

- **Introduction & Significance**

- To begin, the sibling relationship is unique: The sibling relationship is commonly characterized by shared cultural background, experiences, and genetics. With increases in family mobility, divorce rate, and subsequent remarriages, it is possible that the sibling relationship has more chances to prevail as the stronger familial relationship. Sibling relationships can show unique patterns throughout changes in developmental periods and can be one of the most enduring human relationships.
- Early Adulthood is important: Previous researchers have established the importance of this developmental period regarding psychosocial and cognitive transitions that occur as individuals enter young adulthood from late adolescence. These include the following particularly relevant developments in the early adult individual:
 - the ability to acknowledge and accept his or her emotions
 - becoming more self-reliant in decision-making and taking responsibility for actions
 - establishing interpersonal relationships by accepting of the differences of others
 - establishing a sense of purpose
 - Finally developing identity, which is the individual's acceptance of his or her own characteristics. Identity is typically not developed until the late 20s and is never complete.
- More people than ever: More people than ever are living through early adulthood as siblings of a person with a developmental disability. In 2014, there was a 5.76% lifetime prevalence of developmental disabilities in children aged 3-17; this included children with intellectual disability, autism spectrum disorder, or other developmental delays. Additionally, the trend in deinstitutionalization is increasing the number of individuals with a developmental disability residing both at home and in the community Finally, the

life expectancy for individuals with developmental disabilities is now similar to that of the general population unlike in previous decades when individuals with developmental disabilities died at a younger age.

- Few studies: Finally, only two qualitative studies were found, and neither focused specifically on the time period of early adulthood.

- **Purpose**

- The purpose of this study was to explore the early adult's experience of having a sibling with a developmental disability. We did this by interviewing early adults who have a sibling with a developmental disability about their experience. Gathering data from the early adult gave perspective into the experience. From this study a descriptive theory of the meaning of and influences on the experience emerged.

- **Methods**

- This research is qualitative, meaning that it is primarily exploratory and is used to gain understanding and insight. This is opposed to quantitative research which, focuses on statistics, measurements, and the analysis of numerical data.
 - The phenomenological approach was used in this qualitative study, specifically the hermeneutic phenomenology approach elucidated by van Manen.
 - Hermeneutic phenomenology involves four methodological activities: 1) selecting phenomenon which genuinely interests us and commits us to the world; 2) exploring experience as we live it rather than how we think about it; 3) contemplating on the themes which characterize the phenomenon; and 4) transcribing the phenomenon in writing.

- Three approaches described by van Manen (1990) were used in the thematic analysis. First, the wholistic approach involved reflecting on the description of the participants as a whole. Second, the selective approach involved reading the transcript multiple times to find aspects of the description that were essential to the phenomenon and highlighting those specific statements or phrases. The detailed approach involved reading each line of the description to reflect on how the participant worded or phrased the description.

- **Limitations**

- Situational factors such as the location and time of the interview might have influenced the findings. To help minimize this, the participants were able to select the interview location and time to avoid inconvenient hours in their schedule that might cause anxiety or places in which the participants didn't feel comfortable discussing their sibling. A reactive effect might have resulted from the presence of the tape recorder or knowledge that the interview was being recorded, but this was expected to have minimal effect. Intentionally clear wording and re-phrasing of questions was implemented to minimize the misunderstanding of questions that I asked.

- **Lit Review**

- The literature review consisted of two areas of research: sibling relationships in early adulthood and sibling relationships in adulthood with a sibling with a developmental disability. Research in the area of sibling relationships in early adulthood regarded: warmth, conflict, and rivalry in early adult sibling relationships; how sibling relationships change during early adulthood, and communication and closeness between siblings during early adulthood.

- In the second area of research, sibling Relationships in Adulthood when one Sibling has a Developmental Disability, researchers focused on quality of relationships between siblings when one sibling has a developmental disability; sibling involvement in future planning; and support needs and also symptomatology of early adults with a sibling with a developmental disability.

- **Study Design**

- Data collection took place in a location of the participant's choosing or by phone. Only the participant and the researcher were present for the interviews. The interviews were conducted in a room in which the confidentiality of the participant's conversation was ensured.
- The researcher for the study, as in all phenomenological study, was the main instrument for collecting data. The interviews were recorded using the AudioNote application for iPads for later transcription and analysis.

- **Study Design cont'd**

- Participants: There were six participants in the study. There were no exclusions related to race or gender. Participants in the research study met the following criteria: (1) were between the ages of 21 and 35 years old, (2) had a sibling with a diagnosed developmental disability according to the guidelines set by the Federal Developmental Disabilities Act (2000), per participant report, (3) were able to communicate efficiently in the English language, (4) were able to hear (with or without assistive devices). In this study, we used a non-categorical approach to recruiting participants, meaning that we accepted participants as they came through snowball sampling as long as they reported their siblings met the criteria for a developmental disability. The criteria for this study did not require a singular

category of diagnosis for the siblings with a developmental disability. The study, therefore, includes heterogeneous group of diagnoses for the siblings with a developmental disability. We made the assumption that this non-categorical approach was appropriate for this study, as the purpose of this study is not generalization.

- Data collection: Participants were recruited by announcements in person or in the Honors College e-mail newsletter and also through snowball sampling. After the participant expressed clear interest, the interview was scheduled and the participant gave consent for their recording to be used, that they were over the age of 21, and agreed to participate in the study. The participants were asked to participate in a singular interview lasting for one to two hours. Prior to the interview, demographic data for the participants and data about the sibling were collected to provide context. The interview began with the question: "What is your experience in early adulthood of having a sibling with a developmental disability?" All other questions evolved as the interview proceeded.
- Protection: Approval of this research was obtained from the University of Mississippi Institutional Review Board. Informed consent was obtained from the participant prior to the initiation of the interview. Each participant was assigned a participant number, and only the participant number was attached to the data. Participants were also assigned a pseudonym. A chart connecting participant name, pseudonym, and participant number was kept safely.
- **Study Design cont'd**
- Following the hermeneutic process of van Manen (1990), notes were made as themes and thematic statements were encountered and identified. We then investigated and selected

which certain experiential themes were common or possibly common among all participants and represented the meaning of the experience.

- In qualitative research it is assumed that there is no objective position from which to study human beings. The researcher is a self-interpreting being, as is the participant in the study. Meanings in the participant descriptions were not described unless supported by textual evidence. To increase credibility and dependability, Dr. Wilkerson, my adviser, analyzed the data for individual and common themes separately, and later we together discussed and selected the individual and common themes.
- For this study, the phenomenological nod was used to establish credibility. The phenomenological nod is the agreement of others reading or hearing the phenomenological writing of the investigation (Munhall, 1994). All participants contacted concurred that the findings of the study reflected their experiences. The purpose of qualitative study is not to seek generalizability. The task of transferability is that of the person seeking it. Confirmability in this study was established by following closely the analysis process and through the use of phenomenological nod.

- **Research Question**

- The research question was:
What is the early adulthood experience of having a sibling with a developmental disability?

- **Essential Themes**

- Next, I'll discuss the essential themes and influences on the participants' experiences. The findings will be presented in terms of themes and will be supported by quotes from

participants. Five essential themes and eight variations were identified. The variations display how the themes presented differently among the participants.

- **Lessons Learned**

- Each participant expressed that their experience offered lessons to learn. The two variations on this theme were: that there was a lesson to be learned from their sibling and that others had something to learn from their experience. Participants spoke of their siblings with gratitude for the lessons that their experience has afforded them. One participant thought that her sibling was able to teach her a lesson through her perspective on life and even believed that her sibling served as a role model. Some participants expressed that they are the person they are today and have the perspective that they have because of their siblings.
- Kara said *I know for a fact that if she was not my sister that I'm pretty sure I would be a lot more selfish. I guess I would take a lot of stuff for granted honestly. I know I would. I mean I'm not proud of that at all... it's been a lot easier as a teaching lesson for her to be my sister to learn: don't take stuff for granted.*
- Some participants expressed that others have something to learn from their experience. Participants thought that if other individuals without siblings with a developmental disability were exposed to their experiences, other individuals would also learn valuable life lessons.

- Brad said: *I do think we all could learn something by living a day or two with somebody with a disability and seeing how life is with that and really just kind of seeing for the most part, like yourself, that might not have a sibling with a disability to understand and see just how life- you don't know how that life is until you're put into a position to where you know somebody else is dependent on you no matter what. And I'm not saying it's a bad thing. It's not, but it's just more- I consider it knowledge. You know, its more knowledge for somebody to have to understand what it's like to have to go through life like that.*

- **Protective**

- Participants demonstrated their protectiveness in two different ways: by expressing concern and by advocating for their sibling. Participants expressed concern regarding their sibling's safety and well being. One participant expressed concern regarding her sibling's safety as she and her family encouraged more independence. Another participant expressed concern about his sibling being able to handle being in the real world without his help. Another participant similarly expressed concern about her sibling living in a group home or anywhere where she was not able to care for her sibling.
- Brandon said: *It's hard, because I see him- suffering is a harsh word- but suffering down here with no friends, still living with mom and dad, and here I am trying to put my life together. At the same time I want to help him put his life together too. I feel like he counts on me for things that are out of my control.*
- Participants advocated on behalf of their sibling, which was interpreted as a variation of protectiveness. Participants expressed that their sibling should not be messed with and

expressed that their sibling should not be underestimated. One participant demonstrated this variation of protectiveness as he tried to stop a bully from picking on his sibling. One participant advocated for his sibling as he tried to facilitate social situations in which his sibling was involved. He sat down and talked with his friends and also his sibling before his sibling came to stay with him in college. He wanted everyone involved in the social situation to be prepared for the encounter in order to protect his sibling. Participants thought that others underestimated the intelligence and the abilities of their siblings. They defended the intelligence of their siblings despite the fact that they were aware that their sibling had a developmental disability. They also believed that underestimating their siblings was not helping them reach their full potential and full range of capabilities.

- Regan said: *He does make eye contact with you. He's not like not present. I really do believe that something is, you know, he knows more than you think. Just because he can't communicate it with you- there's like little things. You know, I'll talk to him and tell him to close the door of the car, and he closes it. He like takes some time, but he'll do it himself. I'll talk to him. He knows the way home. It's really funny on the way home, if you take this right instead of a left to go to like Starbucks or Publix to get something, and he'll scream in the car and freak out. All I have to do is tell him where I'm going and why I'm going there, and it's really funny.*

- **The Future**

- Each of the participants discussed their contemplations on the future. There were four variations regarding thoughts on the future: financial responsibility for their sibling; future living arrangements for their sibling; having children; managing the future care of their

sibling. Participants said that they intended to become financially responsible for their siblings in the future and had already made some efforts towards that goal. One participant knew she was the executor of her sibling's special needs will and trust. Participants discussed the possible future living arrangements for their siblings. Some participants intended for their sibling to co-reside with them. Some participants intended for their siblings to live in their own space but very close by. One participant thought that his sibling would live with one of his aunts in the future.

- Kara, who intended for her and her husband to co-reside with her sibling, said: *I've mentioned it to my brother, and he's said she is welcome to stay there or it depends on the situation, if she stayed with us for a year or two and then went over there for a year or two. He seemed okay with it, so if something ever happened she was with one of us. That's the most extent that we've talked about it, but I guess when that bridge comes we'll have to make a decision.*
- One participant discussed the intention to have children. She reported that she had already sought the advice of a doctor on whether or not she was at a higher risk for having a child with a developmental disability because of her sibling. Participants discussed the intention to manage care for their sibling. Each intended to participate in the caring for their sibling in some capacity. Some participants reported that their sibling and their care needs influenced their job choice.
- Regan said: *My priority is feeling comfortable in making the next steps that I can make to support him [brother]. So yeah, I'm going to take a better paying job over maybe a cool*

unique job traveling around Europe. I'm going to take the higher paying job that's in America, because its closer to my family and its more financially sound, and it can help me almost, if anything, have a higher and higher salary. I feel almost guilty for thinking that way and thinking that you know I want to get a job that pays a lot. I hated that idea. I'm the most "Follow your passions. Do what you love. Like live through your experiences" type of person, but I also realize like what is my passion? And my passion is my brother and making sure that he's okay always.

- **Intimate with Sibling**

- Each of the participants reported an intimate relationship with their sibling. The participants talked to their sibling frequently and reported a close bond with their sibling, despite varying physical distances between them. The siblings of four participants had cell phones and frequently used them to contact the participants. Some participants illustrated their close relationship with their sibling by describing their continuing communication after they moved away for college or work.
- Harley said: *It was tough at first. He called me a lot. He has a cell phone, which by the way he can operate masterfully. He called me a lot, like every single day. It took him a while to really kind of grasp what I was doing there, why I left, why I wasn't coming home every day. Then it just became that he wanted to do it too. He's always looked up to me and always kind of wanted to do what I'm doing. Then he got it in his mind like, "Well I want to move out and go to college too." The hardest part was him understanding what I was doing and why I was there.*

- The participants described having relationships with their siblings that were intimate and strong enough to overcome obstacles that they faced. They elaborated on the difficulties of maintaining a close sibling bond while also knowing they are in a caretaking position for their sibling as well. The participants seemed eager and willing to make the efforts necessary to help their sibling feel loved and befriended, and the participants also seemed to genuinely have a friend in their sibling.
- Sara said: *She gets a little headstrong. I think we both do, because it is hard because in a way first and foremost we are sisters but at the same time I'm caretaker-ish. I'm very momma-bear, even though she already has a momma-bear.*

- **Pragmatism**

- Pragmatism was a characteristic of participants in this study. The participants realized the good and the bad in life was unavoidable, and they made their best efforts to accept the events of life as they came. They were accepting of their situation and the differences their situation had from others. One way pragmatism manifested was in accommodations made by participants in order to fit their siblings' needs. They described these accommodations as a necessity more than a choice.
- Sara said: *But there are just certain things we couldn't do or had to do in a different way. You know, going out to dinner, we would go early. We would always be the early birds, with the people who were older for the early bird special, because putting your name in and having to wait, and those kinds of things. Going to stores, having to be in line, we would tag team and have someone walk around the store with her while someone else waited in line.*

- One participant expressed pragmatism by discussing the fact that his situation could actually be worse.
- Ben said: *I will say for her personally, there are a lot of Angels [persons with Angelman syndrome] that we know about and are confined to a wheel chair. And she is not, so we feel very fortunate that she can walk on her own, because having someone in a wheelchair on top of not being able to talk and not being able to kind of explain yourself is you know, it just makes things harder. There's really no nice way of putting it, but it's just not great for anybody. We are definitely fortunate that she can walk on her own and get around on her own.*
- Another participant expressed pragmatism by discussing how their family's accommodations were actually not helping his sibling. He expressed that realistically his sibling could achieve more if the family pushed the sibling to do more things instead of catering to the things that the sibling cannot do.
- Brandon said: *I guess when you have a kid, or a brother, with a disability you really want to treat them the same as if they didn't have it you know, like there was no disability, especially with [my brother]. For [my brother] when you're trying to get to the point where he can be independent and live by himself, you have to treat him like a normal person without a disability. Every time you treat him like he has a disability, it cripples him.*

- **Influences**

- The participants described two influences on their early adulthood experience of having a sibling with a developmental disability: their parents and their perception that their experience was normal.

- **Normal to Me**

- Participants related that their perception that their life and their sibling were normal had influenced their early adulthood experience. They had always known their sibling with a developmental disability and would never know their sibling without it. They acknowledged that over time they realized other families were different than their families. While some participants discussed coming to an understanding, they did not remember ever being unaware of their situation. They described their situation as being their version of normal.
- Regan said: *I knew that he had- that he was different, but it was also very confusing, I think to me, because he was my brother and I recognized that it was normal to my family, but then I also started recognizing that it was different to others.*

- **Parents**

- The participants described how influential their parents were on their experience. They identified how their parents facilitated their relationship with their sibling, helped explain to them their sibling's disability, and modeled the accommodations in their daily life in order to help the sibling.

- Sara said: *I think my parents have done an amazing job always being advocates for her, and that's what has gotten me into the field. I think the reason she has progressed as much as she has is because we do know her rights. My parents have always killed with kindness... They were always well educated and worked together. I do see an impact that it had on my parents' marriage. I do think that that's something just like with any children. But their faith was a firm foundation, which taught me a lot of things now that I'm married, you know, how to approach relationships. I generalize what they went through and how they dealt with things, and I think it's a testimony to their faith.*

- **Discussion & Implication**

- Implications: The findings of this study represent new knowledge discovered through descriptions of the participants' accounts of their experiences and has the ability to clarify issues that have been discovered by previous research.
- Practice: Some of these themes and influences pose relevant possibilities for interventions in practice. Firstly, participants believed that there were lessons to be learned from their sibling and their experience. In practice, early adults may feel more supported and understood by others, if others were more knowledgeable about the experience. Secondly, participants expressed protectiveness over their sibling. Because they expressed concern for the mental and emotional health of their sibling when they left for college or work, it could be beneficial for early adults to have access to information on how to best prepare their siblings for the transition and on how to make the actual transition. The majority of participants advocated on behalf of their sibling in situations where they felt someone was messing with their sibling or underestimating their sibling. If more people had knowledge of the practices that upset siblings of individuals with disabilities, less stress would be

placed on the siblings to stand up for their brother or sister. Also, professionals who interact with early adults could help them advocate for their sibling. Thirdly, participants heavily discussed their thoughts about the future. It was reiterated by all participants that they had not been able to create an exhaustive plan for the future and discuss it with their parents. One participant admitted to being scared to initiate the conversation about the future with her parents for fear that she would upset her parents. In practice, it could be beneficial for the parents to initiate the conversation regarding the future. It could also be beneficial in easing the stress of the early adult sibling for parents to discuss with them their plans and desires for the future and to ask for the early adult's input in the plan.

- The reported influence that parents had on participants pose relevant opportunities for interventions in practice. It is possible that parents were such a strong influence in their lives, because in a sibling relationship in which one sibling has a developmental disability, parents are needed to provide a bridge between the siblings and to help the non-disabled sibling to navigate his/her relationship with the sibling with a disability. In practice, it could be beneficial for parents to be cognizant of their role as a mediator so that they may best facilitate the relationship. Parents need to be aware that their approaches and their support influence this experience.
- Education: No other qualitative studies have been conducted to investigate the subjective early adulthood experience of having a sibling with a developmental disability. Those who interact with early adults who have a sibling with a developmental disability could benefit from knowing that by asking the early adult what the experience is like and listening to their account of their experience, they can learn much about the sibling, their experience, and interventions that could help them. Knowledge of the findings of this study could assist parents in better understanding more about the experience of their own early adult who

has a sibling with a developmental disability and could also assist them in initiating conversations with them regarding their experience and how the parents can help them in the experience.

- Research: Replication of this study with samples in setting other than the southern region of the United States with a wider range of ethnic and socioeconomic groups would serve to broaden the existing understanding of the early adults' experience. Longitudinal studies on the subject may provide useful information about differences and similarities of the experience throughout various developmental stages. Additionally, a replication of the study with more numerous diagnoses of the sibling with the developmental disability and increased number of participants in each category of diagnosis would be beneficial in gaining knowledge on the early adulthood experience. This would provide useful information regarding the experience of early adults with siblings with one diagnosis compared to the experience of early adults with siblings with another diagnosis.
- Questions?