

# Kindred Stories of Disability: Sharing Personal Experiences to Impact Public Policy

A Project Replication Manual

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**VANDERBILT**  
**KENNEDY CENTER**  
for Excellence in Developmental Disabilities



**The Arc**  
Tennessee

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# Introduction

Stories have power. They spark listener attention and are immediately memorable for one simple reason--human beings are innately programmed to relate to human beings. This is pivotal because when we relate, we begin to care and to take action. Perhaps this is why stories have served such an important function throughout history. Notable leaders, from Abraham Lincoln to Martin Luther King have understood this phenomenon, utilizing the power of stories to herald their calls to action. Tennessee Kindred Stories of Disability, an advocacy story project facilitated through the Vanderbilt Kennedy University Center for Excellence in Developmental Disabilities (VKC UCEDD), also seeks to harness the power of the story and to make disability-related issues both concrete and personal. In doing so, personal stories of disability are used as tools for advocacy, bringing awareness to communities from Nashville to Capitol Hill.

The project benefits so many. University students, who contribute by interviewing individuals with disabilities and their families and writing their oral histories, are given the opportunity to get to know people with disabilities personally. The students are often exposed to issues that take them beyond their particular academic pursuits and career goals. After the interviews, the students share these stories with their classmates, their professors, and the service organizations with whom they work closely. So far, this has sparked not only greater understanding and identification from students, but it has also inspired several ongoing service projects to better support

the families who were interviewed. Disability service organizations also stand to gain a lot from Kindred Stories of Disability. The project has provided them with a wealth of new oral histories, bringing attention to disability-related issues that are relevant to their organizational missions in a personal way. As a unique contribution, many of these histories have come from a diverse pool of individuals from varying socioeconomic and cultural backgrounds. Most importantly, collective participation on the project has brought many of these organizations into closer communication with one another. This may foster greater dialogue among them in the future to promote further collaborations.

Benefits also extend to the greater disability community because families who share their stories speak not only for themselves. They speak for a broad network of people who may share their challenges and feel marginalized. It is a common occurrence for people in the disability community to harbor a sense of isolation, but Kindred Stories of Disability can let them know they are not alone.

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Most importantly, the families who share their stories are given an opportunity to have their trials and triumphs heard. This is not only cathartic, but also has a more far reaching purpose. It offers those with disabilities a chance to let their personal experiences be insightful to lawmakers, and experience is a truthful teacher. By reaching out in this way, families have the ability to affect potential legislation that benefits not only themselves but those around them who have undergone similar challenges. This is self-determination expressed most powerfully.

This manual will outline the Kindred Stories of Disability program's process as it has been developed and is currently being coordinated at the VKC UCEDD. Implementation of this program may vary for different organizations and classrooms, and all or part of the manual may be used in classroom application. Please view this manual more as a guide than as a set of explicit instructions.

The first section outlines the history of the development of the project, which may be helpful in thinking about what pieces need to be in place for replication. To direct the process, the replication manual will cover all aspects of collecting and sharing stories with policy makers and the general public. It will first delineate the project's development of interview assignment procedures, consents, and materials. Secondly, it will instruct on how to recruit, identify, and train classes of student interviewers, and invite participation of faculty members, interagency collaborators, and individuals with disabilities and their families. The manual will then explain processes for collecting, editing, and compiling stories and will lay out a description of its methods for facilitating the dissemination of stories to legislators and others. Finally, the Appendix

includes sample assignments, consent forms, interview questions, and an example of a booklet for legislators.

Our hope is that this manual will serve as a useful tool for the creation of more projects like Kindred Stories of Disability. There are many more stories still waiting to be told, many more families who deserve the opportunity to serve as their own self-advocates, and many more policymakers who deserve to understand the challenges and opportunities for their constituents with disabilities.

## Brief History of Kindred Stories of Disability

Stories have the power to inspire and connect us in ways that few other mediums can. When families generously speak of their own unique challenges, they become more than academic subjects or faceless statistics; they become friends and advocates who share our confidences. Kindred Stories of Disability has created a unique set of such personal accounts by asking individuals with disabilities and their families to share their experiences in areas like health care, education, and employment. So far, the results have been far reaching, broadening awareness within local communities and personalizing advocacy on Capitol Hill.

The project began in 2004 when staff at the Vanderbilt Kennedy Center (VKC UCEDD) recognized the tremendous need to illustrate the diverse issues surrounding citizens with disabilities. This sparked the Kindred Stories initiative, and by 2005, many of the key players at the VKC UCEDD had united to form a Public Policy Team. After much discussion, the fledgling group determined that an effective and meaningful way to communicate with legislators was to share personal stories.

Initially the planning phase of this project was complicated by its scope. As Elise McMillan, J.D., co-director of the VKC UCEDD, explained, "Too often (legislators) may think, 'It's just a problem in rural areas, or it's just a problem in urban areas. That doesn't affect the folks in my Congressional district.' As we know, it really does, and the more concrete we can make these issues, the more effective we can be."

McMillan elaborated that this political reality necessitated the project's goal of gathering stories from all 95 counties in Tennessee. The idea was that every legislator or policy maker should be getting a message from his or her own constituents.

To implement this, collaborations began with professors from Vanderbilt and Belmont Universities who would use the interview and oral history writing process as class assignments. Robert Hodapp, Ph.D., professor of Special Education at Vanderbilt, was the first to pilot this program with his undergraduate and graduate courses. Hodapp had been looking for a service project where students could talk directly to people with disabilities, when he learned of the Public Policy Team's interest in stories that could be used from both literary and policy perspectives.

An agreement was reached that Hodapp's students would interview families with disabilities, and the resulting accounts would be compiled and distributed to legislators. At that time, Meghan Burke, Ph.D., was a graduate student under Hodapp's tutelage. Burke was able to add depth to the project through her personal knowledge and involvement as a family member of someone with disabilities. Burke worked closely with the Public Policy team and was instrumental in the development of the project.

Eventually, Courtney Taylor, M.Div., associate director of communications and dissemination for the VKC UCEDD, began coordination of the project. Taylor

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decided to diversify the story compilations by having Hodapp's students focus on specific topics within various socioeconomic and cultural backgrounds. To do this, Taylor began forming targeted partnerships with organizations and groups, such as The Arc Tennessee and the Tennessee Multicultural Alliance on Disability. The organizations assisted in recruitment of families who would share stories in areas that illustrated both timely legislative issues and that supported work the organization was already doing in particular topic areas.

This pairing was a meaningful one for all involved. Most of the students gained new perspectives from truly getting to know diverse families with disabilities and interacting with them on a more personal level. Hodapp remembers a student who interviewed one particularly impoverished family. The student had an intense personal experience when she learned how much financial difficulty these parents faced and how this impacted and limited what they could do for their child with disabilities. Something as simple as having enough money for the child's diapers was a daily struggle. As a result of her first real experience with people who could not easily afford such a basic need, the student decided to coordinate a "diaper drive" to assist them.

While involvement with Tennessee Kindred Stories of Disability clearly impacted all of those who worked with Hodapp, there were benefits for other parties as well. The VKC UCEDD received a variety of new oral

histories from diverse socioeconomic and cultural backgrounds, and this indirectly brought it closer to other organizations in the disability community. Families were given the opportunity to share their stories with others and feel that what they contributed could make a difference. But most importantly, the project was on its way to achieving its primary purpose—to share these powerful stories with legislators, both on the local and national level. As Hodapp later surmised, "Disabilities is not on the radar of most legislators. Personal stories make the issues more salient and tell more specifically where the areas of need are. This project has put policy on the map with a human face."

The dedication of all those involved at Vanderbilt was instrumental in moving Kindred Stories forward, but this was only the beginning of the collaboration among Kindred Stories, university partnerships, and engagement of the broader disability community. As the project evolved, it was integrated into an English course at Belmont University taught by Lacey Lyons, MFA. Since Belmont has always placed a heavy emphasis on service learning, it was a perfect match. Students in her class took on a semester-long assignment in which they developed research papers about specific disabilities, interviewed families who have a family member with that particular disability, prepared questions, and wrote up the families' stories as personal narratives. Lyons has been extremely pleased with the partnership between her classes and Kindred Stories. Many of her students have

gone on to continue working with families with disabilities in different ways after their projects were finished. In one particularly poignant story, one of her students conducted interviews based on a larger service project, offering Zumba, jazz dance, and swimming classes specifically to people with autism. The student kept the project going after his interviewing assignment was over, and his employer was eager to support continuation of the classes.

One unique aspect of the Kindred Stories partnership with Belmont is that Lyons' classes are designated as service-learning courses. This means the students have a volunteer service requirement. Each semester, Taylor matches Lyons' classes with an organization that identifies families for the students to interview, and in return, the organization benefits from each student's commitment to donate 8 service hours. So far, students have had the opportunity to work with the Vanderbilt Kennedy Center, Autism Tennessee, Tennessee School for the Blind, Down Syndrome

Association of Middle Tennessee, and The Arc Tennessee. Lyons says that working with each of these organizations has made the project more meaningful for her students by helping them to step out of their comfort zones. She explained, "College can be very insular, and this was a way to get them into the world and broaden their perspectives."

Other issues emerged as the personal stories began to accumulate. Despite the fact that Kindred Stories was seeing some

circulation, it was clear that the project's reach and organization had to improve before it could expand. Searching for a solution, Jan Rosemergy, Ph.D., director of communications at Vanderbilt, came across a British website that focused on families affected by genetic syndromes. This site utilized the power of personal stories to impact decisions of public policy, and so Rosemergy proposed the idea of a website to accelerate exposure to Kindred Stories. This became the Communications department's top priority, since one of a UCEDD's chief functions is the dissemination of information to public policy makers and individuals with disabilities in accordance with the National Developmental Disabilities Act. Once completed, the resulting site not only gave families a voice with lawmakers, but also allowed them to feel less isolated

from others in the disability community and helped them find shared solutions through stories like theirs.

Each semester, Taylor coordinates with Lyons and Hodapp to determine how many families need to be recruited for

interviews and decides on the topics and community agency partnerships. One of Taylor's goals is to select themes that are relevant to what is happening with current legislation. For example, one semester Taylor recruited families based on the topic of aging with disabilities, and this coincided with potential legislation to qualify adults with disabilities for state services once their parents reached a certain age, preventing them from entering a crisis state. After recruitment and topics are finalized, Taylor

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and others craft open-ended questions for the student interviewers to use to facilitate the telling of the families' stories. (Belmont students craft their own questions as part of a journalism assignment.) Once the interviews take place, Taylor edits the stories, pares them down, and sends them to the families for revisions and approval. In the process of preparing the booklets, Taylor has also more recently begun adding photographs of the families to personalize the stories even more. The booklets are printed by the University printer, which provides quick turnaround and competitive pricing. The VKC UCEDD assumes responsibility for all printing costs. The final result has been the creation of printed booklets to hand out to legislators and families each year and also web-based versions of the stories.

Whenever a Kindred Stories of Disability collection has been printed, dissemination has always become the next main objective. The printing of the booklets is timed so that they are ready for dissemination during Tennessee Disability Day on the Hill, which takes place each January. The Arc Tennessee's executive director, Carrie Guiden, M.Ed, is very involved in the project, and The Arc Tennessee is instrumental in distributing the booklets each year to legislators and families as a tool for advocacy.

These booklets continue to be issued to countless lawmakers annually. At the state level, they are passed out individually to every Tennessee legislator during Disability Day on the Hill, and at the national level, they are given to the Tennessee Congressional Delegation. The booklets have become an extremely effective tool for shaping public policy by making disability-related issues both personal and accessible. As Guiden observed, "This is the

one thing we send out where legislators will tell us, 'We look forward to seeing this every year . . . these are so powerful.'" She went on to explain that these messages carry special meaning because "legislators don't really need to care about what professionals have to say. It hits home when it's their constituents."

Since its inception, Tennessee Kindred Stories of Disability has become a powerful tool for reaching legislators, involving students in service, and building relationships with families. It is a way to give a voice to families to who are too often not heard, especially by public policy makers.

Several key ingredients will ensure continued success and the expansion of the project's scope. McMillan cited many critical components that must be in place to allow for ongoing, positive results. She stressed, "We need quality students who understand and are interested in the issues individuals with disabilities face. We need individuals and families with disabilities willing to share their stories, sometimes over and over again. And we need the time and leadership of the Communications department, and more professors, like Bob Hodapp and Lacey Lyons, who see the project as a true service and opportunity for their students."

# Kindred Stories Replication Manual Steps and Procedures

This section outlines the Kindred Stories of Disability program's process as it has been developed and is currently being coordinated at the Vanderbilt Kennedy University Center for Excellence in Developmental Disabilities (VKC UCEDD). Implementation of this program may vary for different organizations and classrooms, and all or part of the manual may be used in classroom application. Please view this section more as a guide than as a set of explicit instructions.

## Identifying Project Coordinator(s)

A good project coordinator will be the main liaison for keeping everyone on the team in direct communication. It is possible to assign one person to this task or to divide specific activities among individuals within a team. For the sake of clarity, this manual will refer to a single project coordinator, but this is not meant to limit the number of coordinators who may be involved. To begin collecting and sharing stories with policymakers and the general public, a coordinator should be identified. It will be his or her responsibility to facilitate the development of interview assignment procedures, provide consent forms, and issue all other related materials. Upon procuring these, the coordinator will then be in charge of recruiting, identifying, and training classes of student interviewers. Serving as a point of contact for faculty members, student interviewers, and agency collaborators will be the coordinator's next major responsibility. Finally, he or she will need to collect, edit, and compile the completed stories and facilitate their printing and dissemination to legislators and others.

There are many ways that the coordinator's role may be fulfilled. At the VKC UCEDD, a member of the Communications and Dissemination staff has been the natural choice for this responsibility. This is particularly true because one of the UCEDD's chief functions is disseminating information to public policymakers and individuals with disabilities in accordance with the National Developmental Disabilities Act.

In addition to the project coordinator, it is advised to consider the value of a formal or informal advisory team. At the VKC UCEDD, the Public Policy Team has been the perfect fit. Made up of representatives from VKC staff as well as representatives from community agencies that also have a commitment to educating and advocating on behalf of people with intellectual and developmental disabilities, this team provides valuable insight into timely and relevant disability-related legislative issues. The VKC UCEDD Public Policy team includes representatives from The Arc Tennessee and the Tennessee Council on Developmental Disabilities. It includes a VKC UCEDD Community Advisory Council member, who is the parent of a child with disabilities, as well as VKC UCEDD staff. VKC UCEDD trainees may cycle off and on when an interest is identified.

## Designing the Assignment

By working closely with university faculty members and their students, the project coordinator should be able to create course assignments that will aid in the collection

of stories from families with disabilities. To facilitate this, the coordinator will need to develop three major components—interview assignment protocol and instructions, questions to guide the interviewers, and consent forms. Examples of each are included in the Appendix.

The **interview assignment protocol** is a document which outlines procedures that students will use to set up and conduct the interviews. Examples of information provided in this document are timelines for contacting and scheduling interviews, suggestions for meeting places, guidelines for writing the stories, and more. The information may shift from assignment to assignment, and depending on the organization's goals and topics.

There are many ways to develop **interview questions** to guide students. The VKC UCEDD has taken two approaches for its process—designing the questions in advance for the students and having students create their own interview questions.

It may be helpful to note that depending on the story topics and the academic interests represented in the course, students will have varying degrees of knowledge of subjects. So, when a more targeted story collection is desired, it may be beneficial to design the interview questions beforehand and give all students the same questions, so that they are covering the issues that will best support the educational purpose of the collection. One example from the VKC UCEDD's history of booklets was a collection highlighting families on the waiting list for home and community-based waiver services. Questions were designed for the students, as they were less familiar with our state waiver system and may not have been able to tease out the issues most relevant for legislators.

The students who have devised their own questions have done so as part of a journalism assignment. An important component of their assignment was to learn to ask thoughtful, carefully considered questions. It should be noted that the topics for these assignments have been more general, such as "Exploring Autism Spectrum Disorders" or "What the High School Experience is Like for Students Enrolled in the Tennessee School for The Blind."

Regardless of which method you use, it will be up to your project coordinator to identify a topic each semester on which students should focus. Consider choosing a topic that will support the work that the UCEDD or community partners are doing already or that reflects current legislation or areas of advocacy. By choosing topics in this manner, the stories will be relevant and timely and thus more effective.

For more ideas, please see the Appendix, which contains two examples of interview questions that have been developed for past Kindred Stories of Disability compilations. Note that one of these sets of questions was created solely for interviewing parents of someone with a disability, while the other included questions for parents as well as self-advocates. Also, please understand that once these questions have been developed, it will be the responsibility of the students to turn interviewee responses into fluid accounts using an oral history format.

The third component of developing the interview assignment is providing the **consent forms**. These need to be collected from each interviewee, and the students will generally gather signatures from the participants when they conduct their interviews. In addition to providing permission to use the stories, consent forms should outline how the stories will be used

and with whom they will be shared. If photos are going to be incorporated, the forms should also be utilized to obtain permission to use them. There also should be a section on the form for the student interviewers to grant consent for the stories they write to be used. A sample consent form is provided in the Appendix. If the students are conducting phone interviews, which may be desirable to expand reach across the state, the project coordinator may want to take on the responsibility of obtaining consent prior to the interview.

### Recruiting, Identifying, and Training Classes of Student Interviewers

To identify and recruit student interviewers, it helps to use a bit of creativity. Certainly, the most likely channels are in special education departments within the University. At the VKC UCEDD, the Director of Research is also a professor of special education at Vanderbilt University. This has made for a natural partnership between Kindred Stories and his graduate and undergraduate classes each semester. But recruitment need not stop with the special education department. For our project, other departments and universities have been approached as well. For example, Belmont University's undergraduate English course collaborated with our team by blending interviewing techniques with advocacy and service learning. We have also worked with Vanderbilt Divinity School, matching students with families who share their experiences on inclusion within faith communities. The Public Policy team hopes that these expansions will enrich the wealth of advocacy stories available. Start by approaching faculty members who are already involved in the UCEDD and then expand out to other departments and schools. The possibilities for student recruitment are really only limited to the imagination.

Once students have been identified and recruited, the next step is training them. The coordinator should present the assignment and its accompanying materials to the class. One aspect of training that has proven highly successful is to invite a representative from a disability service organization or a family member to speak about the topic chosen for that semester's booklet. For instance, the VKC UCEDD brought in the director of The Arc Tennessee to speak with students about issues related to aging with disabilities during the semester when that topic was the focus. This gave students an opportunity to internalize the key points of the issue before meeting with families and asking for their stories. In another example at Belmont University, a VKC UCEDD staff member, who has a physical disability, was invited to speak with the students about disability-etiquette and person-first language. She encouraged the students to ask her absolutely anything. They did. It turned out that several students were very nervous about interacting with people with disabilities, but once they were able to ask their questions and acknowledge their discomfort, they moved forward more confidently and produced very effective stories. It is highly recommended that the training include the topics of person-first language and disability etiquette. There need not be a formal speaker, but educating students on this will be of great importance. Other training topics might include being respectful of the family's time, conducting oneself professionally, and being safe when making a home visit. The Appendix includes resources on many of these training topics.

## Recruiting Individuals with Disabilities and/or Family Members to Interview

When recruiting people with disabilities and family members it helps to reach out widely to all available constituents. This could include asking students to identify people they know who may be interested in being interviewed for the project. Investigate connections with service providers who know of families who would like to participate. Reach out to disability service organizations, especially those who help individuals in ways related to the current topic. For example, when the VKC UCEDD chose the topic of aging, we wanted to specifically target adult populations with disabilities. We approached contacts at Best Buddies, the Area Agency on Aging and Disabilities, the Department of Intellectual and Developmental Disabilities, and many others to find age-appropriate individuals and their families who would be willing to participate. Brainstorm with faculty and staff on how to reach the appropriate families. Send out recruitment requests via mass emails, through social media, and with fliers and newsletter announcements. Families want to share their stories and are especially excited when they know they are contributing to improve outcomes for others. It's just a matter of connecting.

When a self-advocate or a family expresses interest in participating, the coordinator should gather information that will be helpful for the student to know prior to the interview. This information may vary, depending on the topic. Generally, students will need the name(s) and contact information of the person(s) they will interview. For the classes at Belmont University, we also collected the primary diagnosis, because part of the students' course assignment was to write a research paper on the disability prior to the actual interview. Sometimes parents

might share other information about their son or daughter that will enhance the quality of the interview, such as how they best communicate with others. When we were collecting stories about employment, we wanted to hear accounts both from people with disabilities who were employed and who were unemployed. It was helpful to ask about employment status as we had developed two sets of questions, a set for the employed and another set for the unemployed. The information needed will vary with each session and each topic. Be sure to let the families know when the interviews are expected to take place. We usually give a one month window.

## Matching Students and Families

Our students generally work in teams of two. So, if the class has 30 students, at least 15 families will need to be recruited. It is also recommended that there are a couple of families willing to be on standby in case an issue arises and another family can no longer participate. The student pairs or teams may be selected in whatever way works best with the class. At Vanderbilt, freshmen are not allowed to have cars on campus, so often we match students based on whether or not they have access to a vehicle. If transportation is not an issue, students can just pair up themselves, or the professor or coordinator can assign matches. Once the coordinator has a list of student pairs, it's just a matter of assigning families, which is usually done at random, and then sharing the families' information with the students. Be sure the students reach out to families right away. While the interview does not have to take place right away, the students should make contact and try to set a date to avoid scheduling conflicts.

## Serving as the Point of Contact for the Faculty Members, Student Interviewers, Families, and Agency Collaborators

To ensure that everyone can complete the interviewing process as seamlessly as possible, it is critical to have a contact person to provide for any needs as they arise. This person must be prepared to handle a wealth of duties and unexpected glitches. The most common issue that arises for students is not being able to get in touch with their interviewee. There may be cases where the coordinator needs to reassign students to a new family. Be sure to have a small pool of alternates from which to choose each session. While most students and families meet in the families' homes or other meeting place, the coordinator may sometimes be responsible for setting up interviewing locations. Another common request from students is borrowing recording equipment. Be sure the coordinator is readily available during the time in the semester that the interviews are taking place.

## Collecting, Editing, and Compiling Stories

An effective story will be one that has an organized focus on the subject matter and that relays the voice of the person(s) telling it. Quality of stories will vary. Not all students are writers. Not all students will have a grasp of the subject matter or understand the service system or even agency names and acronyms that come up in interviews. Various levels of expertise should be taken into account as questions are developed, as students are trained, and as they are given instructions on how to write the stories.

One of the most critical tasks of the project coordinator is to collect, edit, and compile the finished stories, which can be made into

the booklets. When collecting the stories, make sure to keep an eye on variety, and pay close attention to the overall flow of the booklet. When the VKC needs to organize Kindred Stories, its project coordinator, Courtney Taylor, mixes stories told from the perspective of the person with the disability with stories told from a parent's point of view. She also pulls important quotes from the stories and puts them in large font to accompany some of the pictures, an effective technique used by many major periodicals.

Once the booklets have been compiled, editing the stories may also require some finesse. While it is important to keep the content uniform in structure, it is a delicate balancing act to do this without altering each interviewer's unique voice. To approach this issue with Kindred Stories, Taylor is careful to trim each account down to between two and five pages, make sure the stories are in first or third person, and ensure that they are grammatically correct and stylistically similar. Consider a word about the storyteller's voice. First person narratives tend to be the most impactful with legislators, but if the interviewer does decide to use third person, it is important to include at least three direct quotes to give the stories a more personal feel. Adding photographs of the individuals who have been interviewed can give a unique touch to each account, too. Putting faces with the stories increases their power for advocacy.

Once stories have been edited, it is important to share them with the families so they can have an opportunity to revise and clarify. As stated earlier, students have varying degrees of knowledge about the topic being discussed and may, unknowingly, misunderstand or misrepresent the experiences of the interviewee. Giving the interviewee the opportunity to view and

revise the story prior to publication and will only enhance the validity and integrity of the story.

While most of the space in these booklets should allow families' stories to speak for themselves, sometimes statistics can be useful to include as well. When organizing booklets for the VKC, Taylor sometimes includes statistics that are pertinent to the project's overarching theme. For example, when the topic was employment considerations for those with disabilities, she began the booklet by comparing data on the number of people with disabilities who were employed to the general working population. When the focus of another booklet was on stories from families on the waiting list for home and community-based waiver services, she included a map of Tennessee's counties, highlighting the number of people waiting for services in each county. It is a powerful image that hooks legislators, their eyes eagerly locating their own county and numbers. Images and statistics enhance the stories. Be creative in how to best convey the message.

### Facilitating the Dissemination of Stories to Legislators and Others

The VKC UCEDD approaches dissemination of the stories in a number of ways. The main avenue is through the printed paper booklets that are distributed to legislators at events, such as Disability Day on the Hill. While the VKC UCEDD assumes responsibility for all printing costs, The Arc Tennessee has been instrumental in disseminating the booklets. Each year, representatives from The Arc Tennessee deliver a copy of Kindred Stories to every member of the Tennessee General Assembly. Representatives from the VKC UCEDD and The Arc Tennessee also deliver copies to each Congressman and Senator during the Federal Disability

Policy Seminar in Washington each year. Any remaining copies are shared with the Tennessee Governor and other government officials, as relevant. They also are shared with families, so that they not only see the collaborative efforts of The Arc Tennessee and Vanderbilt Kennedy Center, but also realize that they are not alone.

Another way to share the stories is by creating e-booklets. That is an excellent way to send out unlimited copies of the same materials at no cost. One more dissemination tool is the Tennessee Kindred Stories of Disability website ([kc.vanderbilt.edu/kindredstories](http://kc.vanderbilt.edu/kindredstories)). The website was developed with the assistance of the VKC web developer, but with free and relatively easy website builder services like WordPress, this option is more accessible than ever. The site incorporates a database that makes stories searchable by disability, topic, county, age, and storyteller perspective. The VKC has also shared its story collections through national networks like the Association of University Centers on Disability (AUCD), and this has expanded its reach.

### Conclusion

It is our hope that this guide has given you some useful ideas to start an advocacy story project. Once again, the main goals to keep in mind are to designate a project coordinator, design an assignment, find and train interviewers, recruit interviewees, determine a point of contact for all involved parties, edit and compile the stories, and find ways to distribute the final product. Once these steps have been undertaken, you will have an excellent advocacy tool and the groundwork to disseminate it. Nonetheless, please view the above procedures as a guide. Feel free to experiment and be creative, and we wish you the best with your own future project.

# About the Authors

**Carrie Glover** is a graduate student at Vanderbilt University studying low instance special education and ABA. In her research for her advisor, Robert Hodapp, she has worked on the Replication Manual for Kindred Stories, the history of the PSE Alliance, the Ambassadors study on volunteerism, and Project Pathfinder. Before coming to Vanderbilt, she was a music teacher and tutor for both typically developing students and students with disabilities. After graduation, she hopes to become a board certified behavior analyst and work with students with autism.

**Courtney Taylor, M.Div.**, is the associate director of communication and dissemination for the Vanderbilt Kennedy Center (VKC). She coordinates the VKC's Tennessee Kindred Stories of Disability Project and the Disabilities, Religion, and Spirituality Program. She also coordinates the VKC's Research Ethics Grand Rounds and facilitates a Next Chapter Book Club for students with intellectual and developmental disabilities. Taylor is a graduate of Vanderbilt Divinity School. Before coming to Vanderbilt, Taylor worked as a playwright in Chicago, Illinois.

## Sample Assignment

*This sample assignment was given to students who were collecting stories from families on the topic of aging.*

**Please make initial contact with your assigned family or professional before Spring Break (March 3).** The families are busy. You are busy. Touching base early to explore the best month/week/day for the interview will ensure availability and convenience for both of you. The interview can happen during the month of March or early April, but please touch base early so that the family has time to work it into their schedules. Plus, it will give us time to find replacements, if necessary. Reconfirm a few days before the interview.

**Student:** *Hi, my name is \_\_\_\_\_ and I am working with another student, \_\_\_\_\_. We are graduate/undergraduate students enrolled at Vanderbilt University. We are calling because of your willingness to be interviewed for the TN Kindred Stories of Disability project. We are interested in learning about the experiences of Tennesseans with intellectual and developmental disabilities related to issues of aging. These interviews will be the basis for written stories that we will share with our classmates, and that the Vanderbilt Kennedy Center and The Arc TN will share with members of the Tennessee Legislature and the U.S. Senate and House of Representatives for educational purposes. Can we settle on a convenient time to meet and talk for about an hour?*

**Location for the interview: In person.** You and the parent/family will need to decide when and where to meet. You may meet in the community or in the family home. Community locations might include: Vanderbilt Campus, public library, community center, coffee shop, or restaurant. Be aware that noise levels and distractions may be a nuisance. If you would like to meet in the Vanderbilt Kennedy Center during the work week, arrangements can be made for a room (contact Courtney with several options of dates and times). It is also fine to meet in the family home. In fact, it may put the family at ease to be in familiar surroundings. If both you and the family decide upon this option, please review the tip sheet: "Making Safe and Effective Home Visits" prior to your visit. <http://vkc.mc.vanderbilt.edu/assets/files/tipsheets/homevisittips.pdf>

**Location for the interview: Phone conversation.** In order to widen our reach in the state, some interviews will take place via phone so that we can hear from families in the eastern and western portions of our state. Since you are working in pairs, a speakerphone may be useful. Contact Courtney if you want to use the Vanderbilt Conference call line.

If you are meeting in person, have the family member sign the **consent form** (you will sign as well) before the interview begins. Consent forms will be provided to you. If you are doing your interview over the phone, Courtney will coordinate obtaining consent, but you must make arrangements to stop by the VKC (room 237) to sign the consent form as well. Families may elect whether to use their first names or change all names. The consent form also includes an Impact Survey. This survey is to help us better understand who we reach with our programs. Return consent forms to Professor Hodapp. This is very important. All stories must be accompanied by signed consent forms.

Please **record the interviews** to ensure high quality, accurate stories. Stories will be approved by families prior to being published. You may use your personal recorder/phone or check out an audio recorder from the Peabody Technology Support Center in the Wyatt Building. Reservations are encouraged. Recording Apps also are available for smart phones. Please inform the families you will be recording the interview.

When speaking with families and when writing the stories, **use person-first language** (“person with autism” not “autistic person”). Please see the TN Disability Coalition’s brochure on disability etiquette here:

[www.tndisability.org/our-publications](http://www.tndisability.org/our-publications)

**Stories should be 2-5 pages in length.** They may be written in the first or third person point-of-view. If you choose to write the story in the first person, you may transcribe the interviewee’s words and then edit a bit to clean up grammar and style (without compromising the voice of the person), and craft the narrative so that it reads less like a spoken conversation and more like a written story. If you choose to write in the third person, **you must include at least three direct quotes.** Again, recordings of the interviews will be very helpful, especially if there is a good amount of time between the interview and the writing process. Courtney Taylor will edit your final stories and the families will have final approval before they are shared. As soon as possible, please submit an electronic copy of the story to Professor Hodapp and to [courtney.taylor@vanderbilt.edu](mailto:courtney.taylor@vanderbilt.edu).

Tennessee Kindred Stories of Disability Interview Questions  
Special Edition: Aging - Spring 2014

QUESTIONS FOR PARENTS

1. Tell me about your family. Would you mind sharing your age and the ages of your family members?
  - Does (name of son/daughter with a disability) live with you in your home?
  - If not, where does he or she live? (if name of place or agency given: Is that a group home, supervised apartment, larger facility, apartment, other?)
    - Tell me about that arrangement. Roommates? Support person?
    - At what age did he/she move out? What prompted the move at that particular time?
2. In thinking about the past, was there any support/plan/program/decision that your **child's teacher or other school personnel** might have made that would have made a difference now in helping your son/daughter?
3. Again thinking about the past, was there any support/plan/program/decision that **you or your family** might have made during that time that would have made a difference now?
4. When you think about your current life with your son/daughter right now, what are your biggest challenges in supporting him/her? Does he or she have unmet needs? If so, what are they?
5. When you think about the future, what are your biggest concerns?
6. Is your son/daughter on the waiting list for DIDD home and community-based waiver services? If so, how long has he/she been waiting?
7. How would you say that, in general, your health is? (Poor? Fair? Good? Very Good? Excellent?)? Do you feel that you are able to attend to your own health care needs? If no, please explain.
8. How would you say that, in general, your son or daughter's health is? (Poor? Fair? Good? Very Good? Excellent?)? Do you feel that you are able to attend to your son or daughter's health care needs? If no, please explain.
9. If supports were available to your son/daughter, what would be most helpful?

Tennessee Kindred Stories of Disability Interview Questions  
Special Edition: Aging - Spring 2014

QUESTIONS FOR PROFESSIONALS

**Please encourage the interviewees to share stories that illustrate the points they make**

1. Tell me about your job, especially as it relates to working with people with intellectual and developmental disabilities over the age of 40.
2. Thinking in the present, what are the biggest challenges elderly people with intellectual and developmental disabilities are facing? Do they have unmet needs? If so, what are they?
3. When you think about the future, what are your biggest concerns for the people you support?
4. Do the people you work with have waiver supports? Do you work with people on the waiting list for home and community-based waiver services?
5. How involved are the families of the people that you work with? What are THEIR biggest issues over the next 5 years? What would help them most?
6. Let's talk about health care. Do you feel that the health care needs of the people you work with are met? If no, please explain.
7. If supports were available to the people you support, what would be most helpful?

# Home Visits

## TIPS AND RESOURCES FOR MAKING SAFE AND EFFECTIVE HOME VISITS



### Home Visit Best Practices: Using the Elevate AIDET Principle

- Acknowledge all family members. Knock, smile, make eye contact, and be pleasant.
- Introduce yourself and your role.
- **Duration.** At the start, state how long the overall visit will take, and during the visit you may want to state the length of particular tasks.
- Explain all processes and procedures so they know what to expect.
- Thank the family for inviting you into their home and for their time. Ask if there are any other questions before ending.

### Establishing Rapport

Show respect by using titles (e.g., Mr., Mrs., Ms.), be aware of potential cultural differences, and be sure to use people-first language and practice disability etiquette.

### Boundaries and Roles

- Maintain a professional relationship. Becoming “friends” may make it difficult to talk about hard topics.
- Respect personal space. Do not initiate touch unless necessary for the intervention. If touch is necessary, ask permission.
- Use self-disclosure sparingly to communicate understanding/build trust. The focus is not on you.

- Maintain confidentiality. While OK to discuss cases with supervisor as needed, do not share specifics or identifying information with your friends or family.

### Self-Care: Practical Tips Before You Go

- Keep dress simple - avoid jewelry, scarves, clothing that will attract unwanted attention.
- Wear safe footwear with closed toes.
- Take hand sanitizer.
- Avoid wearing scents as some people are sensitive.

### Think Safety Before You Go

- Assess risks by phone before the visit (e.g., animals, other persons in home).
- Ask clients to secure unruly pets.
- Ask clients to turn on lights, meet you at the door.
- If visit presents significant safety hazards, consider an alternative site to meet and/or take a buddy.
- Be sure you have enough gas and a spare tire.
- Program the client’s number into your phone.
- Identify safe routes within the neighborhood.
- Wear a name tag.
- Plan what you want to take into the home. Have items like laptops or backpacks locked away out of sight before arriving at your destination.
- Consider carrying clipboard, pepper spray, or a whistle.
- Carry important phone numbers with you.

### Safety During the Home Visit

- Do not park in someone’s assigned space, or block access to other cars.
- Keep hands free and car keys in hand.
- Walk with confidence.
- Do not walk through groups on street/sidewalk.
- Plan safe physical proximity in the home by positioning yourself between the client and the door. Sit near an exit or facing hallway to view other rooms. Sit on a hard chair or the edge of a soft chair to be able to get up quickly.

*Please see reverse for resources.*



# Home Visits

## TIPS AND RESOURCES FOR MAKING SAFE AND EFFECTIVE HOME VISITS

### If There Are Safety Concerns

- If a family member becomes agitated or says things that make you uncomfortable:
- Respond calmly, using “I” statements.
- Acknowledge what they are saying.
- Redirect using matter of fact, simple, direct statements.
- Keep a physical distance of at least 3 feet.
- Do not reach out to touch the person, stand in front of the person, or turn your back to the person.
- Do not get up from a chair while the person is sitting.
- Do not try to leave too abruptly.
- Trust your instincts regarding impending danger.
- Do not reveal information about yourself or your family that could increase the risk of being harmed.
- If you feel threatened, remain calm but leave as quickly as possible.
- Report any incident to your supervisor.

### Recognizing and Responding to Health and Home Safety Issues

Establish procedures for how to report home safety issues. Examples of health/safety issues are:

- Neglect - unmet medical, dental, personal hygiene, or nutrition needs.
- Unsafe living conditions or injuries.
- Possible abuse – physical, sexual.
- Emotional abuse – name calling, making fun, putting the person down.
- Mental status – depression, anxiety, sleep deprivation.
- Financial abuse – taking money, not allowing the person to get or keep a job when one is desired.
- Caregivers - memory problems, confusion, inappropriate behaviors. Inappropriate behaviors of paid staff.

After you leave, be sure to make notes about any concerning observations or statements.

### Who We Are and Who We Serve

The **Vanderbilt Kennedy Center (VKC)** works with and for people with disabilities and their family

members, service providers and advocates, researchers and policy makers. It is among only a few centers nationwide to be a University Center for Excellence in Developmental Disabilities, a *Eunice Kennedy Shriver* Intellectual and Developmental Disabilities Research Center, and a Leadership Education in Neurodevelopmental and Related Disabilities Training Program. The following are some of the ways the Center’s programs and staff can assist families, educators, and other service providers.

### Tennessee Disability Pathfinder

Tennessee Disability Pathfinder is a free statewide phone, web, and print referral service in English and Spanish. It connects the Tennessee disability community with service providers and resources. Its website database has 1,600 agencies searchable by Tennessee county and service. Pathfinder is a project of the VKC and the Tennessee Council on Developmental Disabilities. Contact [www.familypathfinder.org](http://www.familypathfinder.org), (615) 322-8529, toll-free (800) 640-4636.

### Other Resources

- **Making the Most of Home Visits** - [www.healthychild.net/InSicknessandHealth.php?article\\_id=98](http://www.healthychild.net/InSicknessandHealth.php?article_id=98)
- **The “Home Ranger” Rides Again: Making Home Visits Safer and More Effective** - [hpp.sagepub.com/content/9/4/323.full.pdf](http://hpp.sagepub.com/content/9/4/323.full.pdf)
- **Home Visitor’s Handbook** - [eclkc.ohs.acf.hhs.gov/hslc/hs/resources/ECLKC\\_Bookstore/PDFs/05F613A8CC15D89DAFE1D1568DB0719A.pdf](http://eclkc.ohs.acf.hhs.gov/hslc/hs/resources/ECLKC_Bookstore/PDFs/05F613A8CC15D89DAFE1D1568DB0719A.pdf)
- **Disability Etiquette: Engaging People With Disabilities** - [www.tndisability.org/our-publications](http://www.tndisability.org/our-publications)
- **Disability Etiquette Brochure** - [www.crinet.org/education/Independent%20Living/Etiquette](http://www.crinet.org/education/Independent%20Living/Etiquette)
- **Confidentiality in Research** - [vkc.mc.vanderbilt.edu/assets/files/tipsheets/confidentialitytips.pdf](http://vkc.mc.vanderbilt.edu/assets/files/tipsheets/confidentialitytips.pdf)

**Contact the Vanderbilt Kennedy Center  
Nashville (615) 322-8240  
Toll-Free (866) 936-VUKC [8852]  
[www.kc.vanderbilt.edu](http://www.kc.vanderbilt.edu)  
[kc@vanderbilt.edu](mailto:kc@vanderbilt.edu)**



## Tennessee Kindred Stories of Disability Permission

Thank you for participating in this interview. The students interviewing you are from Vanderbilt University. These interviews may be shared with members of the Tennessee Legislature and the U.S. Senate and House of Representatives in a print collection of stories. We have found that these personal stories are very helpful in illustrating to policy makers the challenges that families of individuals with disabilities experience. Stories also may be shared through the websites and activities of the Vanderbilt Kennedy Center, The Arc Tennessee, and through the web-based public database, Tennessee Kindred Stories of Disability ([kc.vanderbilt.edu/kindredstories](http://kc.vanderbilt.edu/kindredstories)). A staff member will contact you to review your story before it is shared.

If you are willing to share your story in the ways listed above, please sign this form. No last names will be used and first names may be changed if you so request. If you have any questions, please do not hesitate to contact Courtney Taylor at [courtney.taylor@vanderbilt.edu](mailto:courtney.taylor@vanderbilt.edu) or (615) 322-5658.

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 PRINTED NAME OF FAMILY MEMBER INTERVIEWED

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 SIGNATURE OF FAMILY MEMBER INTERVIEWED

---

 MAILING ADDRESS (PLEASE INCLUDE STREET, CITY, STATE, AND ZIP CODE)

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 COUNTY OF RESIDENCE

---

 AGE OF THE FAMILY MEMBER WITH A DISABILITY

---

 FIRST NAME OF THE FAMILY MEMBER WITH A DISABILITY

---

 PRIMARY DIAGNOSIS

---

 E-MAIL

---

 PHONE NUMBER

You may use first names when sharing our stories. Yes  No

I would like for all names to be changed. Yes  No

You may contact me for future story projects. Yes  No

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Student(s) I am willing to have the family interview that I conducted shared in the ways listed above.

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 STUDENT NAME

---

 STUDENT SIGNATURE

---

 STUDENT NAME

---

 STUDENT SIGNATURE

TENNESSEE KINDRED STORIES OF DISABILITY

2014

Special Edition:  
Employment



**VANDERBILT  
KENNEDY CENTER**  
for Excellence in Developmental Disabilities



tennesseeworks



**The Arc.**  
Tennessee

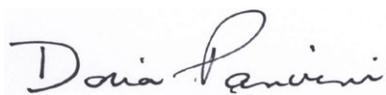
# A Letter of Thanks

The stories in this collection were compiled by students enrolled in a Vanderbilt University course on families. This course provides an introduction to the field of family studies, with special attention paid to families that include children and adults with disabilities.

The course offers future educators, advocates, and researchers an opportunity to learn what it's like for a family to include a member with a disability. As part of the course, students conduct interviews and learn firsthand about encounters with education, health care, housing, employment, and disability services in Tennessee. This particular edition focuses on the topic of employment. The stories illustrate why employment matters in the lives of people with disabilities. They introduce people who want the opportunity to choose work that is meaningful for them, earn a paycheck, be as independent as possible, share and improve their skills, and make connections with others. And while access to competitive and integrated work opportunities greatly increases quality of life, the average unemployment rate for people with intellectual and developmental disabilities is 83%.

The Vanderbilt Kennedy Center and The Arc Tennessee thank all the families who shared their stories. By reading them, you will receive snapshots in time of a diverse group of individuals with disabilities, across a spectrum of age, disability, geographic location, socio-economic status, and race. These stories demonstrate the limits as well as the lack of supports and services in Tennessee for individuals with developmental disabilities and the impact this has on family life. By sharing these stories, the students and families hope to demonstrate the great importance of eliminating barriers to increase competitive integrated work opportunities for all persons with disabilities.

To view additional stories from Tennesseans with disabilities, please visit:  
[kc.vanderbilt.edu/kindredstories](http://kc.vanderbilt.edu/kindredstories)



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Vanderbilt Kennedy Center



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The Arc Tennessee  
[www.thearctn.org](http://www.thearctn.org)

Vanderbilt Kennedy Center for Excellence in Developmental Disabilities  
[kc.vanderbilt.edu](http://kc.vanderbilt.edu)



## Scott (age 45)

In high school I had volunteer jobs. During my senior year, I had a car shop job. I was behind the desk. I was kind of a supervisor. I made sure the workers had the parts they needed to do their jobs. I did those as part of my high school curriculum before I graduated. I also worked at a hospital in Illinois-the same one I was born in- as a janitor. It was both volunteer and I got paid. High school did not really prepare me for life after graduation. I tried my best on the SAT test. When it came to those tests I just completely blanked out. I didn't get to go to college, but my sister did get to go.

When I first moved to Nashville, Tennessee I had to go through Vocational Rehabilitation to get a job. I got a job right away. I went through New Horizons and I worked for the Sheraton Hotel. It was a paying job. I worked at the Sheraton from 1987-1988. I kind of liked that job. I used to be a janitor and then they moved me to the linens. That was the best part of the job. I got to use the steam machine to fold the linens, which I liked. Eventually they referred me to The Arc Tennessee.

I have worked with The Arc for almost 26 years. I am the administrative assistant and the receptionist. My parents take me to work and bring me back at the end of the day. I live about 30 minutes away from work. I like all the staff here. I helped train all the staff, too. I work 40 hours a week. I answer phones and take messages. I am the gopher for the office. I run back and forth. I attend board meetings too. I love multi-tasking, computers, and I get my assignments done.

I have done speaking engagements for 25 years for The Arc. I have presented to students in pre-school, junior high, and high school. I speak at parent associations and colleges around Tennessee. I speak about employment and about how to keep a job. I tell them about the "R" word, which is the bad word. I give a lot of talks about self-advocacy. I like talking to high school level age the most, especially the ones that are about to graduate. I talk about life after high school such as getting a car, maintaining a job, and postsecondary education.

My dream job is to become a high school teacher either in government, history, or social studies. I would like to teach young adults or all adults with disabilities. I would like to attend night school so I can continue my education. Since I have acquired these new abilities and skills from working here at The Arc maybe it will help me. But for now I guess I would have to go to night school first. I would also like to move out and get my own place. I am 45-years-old and I am still living with my parents in their house. I say to myself that it is time to move out. The only barrier that is keeping me from that is my parents. They fear for my safety. They want me to live with them, but they are both 90 years old. I am just going to take it one day at a time. Maybe some day I can make it after all.

What I see about employment out there is that it may be a rat race, but every person needs a chance to have a job. It is important to stick to it and keep pushing and pushing to find a job. If I never had a job, I would push hard to get a job. Having a job not only gives me money and health care, it gives me self-esteem. So, I'm going to stay where I am right now because I like it here. ■

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***“Having a job not only gives me money  
and health care, it gives me self-esteem.”***

***~Scott, The Arc Tennessee***

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Vanderbilt Kennedy Center for Excellence  
in Developmental Disabilities  
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