or their contractors that serve people who are deaf or hard of hearing is small, and resources are sometimes scarce. Also, the researcher found that all but one state of those that participated in the research (Maine) utilize lay advocates. This means that those who provide the services likely do not have formal training and certification. Connecting states with each other across the country to network for support, resource

sharing, and information exchange could lead to significantly greater outcomes for the people they serve.

- Advocates can utilize the formalized and nationally recognized Deaf Self-Advocacy Training (DSAT) curriculum. Promoting self-advocacy is the most prominent type of advocacy utilized, according to the survey results. The curriculum is available at no cost through the National Association of the Deaf website (www.nad.org).

- Efforts can continue to implement formal performance management strategies to gather quantitative and qualitative data and inform the program of its effectiveness. The survey showed that informal conversations is the most-utilized evaluation method to gather input about a state's advocacy program. This implies that there is room for more formal processes to be put in place for all the reasons listed in Chapter 2: accountability, celebrating successes, and improving services, which includes identifying, acknowledging, and learning from mistakes.

- Agencies can maximize the use of their website and social media platforms. Survey results showed that an agency's website is the tool most often used to engage their stakeholders and the public, followed by social media. Agencies can ensure that information on the website is up-to-date and simple to navigate. New, relevant content can be developed, such as videos in ASL with captioning. This is a way for the agency to be more fully accessible and to deliver information directly in the users' native language.

Build Capacity

In addition to maximizing existing resources, opportunities to build capacity and develop new approaches emerged through the research to enhance advocacy services:

- Advocacy can be made a core program within the agency, rather than a secondary service provided. The activities would need to be reflected in the agency's mission & vision statements and core values. Agencies that employ or contract with advocates who carry out additional duties would need to strive to make some of them full-time advocates. As explained in Chapter 1, advocacy plays a vital role in achieving equal access and equal opportunity for this population, and the demand for these services is great.

- States may consider contracting with a formal advocacy organization rather than utilizing lay advocates. Chapter 4 described how the State of Maine contracts with their state's Protection and Advocacy agency, Disability Rights Maine, which has a Deaf Services unit staffed by attorneys and advocates who are Deaf. Services are linguistically accessible and culturally competent. There is potential for a great advantage to this model because advocates are supervised by attorneys and potentially have formal training and expertise. They are also held to ethical standards, unlike lay advocates, which brings more accountability.

Formalize Lay Advocacy Programs

As established in Chapter 1, working as a lay advocate does not typically require formal training, education or experience in the field, and there is no entity yet that regulates lay advocates. This potentially creates a substantial gap in services to the target population and points to a great opportunity for the work of lay advocates to become a formal profession. The recommendation is for a national organization, such as National Association of the Deaf or Hearing Loss Association of America, to develop and oversee a lay advocacy certification program to ensure lay advocates are proficient in their knowledge, skills, and ability to carry out

their function. States could then require certification as a minimum job qualification. Some of the components of the program could include:

- developing standards for the field of lay advocates serving people who are deaf or hard of hearing

- designing a nationally recognized curriculum to specifically train lay advocates that serve people who are deaf and hard of hearing. Teaching self-advocacy skills could be at its core and could include optional specializations for individual, systems, legislative, and grassroots advocacy.

- providing a formal certification that requires prospective lay advocates to pass a knowledge proficiency test and earn continuing education hours to maintain their certification. Ongoing education could focus on topics such as legal updates, interpersonal skills, and ethics. Other requirements may be put in place to be eligible for certification, such as a minimum education level.

- developing ethical standards for lay advocates and investigating complaints against them

- developing best practices for lay advocacy programs to address the scope of the program, administrative support needed, engaging clients, stakeholders, and the public, and implementing sound performance management practices

Limitations

The information gathered from the 18 states that participated in the survey and the 10 states that participated in the follow-up interview was valuable to gain an understanding of how their advocacy programs are structured. The research did not contain data from all 39 states with advocacy programs, however, so comprehensive data was not presented. Other states may have other perspectives to contribute to a model lay advocacy program. Also, existing research on lay

advocacy programs serving persons who are deaf or hard of hearing is scarce. Scholarly articles

on the exact topic to review and form the initial model were not found, so the researcher sought

out literature from the broader field of advocacy and drew from her own experience working as

an advocate and overseeing an advocacy program in a state government agency. Limited

existing research on the subject means having only a narrow perspective to present.

Suggestions for Future Research

Further study is recommended to continue refining components of an effective advocacy

program housed in or contracted by state government agencies around the country. Information

could be compiled for the 21 states that did not participate in the research to complete the data

set for all 39 states with dedicated state agencies serving people who are deaf or hard of hearing.

For the remaining 11 states that do not have a dedicated state agency serving this population, a

study could be conducted to identify any organizations that provide specialized advocacy

services to analyze their structure and make-up and add to the larger data set.

To maximize the efficacy of existing advocacy programs, more research could be

conducted on the topic of lay advocacy programs to determine what outcomes make them

effective and how they define "success." Both quantitative and qualitative performance

standards could be developed so both government agencies and non-government organizations

could establish appropriate performance measures as part of sound performance management

practices. One state (Minnesota) mentioned using the Results-Based Accountability framework,

which is something other states may be interested in exploring.

Another suggestion for future research to maximize existing resources involves

identifying states that have expertise in a variety of areas: systems advocacy, mental health

advocacy, educational advocacy, etc. If those states were willing to take the lead in their highly

specialized field and provide support to others, advocates in other states could benefit by learning from them to better serve persons who are deaf or hard of hearing in their own states. Advocates from each state would need to be networked together to communicate and share their knowledge.

Since one of the recommendations from the previous section is for states with advocacy programs to consider contracting with a formal advocacy organization rather than utilizing lay advocates, further research is necessary to study this approach. The benefits and limitations would need to be examined and weighed to determine if this could be in the best interests of the target population, and state governments would need to determine if contracting services with these types of organizations would be feasible for them.

The final suggestion for further research is centered around the goal of formalizing the advocacy profession. For an organization, such as the National Association of the Deaf or the Hearing Loss Association of America, to create a lay advocacy training program and offer certification, information would need to be gathered on the process of establishing standards for a formal profession, developing a training program, and creating a national certification and accompanying ethical standards. Organizations that are certifying bodies may not typically also take on the role of offering a training program. If that is the case, research would need to be conducted to identify suitable entities for each. The formal advocacy profession serving this population could be modeled after advocacy groups that focus on other populations or causes that have already advanced. In addition, there may be other countries with a formalized advocacy profession where information could be gleaned.

Conclusion

The stakes are high for people who are deaf or hard of hearing when it comes to having access to information and communicating effectively in a society comprised mostly of hearing, speaking people. It means the difference between being employed or unemployed, receiving the same level of education as their classmates or not being on par with their peers, and having the opportunity to give informed consent to healthcare treatment or not. It means being viewed by the greater society as respected, equal members or feeling like second-class citizens.

This population of individuals values effective communication, access to information, increased opportunities for education and employment, and social justice (National Deaf Center, 2017), yet they are often denied the accommodations needed to achieve equal access and equal opportunity. As long as discrimination and oppression exist that force people who are deaf or hard of hearing to face ongoing injustices, there will be a need for advocacy and efforts to promote equality and inclusion. It is crucial to perform the work with excellence, always striving to improve. As previously quoted by Edwin Osgood Grover (1909), "I am only one, but still I am one. I cannot do everything, but still I can do something. I will not refuse to do something that I can do."

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Appendix A

IRB Protocol Approval

IRB Protocol Approved
no-reply=kuali.co@mx3.kuali.co on behalf of; Kuali Notifications no-reply@kuali.co
To: Bell, Melissa B mbb110@txstate.edu
Tue 10/6/2020 1:10 AM

Dear Rangarajan, Nandhini

The Initial submission protocol number 7448 titled "Toward Equal Access: A Model for Lay Advocacy Programs That Serve People who are Deaf or Hard of Hearing" (PI: Rangarajan, Nandhini) was approved on Tuesday, October 6th 2020.

The protocol will expire on no date provided unless the expiration date is extended in the continuing process.

Please note face to face interactions are not approved for implementation until all other University COVID 19 conditions are approved if your project involves in person contact. Refer to the IRB website for updated information on IRB expectations and additional requirements to be met before implementation. It is the researchers responsibility to stay current on latest COVID 19 guidance and notify the IRB of any changes to protect participants within 5 business days if implemented to protect participants.

Research Integrity and Compliance