Lived Experiences of Disability: Two Life Stories

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Lived Experiences of Disability

Two Life Stories

By
Madison Adrian

An Honors Thesis Submitted in Partial Fulfillment of the Requirements for Graduation from the Western Oregon University Honors Program

Dr. Maria Peterson-Ahmad,
Thesis Advisor

Dr. Gavin Keulks,
Honors Program Director

June 2018
Acknowledgements

Special thanks to:

My parents who have always supported me in everything I do, encouraging me from the very start.

Capernaum YoungLife for fueling my love, fervor and joy for those who have varying abilities and showing me how to love without borders.

Dr. Maria Peterson-Ahmad, who has guided me through this entire process and has consistently challenged me to seek out the purpose and passion of my writing.
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Abstract

This thesis will focus on the lived experiences of two individuals diagnosed with a specific disability and their families. Both individuals present disabilities in different ways: one has a physical disability (Cerebral Palsy) and the other has both a cognitive and physical disability (Down syndrome). Throughout this case study research, the families of these two individuals will be interviewed on a variety of questions including question stems pertaining to:

1) Family and/or individual stress level with raising a child with a disability or self-perceptions of having a disability.

2) How the specific disability may have affected siblings who were diagnosed with a disability and the contribution that had on the family as a whole.

3) How helpful early intervention was and continued to be throughout their school journey.

4) Peer relationships in both the school setting and their personal lives.

The qualitative results from this study will be analyzed through hand coding and through the use of a qualitative coding software (NVivo), depicting specific themes to what each individual/parent discussed. This information will then be reformatted into a poster board presentation, ready to share with a classroom of future educators such as the Introduction to Special Education courses offered in all initial teaching licensure programs at Western Oregon University.

Too often families who have a child with a disability are overlooked, forgotten, pitied, or stereotyped. The results collected from this study aim to
enlighten myself and others in regard to what the families have experienced (both positive and negatively), allowing others to be more knowledgeable in this topic.
Literature Review

Having a child and growing one’s family is something to be celebrated. It is a joyous time for the parent(s) and a time in life where everything is changing, and nothing will be the same again. What most individuals do not think about though, is the fact that there is a possibility of having a child with a developmental disability. The impact that a child with a disability brings to a familial unit cannot be limited to generalizable terms. Rather a developmental disability can include a variety of factors and is categorized as a “group of conditions due to an impairment in physical, learning, language, or behavior areas.” In addition, these conditions occur during the developmental period of a child and have the opportunity to affect day to day motor functions and is usually a lifestyle that cannot be “cured” or “fixed”.

Identifying a child with a disability is not always an easy task. Sometimes one can tell right away and other times the developmental disability does not reveal itself till later on. The way it is revealed later on has to do with the milestones that children accomplish. These milestones are most commonly categorized into three categories: motor development, language development, and social/emotional development. For the first month of a child’s life, most often it has to do with the reflexes of the baby in addition to raising their head while they are on their stomach, keeping their hands in tight fists, focusing on objects/people about 12 inches away and showing a behavioral response when hearing a noise. These milestones jump

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tremendously and by months 8-12 children should be doing a plethora of different things in regard to each category. For their motor skills they should be crawling, placing objects into a container and taking them out again, pull themselves into a standing position and using a pincer grasp. Language skills should be rapidly developing as well with children imitating words, using “ma-ma and da-da”, waving goodbye and using exclamations. Social/emotional skills involve crying when a parent leaves, acting shy around strangers, finding objects hidden easily, and using objects correctly.³ Even though each child develops at their own pace, one can measure this using these common milestones. If it is clear that a child is not meeting these milestones, then it is best to contact your doctor to see what can be done and the next steps to take. Typically, the health care professionals and the parents begin to look for delays and share their concerns with one another. This is called developmental monitoring and is followed by developmental screening where short tests will be given to the children to determine whether they are learning basic skills or not. Once this is determined then early intervention may take place depending on the parents and what they wish for their child.⁴

Often time’s children with a diagnosed disability and their families face many stressful factors in their early years. Parents may be trying to determine what


happened to their child and how they are going to be able to support them; they are grasping at straws to try and be the best parents they can be - focusing on their child but also knowing they still have other responsibilities.⁵

A way to alleviate some of this stress is by entering into the early childhood intervention program which is “designed to mitigate the factors that place children at risk of poor outcomes.” A program like this is designed to provide support for all parts of the family, the parents, children, and the family as a whole. It is there to give training to the parents and structured experiences to the child in order to get them on the right track for their future.⁶ This is primarily done through an Individual Family Support Plan (IFSP) and the services it provides. This plan is the foundation for a family's involvement with early intervention services. It provides the opportunity to lay out all of the services the child should receive and what the hope is for the end goal. This plan takes into account where the child is currently at in regard to their level of functioning and demands. The main focus for this plan is the integral parts a family needs in order to best support their child. However, it is important to note that no action will be taken until there is written consent and it can be declined at any time. There are plenty of opportunities since the IFSP is

reviewed every six months and needs to be updated once a year. This is done together with the family and team, working together every step of the way.  

There are a range of benefits to provide early intervention for the child. If used from the start of a child’s life the program begins at prenatal and ends when the child reaches Kindergarten. There are a variety of approaches to early intervention and they fall into three different categories. In the first program the main concentration is on providing the parents education and support through home visits and/or services in other settings. The second approach is based on pure education, getting each of the children ready for school before they enter into the school system. This way the children can become accustomed to the school sort of environment and they can become comfortable with the idea of it. The last strategy is a combination of the two other approaches, so the parents are being educated but in the same setting as the child. Deciding on which type of these services is best will vary depending on the family, but it will always be a collaborative decision - one that will benefit the entire family with the best possible outcome for all.

As a child enters Kindergarten they will not lose the services that have been provided to them previously through the IFSP. Rather, this student will transition into an Individual Education Plan (IEP) and a team will gather before the child begins Kindergarten in the fall. The IEP will be more geared towards the student’s

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academics and how they can be supported in that particular realm. A team consisted of the parent(s), regular education teacher, special education teacher, school district representative, an individual who can interpret results of the evaluations and anyone else who has special knowledge about the child will meet for an allotted time to discuss how progress of the child will be measured and how often. This plan will be evaluated periodically to determine if there needs to be any changes and if everyone is still in agreement with the trajectory in regard to the students’ academics. An IEP will continue to follow a child as they move on to higher grades and will stay with them until they reach the age of 21 and have graduated from all school resources and support.  

**Down syndrome**

One specific type of developmental disability that will be discussed within this thesis is Down syndrome. This disability occurs when chromosome 21 in an individual is either copied fully or partially and originates in the development of either the sperm or the egg during fetal development. The cause of why this extra chromosome occurs is not known for certain, but one factor has to do with the age of the mother - the older the mother is the more likely it is for a child to be born with Down syndrome. Although each individual is special and unique, there are common physical traits that a majority of those with Down syndrome possess. Most individuals have low muscle tone, an upward slant to the eyes, a smaller stature and

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instead of multiple creases on their palm one single crease across the center.\(^\text{10}\) This disability can be screened for and then examined further through a diagnostic test, so a parent would know before the child is born.\(^\text{11}\) To be even more precise the type of Down syndrome that will be researched thoroughly and interviewed on is trisomy 21. This specific type of Down syndrome is the most common one and makes up for about 95% of all cases of Down syndrome. The cause of why this extra chromosome occurs is not known for certain, but one factor has to do with the age of the mother - the older the mother is the more likely it is for a child to be born with Down syndrome.\(^\text{12}\)

When working with young children diagnosed with Down syndrome there are a few areas to be aware of which is where early intervention services can assist. Often, there may be limitations in speaking to others and language in general. There can also be problems with cognitive levels and nonverbal problem-solving abilities. More specifically, there is a pattern and tradition of young children with Down syndrome to be disruptive, impulsive, hyperactive and defiant behaviors.\(^\text{13}\) These defiant behaviors are often linked to a frustration of not being able to communicate.


effectively or a lack of understanding due to their language complications. Along
with the behaviors is the high likelihood of individuals wandering off. Safety is
incredibly important for everyone, but even more heightened for those who do not
have the language function to ask for help/assistance if needed. Visual supports,
clear distinct plans and consistency are all key in ensuring the safety of individuals
with Down syndrome. In addition, individuals are often very skilled in distracting
adults when they are presented with a difficult task since they do not want to
complete it. This can add to the defiant behaviors causing more disruptions. Studies
have also shown that more often than not these individuals are more anxious about
what is happening around them and have a stubborn bone in their body, not
wanting to be flexible about anything. As far as social behaviors, there is a
commonality of having issues relating to others and being primarily focused on
themselves and what they are doing. Lastly, young children with Down syndrome
usually have more difficulty sleeping and so they are more tired throughout the day
which causes mood problems regularly. By providing early intervention services,
not all the problems families may face are going to instantly go away; however, it
does provide more resources and answers for the family and is another support
system for them to lean on.

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16 Co-Occuring Conditions. (n.d.). Retrieved from 
http://www.ndss.org/Resources/Health-Care/Associated-
Conditions/Mental-Health-Issues--Down-Syndrome/
Cerebral Palsy

The other specific disability that will be discussed and reviewed within this thesis is Cerebral Palsy. Cerebral Palsy affects the movement of individuals in a variety of degrees and ways. However, it is important to note that unlike Down syndrome it is not as easy to know from the start if a child has Cerebral Palsy. Often times, doctors will know for sure within the first year of the child’s life due to the normal developmental milestones that children go through. Narrowing this disability further, one of the individuals interviewed has extrapyramidal, otherwise known as non-spastic Cerebral Palsy. Non-spastic Cerebral Palsy is defined as having decreased and/or fluctuating muscle tone. There are also a few different forms of non-spastic Cerebral Palsy that are determined through certain impairments such as voluntary or involuntary movement. The group of non-spastic that the individual being interviewed is a part of is known as ataxic which only comprises about 5% of all Cerebral Palsy cases. Ataxic Cerebral Palsy affects balance, posture, and coordinated movements making it clear to others when they walk that it is a little irregular and often times individuals with this particular disability have trouble. More often than not, fine motor skills such as writing is difficult to produce since the coordination of the eyes and the hands are impaired. The cause of this disability is traced back to an injury in the brain outside of the pyramidal tract. The placement of the injury also means that mental impairment

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19 http://www.cerebralpalsy.org/about-cerebral-palsy/types-and-forms
and seizures are less likely. However, the ability to speak may be impaired due to physical impairment. It is important to keep in mind that with this uncommon form of Cerebral Palsy there is not usually any cognitive issues or delays, but rather it is purely physical. Common characteristics that individual with Cerebral Palsy may include: having trouble when it comes to eating and drinking, drooling, dental hygiene, osteoporosis, and behaviors.

Eating

Often times, individuals with Cerebral Palsy have issues with their food. Most babies are able to start self-feeding around the age of 9 months; however, babies with Cerebral Palsy lack those fine motor skills and muscle control to do this themselves. One way to help encourage and support individuals in this endeavor is by always ensuring that they are able to see the food on their plate and see their bite before it is fed to them. By repeating this pattern and keeping it consistent a child will hopefully eventually mimic this for themselves and attempt to self-feed.

Depending on the severity of the disability depends on how easy it is for them to be fed. For instance, some individuals have issues moving their jaw or closing their mouths making it difficult for them to eat at all. In order to gain knowledge on what is best for your child it is pertinent that one seeks counsel from an expert so in return the parents/caregivers can become experts. One of the most important aspects though is to keep up the consistency and encouragement. The entire process

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is not easy and it will take measures of patience and understanding from both the individual and the caretaker.\textsuperscript{21}

Drooling

Individuals with Cerebral Palsy may also have excess drooling. This is not due to an excess of saliva; but rather, is caused by not swallowing as much or abnormalities while swallowing. Specifically, drooling most commonly occurs in individuals with Cerebral Palsy, because of poor mouth closure and jaw instability. From the excessive amount of drooling, there may be problems eating, the skin and neck around the mouth may be red and sore, and it can cause the individuals clothes to become wet. Treating this issue can be difficult because it varies case to case; however, it is not commonly treated in those who have Cerebral Palsy, so individuals must learn to navigate this side effect.\textsuperscript{22}

Sleep Issues

Another concern that is more prevalent includes a potential lack of sleep and/or issues with sleep along. Those with Cerebral Palsy are more likely to have sleep difficulties due to a plethora of factors. To start with, they may have trouble falling asleep and then staying asleep because of potential seizures, respiratory issues and trouble breathing. One way to assist with this problem is by getting enough exercise daily. Not only does this help tire the individual out, but it can also

help improve balance and coordination all while strengthening one’s muscles. As for dental care, it is more difficult for those with a disability to receive medical care and is vital they see someone that is experienced in handling someone who has a disability.

**Osteoporosis**

In addition, individuals may have osteoporosis, meaning weak and brittle bones, which is why many people with Cerebral Palsy have braces, wheelchairs, and walkers. There is nothing a family can do to help the child get rid of this, but there are measures to help improve. For instance, individuals with osteoporosis can make sure their diet is full of calcium, vitamin D, and phosphorus. All of these nutrients assist in keeping the bones strong. Therefore, it is highly recommended that parents/guardians reach out to doctors and nutritionists to see what they can do to best support their child.

It is due to these potential issues that an early intervention program may be beneficial for the families and their child. With someone else there guiding the process of everything and helping to answer questions it may assist families in feeling more comfortable with their situation and what their next steps should be.

Raising a child is a scary, yet blissful, time in life. There are always concerns when it comes to making sure one is doing the right thing with their child and being the best parent they can be. Parents and families who have children with a

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developmental disability, specifically Down syndrome or Cerebral Palsy, typically have it just a little harder. These families have to quickly become educated on their child’s disability and learn how to navigate life with them and through them for them to succeed successfully. One way to do this is by entering into an early intervention program and getting the help needed from the experts in order to become an expert. There is a lot of unknown when it comes to raising children, but one thing is known - asking questions and gaining help is never a bad thing.

The next portions of my paper will describe more in depth about specific characteristics associated with Cerebral Palsy and Down syndrome. Additionally, data collection and analysis will be discussed.

**Case Study 1**

The data collected from Participant 1’s FQOL survey (above) proved to be interesting and consistent. This survey is split up into five different categories with a different amount of questions within the categories. Each question is based on the range from 1-5, with 1 being very dissatisfied and 5 as very satisfied. The first part of the survey deals with Family Interaction. Participant 1 appeared to be very satisfied with almost each of the questions, averaging a score of 4.66. From the responses to the questions it is apparent that the family is very close with one another and makes it a priority to care for one another and support those within their family.
The second portion of the survey is on Parenting. The average score for this section was 4.16, so a little lower than Family Interaction but still a very high score. One reason this average is a little lower may be due to the age of the child and where they are at currently in their life. Participant 1 still lives at home, but is in their higher 20’s with a life very individual to them and separate from their family. Due to their particular disability (Cerebral Palsy), they have the ability to partake in more extra-curricular activities and lead a life not connected to their parents. This may be the reasoning behind the score since the parents do not need to be as actively involved within their life.
The next section of the survey is Emotional Well-being. The average score is the highest at 4.75, with almost straight 5’s across the board. This once again may be due to the age of the child with a disability and the type of disability. Since Cerebral Palsy does not need as much one on one attention, the parents have the opportunity to take care of themselves emotionally and ensure they are getting the help/support they need in order to function most effectively.

The fourth section in the FQOL survey is related to Physical / Material Well-being, this portion received an average score of 4.4. This shows that the family is doing well but there is room for improvement and for more security. This may be related to the professions the parents hold and/or the profession the participant holds. Since the participant is over the age of 26, they may not be on their parent’s health care system and so they may not be as comfortable in regard to the questions in this section.
The last portion of the survey is Disability - Related Support and the average was a 4.5. This may be because the participant does not have the ability to progress further while at home, and their only opportunities are away from the house at physical therapy. In addition, another reason for this score may be because they do not have a need for as many service providers therefore they do not have the chance to create and build those great relationships. Overall, participant 1 had very high scores in each of the categories. This indicates that their quality of life is quite high, and they are satisfied with the life they are living.
Case Study 2

Participant 2 also completed the FQOL Survey and the results demonstrate extremely high averages along with a clear consistency. In the first section, Family Interaction, the participant almost consistently answered with a score of 4, and then one 5 resulting in an average of 4.2. This may be due to the disability the participant has (Down syndrome) and their lack of communication skills.

The next portion is Parenting in which the participant scored straight 5’s, demonstrating they are very satisfied with the care they have for one another and the family dynamic at home. This may have something to do with the family’s core values and their strong hold on their faith. Since their faith is so centered on relationships, it is quite possible that this is one of their main priorities which could explain their high score.
The third section is Emotional Well Being where the average score was 4.25. This may be because, once again, of the disability and the amount of time is needed to help care for the individual. The individual with Down syndrome is unable to spend time by themselves; therefore, they always need someone around caring for them. Due to this, the parents may not have any time for themselves and feel as if they could use more time without the extra responsibility of caring solely for someone else.
The fourth section is Physical Material/Well Being and the average score is 4.6. This is another high score and shows that the family feels secure in their life and what they are doing. This could potentially change though as the families get older and the parents have to balance working and potential retirement all while still providing financially for their child who is dependent on them.

The last section in this survey is Disability Related Support and is another section in which the participant answered with all 5’s. This shows they are currently pleased with the support they are getting. This may be because they have had experience in this area and have found people/systems that work well for them and the needs of their child. Another possible explanation is the fact that both the mother and one of the other daughters are the prime caregivers of the participant, so their main disability related support is their immediate family. Overall, the scores for this survey were incredibly high and it is clear that they are satisfied with the life they are living.
Common Themes

Upon looking at the responses to the interview questions and analyzing the FQOL survey it was clear that there was quite a bit of overlap between the two. There was a lot of commonality when conducting the interviews and I felt as if the families had very similar experiences even with raising individuals who have two very different disabilities. In the image below are the words that were frequented most during the two interviews, the larger the word, the more often it was said. Within this image it is clear that there are common themes - three in particular (see image below).
The first theme that was common for both individuals was the advocacy that surrounded them. For Participant 1, who has Cerebral Palsy, it is more of a self-advocacy. From their interview it was clear that they learned to advocate for themselves at a young age. Even though their parents were great supporters and were always there to help assist them, their parents are not at school with them and around them every part of the day. Participant 1 quickly gained a mentality that in order to succeed at life, they needed to be confident in their abilities and be confident in themselves as well. In fact, this Participant just recently wrote a book completely by themselves and in it said, that the “words “no” and “I can’t” are not acceptable answers to unique challenges faced.” So, from the beginning creating an
environment in which there was no tolerance for excuses and that there is always a way. This mindset and advocacy for themselves has influenced a plethora of other individuals as this participant shows through their book and their everyday actions. For Participant 2, who has Down syndrome, the advocacy was mostly found in their family and those who surround them. This Participant has parents that have fought for them as individuals and not just someone who is labeled as a disability. This Participant and family have always participated in activities they have wanted to and have not let anything get in the way. Both Participants have showed either through themselves or their families that there is nothing “wrong” with having a disability and that one should be treated the same and fairly, no matter how different they may appear to be.

**Parenting Styles**

Another common factor between the two Participants is their home life and the parenting styles they grew up with. Not only do they have families that advocate for them, but they also have parents that are still together and are heavily involved. It is not necessarily very common for parents in any marriage to stay together, let alone those with the additional strain of having a child with a disability. One of the largest words in the word frequency visual above is the word “parents”. The parents of the individuals are involved within the child’s life and it is clear through the answers to the interviews and the analyzed results of the FQOL survey that they care deeply and do what they can to be there for their child. In fact, when asked if the Participants got along with their parents both responded with a hearty “yes” considering they both live with their parents and spend time with them each day. In
addition, both seemed to have a slight preference over their mother rather than their father. This may be due to the maternal instincts women have and potentially how much more they are involved in their child’s life. From the analyzed surveys it also appears that the parents are aware for the most part about what is happening in their child’s life, proving that they have a more hands on approach as parents.

**Belief System**

The last common theme I found and perhaps the reason behind each of the other themes is their belief system. Both Participants attend the same church on a weekly basis and are heavily involved within it. Participant 2 volunteers with their mom each week and looks forward to going. In fact, it is one of the only times that this Participant interacts with others outside of their immediate family. Participant 1 grew up going to the youth group and admitted that that is where they found the majority of their friends and the people they still talk to today. Sharing the same belief system could be one plausible explanation for the advocacy that surrounds each of their lives. If one is supposed to be confident in who they are and how they were created than that could quite possibly account for the way they view themselves and how their immediate family views them. In addition, it could account for the parenting styles they received and the way the family functions as a whole. Within their particular belief system, it is discouraged to get a divorce and it is highly encouraged to work things out in a marriage and do your best to stay together. So even if the parents of the Participants were having any trouble, what they believe may sway them to seek guidance and help and work hard to fix things - no matter what is going on. As for the close bond the family holds, that could also be
explained through what they believe. Family is vital and is something to take seriously, so most likely they grew up with this value close to heart and important. Sharing the exact same belief system makes sense when looking at the answers to the interview questions and the results from the survey - both were very similar and shared many commonalities, even for the varying disability.

**Conclusion**

When first embarking on the research of both Cerebral Palsy and Down syndrome, it appeared that the two were completely different from one another and had hardly any similarities. In fact, it seemed as if the only commonality between the two were that they were labeled as a disability and needed additional accommodations. Furthermore, from the outside it seemed as if their life experiences would be completely and vastly different from one another. This thought and belief stayed true as both disabilities were researched further, and more information became present. For instance, on paper it seems that Down syndrome requires more intense care and assistance due to the varying medical factors and the limitations associated with the disability. Meanwhile, Cerebral Palsy (specifically the type discussed) appears to have a little bit more of an opportunity to be independent and self-sufficient. On paper both disabilities seemed to have a lot of factors going against them with little commonalities and quite a bit of extra focus and special attention. However, upon interviewing individuals who have Down syndrome and Cerebral Palsy, asking the parents of the individuals to complete a FQOL survey and analyzing the results - it was clear that their lived experiences
were quite similar in a plethora of ways. Both individuals are closely connected with their family and hold strong ties within their church. They are both surrounded by others who encourage them to live their life to the fullest and who help advocate and fight for them. Both of them had positive school experiences and are social with others when provided with the opportunity. The lived experiences of both participants are one full of hardships yet showered with joy and self-discovery. Both have powerful stories to tell and one can learn immensely from taking the time to hear these stories.
Bibliography


This source gives statistics about how many birth defects there are each year and what the ranges of disability can be.


This source has a plethora of facts about Down syndrome and are just in a bullet point list, ranging from statistics to fun facts.


Appendices
### A. GENERAL INFORMATION

<table>
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<tr>
<th>Project/Study Title:</th>
<th>Lived Experiences of Disability: Two Life Stories</th>
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<tbody>
<tr>
<td>Principal Investigator#1 Name:</td>
<td>Madison Adrian</td>
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<td>Faculty Advisor Name:</td>
<td>Maria Peterson-Ahmad, Ph.D.</td>
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<td>College Address:</td>
<td>345 Monmouth Ave. N., Monmouth, OR</td>
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| Other: (e.g., other university, community organization) | |
**Ethics and Compliance Training**: All Principal Investigators and research team members, including Faculty Advisors involved in this project/study must receive training in the ethical use of human participants in research. WOU supports this federal training requirement and has identified an online training program offered through the National Institute of Health (NIH) Office of Extramural Research to meet this requisite. The NIH public access course in the Responsible Conduct of Research is available to the WOU community free of charge.

The NIH training is available at http://phrp.nihtraining.com/users/login.php
IRB applications must have **NIH Certificate of Completion attached** to them unless certificates were previously submitted and are on file with the IRB.

**B. IRB APPLICATION DIRECTIONS**

a. Type your responses to each question. DO NOT leave a question blank. Throughout the application, if a question does not apply to your protocol, write "n/a".
b. Review your application for grammar, spelling, thoroughness, and comprehensive information. Applications with errors such as these will be returned.
c. Have the IRB representative from your College or Department review your application before submitting it to the IRB Chair.
d. Student applications must be signed by a Faculty member. The faculty member’s signature indicates s/he has read and approved the application.
e. Please have one original and appropriate copies of your application depending on the level of review. Exempt and Expedited reviews require one original and two copies. Full Board requires one original and seven copies.
f. Submit your application to the IRB via campus mail. If you have questions that are not answered on the website or in this application, you may contact the IRB by phone at 503.838.9200.
g. The signature page must be mailed to the IRB or scanned and sent via email as a PDF before final review will begin.

**C. ANTICIPATED LEVEL OF REVIEW**

**Investigator Prediction of Type of Review**

*See Level of Review Categories to determine your research – please select one level and category number.*

- **Exempt**
  - Provide category # (1-6) __________
- **Expedited**
  - Provide category # (1-7) __________
- **Full Board**

IRB Application p. 2 of 9
D. PURPOSE & DESIGN (Complete in a Word document & submit with this application).

PURPOSE: Describe the purpose of the study.

DESIGN: Describe the research design and procedures. Clearly specify what the participants will do.

E. DATA COLLECTION

01/01/2018

Estimated data completion date: _______________ mm-dd-yyyy

IRB Approvals are good for one full year from date of approval. Renewal applications are required if data collection is to continue after one year.

1. Check (X) the methods to be used

<table>
<thead>
<tr>
<th>Survey, administered by</th>
<th>Interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>☑ Investigator</td>
<td>☑ One-on-One</td>
</tr>
<tr>
<td>☐ Participant Self-report</td>
<td>☐ Focus Group</td>
</tr>
<tr>
<td>☐ Mail</td>
<td>☐ E-mail or Online</td>
</tr>
<tr>
<td>☐ Phone</td>
<td>☐ Oral History</td>
</tr>
<tr>
<td>☑ In Person</td>
<td>☐ Other</td>
</tr>
<tr>
<td>☐ Online</td>
<td></td>
</tr>
</tbody>
</table>

Note: If you are using a survey or doing interviews, you must submit a copy of the survey items or interview questions.

<table>
<thead>
<tr>
<th>Observation of Public Behavior</th>
<th>Examination of Archived Data or Records</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ In classroom</td>
<td>☐ Academic</td>
</tr>
<tr>
<td>☐ At public meetings</td>
<td>☐ Medical</td>
</tr>
<tr>
<td>☐ Other</td>
<td>☐ Legal</td>
</tr>
<tr>
<td></td>
<td>☐ Other</td>
</tr>
</tbody>
</table>
### Taste/Sensory Evaluation

<table>
<thead>
<tr>
<th>Option</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Food Tasting</td>
<td>Visual</td>
</tr>
<tr>
<td>Olfactory</td>
<td>Examination of Tissue Specimens</td>
</tr>
<tr>
<td>Auditory</td>
<td></td>
</tr>
</tbody>
</table>

### Therapeutic

<table>
<thead>
<tr>
<th>Option</th>
<th>Experimental</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biomedical</td>
<td>Biomedical</td>
</tr>
<tr>
<td>Psychological</td>
<td>Psychological</td>
</tr>
<tr>
<td>Physical Therapy</td>
<td>Other</td>
</tr>
</tbody>
</table>

Other: Please describe.

2. **Data from Participants** – select one (X)

- [ ] Anonymous – You will not ask for participant's name
- [x] Confidential – You will ask for participants' names, but will keep the names confidential. Readers of your research will be unable to tell the identity of the participants and there will be no way to connect particular participants with particular data.
- [ ] Intentionally Identified

If participants will be identified, describe how permission to use data in connection with participants' identities is obtained. If anonymous or confidential, describe how anonymity or confidentiality will be maintained (e.g., coded to a master list and separated from data, locked cabinet, office, restricted computer, etc.). Indicate who will have access to the data.

3. **Will any of the following be recorded?** Check to indicate Yes.

- [ ] Video tapes/recordings
- [x] Audio tapes/recordings
- [ ] Photographs

If you answered YES for any of the above, where will tapes/recordings or photographs be stored? When will this material be destroyed (e.g., within 5 years of a published paper)? How will confidentiality be maintained? Describe below:

Audio recordings will be stored in a digital file within a password protected, online storage folder (Google Drive), that only the researcher and the faculty advisor will have access to.
F. DESCRIPTION OF PARTICIPANTS

1. Approximate number: 3  Age Range (e.g., 18 to 24) 22-50

2. How will participants be selected or recruited? (Attach Word document).

3. Will participants be compensated (include extra credit)? ☐ yes  ☐ no
   If yes, how much, when and how? Must they complete the project to be paid?

4. What form of consent will be obtained? In most situations a written informed consent is required. (See Frequently Asked Questions about the Consent process.)
   ☐ Implied (attach cover letter or describe terms)
   ☐ Verbal (attach consent script)
   ☒ Written – adult participants (attach adult consent form)
   ☐ Written – minor participants (attach youth assent form)
   ☐ Seeking Waiver of Consent (contact the IRB for further information)
   ☐ Consent Not Applicable (e.g., archival data.)
   Explain why consent is not applicable or necessary on a separate page.

5. Are any participants not legally competent to give consent? (e.g., those who are minors and/or under care of guardian). ☒ Yes  ☐ No
   If yes, please describe how consent will be obtained. Please Note: a parent or guardian must sign and return an informed consent form for participants who are under 18 years of age. In addition, it is recommended that you also obtain assent from minors if they are old enough to read and write.

   One of the participants cannot sign the consent themselves, due to physical limitations from their disability. This person’s parent will sign the form and give consent for participation on their behalf.

6. Will any ethnic group or gender be excluded from the study pool? ☐ Yes  ☒ No
   If yes, justify the exclusion.
7. Is this study by design likely to involve any participants who are not fluent in English?  ☐ Yes  ☒ No

If yes, submit both the English and translated versions of consent forms and surveys, if applicable. If research participants do not speak or read English well enough to understand information about the research study/project and the Informed Consent and/or Student Assent forms, these documents must be provided in the language of the participant(s). Qualified translators should be used and translated documents should be included with this application. You should give a full explanation of your procedures in this section.

8. Does this study involve participants located outside of the United States?  ☐ yes  ☒ no

If yes, please explain exactly "who the participants are," and the identities (if possible) and responsibilities of any additional investigators.

G. DECEPTION

If the research protocol is designed to withhold complete information when consent is obtained, then some level of deception is involved. If deception is required for the validity of the research, explain why this is necessary. Include a description of when and how participants will be debriefed regarding the deception. If a participant objects to the deception and does not want his/her data included in the study, explain what you will do.
H. RISKS AND BENEFITS

1. Describe any potential risks to the participants, and describe how you will minimize these risks. These include stress, discomfort, social risks (e.g., embarrassment), legal risks, invasion of privacy, and side effects.

   There are no foreseen risks with this study.

2. In the event that any of these potential risks occur, how will they be handled (e.g., compensation, counseling, etc.)?

3. Will this study interfere with participants' normal routines (e.g., prevent them from going to class and/or work)?  [ ] yes  [ ] no

   If yes, the participant needs to agree that the researcher is not liable for the disruption.

4. Describe the expected benefits to the individual participants and to members of society.

   Potential benefits include increased knowledge and awareness on families lived experiences having a child with Down syndrome or cerebral palsy. This may also inform pre-service teachers about the importance of family advocacy, communication, and interaction.

5. If blood or other biological specimens will be taken please address the following

   a. Brief description of sampled tissue

   b. Describe the personnel involved and procedure(s) for obtaining the specimen(s). Note that the IRB requires that only trained certified or licensed persons may draw blood. Contact the IRB for more details on this topic.
I. DRUGS AND ALCOHOL

1. Will any investigational new drug (IND) be used? ☐ yes ☐ no

2. Will any other drugs be used? ☐ yes ☐ no

3. Will alcohol be ingested by the participants? ☐ yes ☐ no

J. RESEARCH/PROJECT FUNDING

1. Is there, or will there be extramural funding that directly supports this research? ☐ yes ☐ no

If yes, list the funding agency: ____________________________________________

List the PI(s) of the funded grant: __________________________________________

K. INVESTIGATOR’S ASSURANCES

This investigation involves the use of human participants. I understand the university’s policy concerning research involving human participants, and I agree:

1. To obtain voluntary and informed assent/consent of persons who will participate in this study, as required by the IRB.

2. To report to the IRB any adverse effects on participants which become apparent during the course of, or as a result of, the activities of the investigation.

3. To cooperate with members of the IRB charged with review of this project, and to give progress reports as required by the IRB.

4. To obtain prior approval from the IRB before amending or altering the project or before implementing changes in the approved consent form (i.e., changes that would alter what is required of the participant).

5. To not collect any data until full approval by the IRB has been acknowledged.

6. To maintain documentation of IRB approval, consent forms and/or procedures together with the data for at least three years after the project has been completed or paper has been published—whichever is later.

7. To treat participants in the humane manner specified on this form.
Principal Investigators

By signing below, I certify that the information provided in this application is accurate and complete. I understand that research involving human participants, including the recruitment, may not begin until full approval has been granted by the IRB, and that the project will be conducted in accordance with the above assurances.

Signature: Madison Adem  
Print Name: Madison Adrian  
Date: 4/20/17

Signature:  
Print Name:  
Date: 

Signature:  
Print Name:  
Date: 

Signature:  
Print Name:  
Date: 

Faculty Sponsor (If PI is a student)

The information provided in this form is accurate and the project will be conducted in accordance with the above assurances.

Signature:  
Print Name: Maria Peterson-Ahmad  
Date: 4/20/17

Email address: petersonahmad@mmeu.edu  
Phone: 503-838-9286

INSTITUTIONAL REVIEW BOARD: These assurances are acceptable and this project has adequate protections for participants. This project has been properly reviewed and filed, and is in compliance with federal, state, and university regulations.

Signature:  
Print Name:  
Date: 

IRB ONLY: This protocol has been reviewed and approved as:

Exempt  
Expedited  
Full Board
PURPOSE: Describe the purpose of the study.

According to the March of Dimes, one in approximately 33 children who are born in the U.S. has a birth defect. Among that number, there are approximately 6000 babies born with Down syndrome each year and 1-2 babies out of 1000 are born with cerebral palsy. These are significant numbers and definitely play a large role in family day to day life. Dependent on the type and/or severity of specific disabilities, these diagnoses may impact the degree to which the family is involved with their disabled and non-disabled children; variation in daily spousal interactions; relationship among siblings (if applicable), and the family unit as a whole. The purpose of this project will examine the lives of two individuals and how different and/or similar their experiences were, based on the following: disability, early intervention, classroom setting, peer relationships, and family relationships. By comparing each family (N=2) and analyzing their answers to the questions on the FQOL survey and interview, I hope to inform myself and future educators about families lived experiences both with Down syndrome and cerebral palsy.

DESIGN: Describe the research design and procedures. Clearly specify what the participants will do.

This study will be mixed-methods in nature as it will collect data from each set of parents through the Family Quality of Life (FQOL) survey (quantitative), and interviews from family members (qualitative). Interview questions will be driven by answers provided on the FQOL Scale; however, additional questions may arise based on the individual experiences of each family. (Please see attached survey protocol in addition to examples of potential interview questions).

How will participants be selected?

Participants will be selected through convenience sampling, as the researcher already has previous connections with these families.
Western Oregon University
Division of Health and Physical Education
Informed Consent for Research Involving Human Subjects

Title of Project:
Lived Experiences of Disability: Two Life Stories

Principal Investigator: Madison Adrian
Office Phone: 503-860-4195 e-mail: madrian14@wou.edu

Faculty Advisor: Maria Peterson-Ahmad, Ph.D.
Office Phone: (503) 838-9296 e-mail: petersonahmadm@wou.edu

Background:
This undergraduate honors thesis will examine the lives of two individuals and how different and similar their experiences were based on the following subjects: disability, early intervention, classroom setting, peer relationships, and family relationships. Cerebral palsy and Down syndrome are some of the better-known disabilities; however, that does not mean educators and future educators are aware of their impacts on families. Early intervention is essential in order to help minimize any potential delays due to disabilities, this ties into the classroom setting and whether or not it served each individual with what they need in order to succeed. Peer relationships also play an insurmountable role as friendships can really help shape an individual and how they feel about themselves. Lastly, family relationships are vital in either building the individual up and aiding them in their growth or breaking them down. By comparing each family and analyzing their answers to the questions, I hope to inform future educators about two representative families lived experiences with these diseases.

Methods:
Each parent the Family Quality of Life (FQOL) Scale to complete, which is divided into five sub-sections including: 1) family interaction, 2) parenting, 3) emotional well-being, 4) physical/material well-being, and 5) disability. This scale was created by Hu, Summers, Turnbull, and Zuna. These scale responses will allow me to determine specific themes that will assist me to further develop more specific interview questions that will allow for deeper understanding into specific aspects of each family and/or individual within this study.

The interviews will be conducted in a one-on-one setting. First, I will speak with the parent of the individual with Down syndrome, because the affected child is unable to communicate independently. Second, I will speak with the parent of the individual with cerebral palsy. Lastly, I will also directly interview the individual with cerebral palsy as his disability does not deter him from communicating independently. Parents are allowed to be present at any time, even though the interviewed individuals are over the age of 18. As stated earlier, interview questions will be driven by answers given on the pre-interview FQOL Scale; however, potential questions that may arise include, but will not be limited to, inquiry about family school experiences, early intervention, classroom environment and effectiveness of the IEP, and peer relationships had throughout school career.
Data analysis will be completed with qualitative methods including hand coding and the NVivo qualitative analysis software. Themes from the interviews will be noted and used to discuss study findings and potential future directions. The information gathered will then be compiled into a poster board and made into a presentation ready to share with others as a learning experience.

Risks:

There are no potential risks associated with this study.

*It is important for you to understand that you may withdraw from the investigation at any time without prejudice or effect on your relationship to Western Oregon University. If you withdraw, any information/data collected will be destroyed and will not be used in this study.*

Benefits:

While you will not be compensated monetarily, you may benefit from knowing that you are helping to expand the knowledge base.

The results will be kept confidential and will be maintained (your name will not be recorded on the data sheets).

This study has been reviewed and approved by the Western Oregon University Institutional Review Board (IRB). Should you have any questions or concerns throughout the course of the study, you may contact Dr. Researcher by phone or e-mail. If you have questions/concerns regarding your treatment as a subject, you may contact the Chair of the WOU Institutional Review Board (IRB) at 503-838-9200 or via e-mail at irb@wou.edu.

You will be given a copy of this information to keep for your records.
Title of Project:  
Lived Experiences of Disability: Two Life Stories

Principal Investigator: Madison Adrian  
Office Phone: 503-860-4195  
e-mail: madrian14@wou.edu

Faculty Advisor: Maria Peterson-Ahmad, Ph.D.  
Office Phone: (503) 838-9296  
e-mail: petersonahmadm@wou.edu

I, ____________________________, hereby give my consent to participate in the research study entitled Lived Experiences of Disability: Two Life Stories, details of which have been provided to me above, including anticipated benefits, risks, and potential complications.

I fully understand that I may withdraw from this research project at any time. If I do withdraw, and data/information collected will be destroyed and will not be used in this research study.

I also understand that I am free to ask questions about any techniques or procedures that will be undertaken.

Finally, I understand that the information about me obtained during the course of this study will be kept confidential unless I consent to its release. (Return signature page to researcher; keep remaining pages for your records.)

______________________________  
Participants Signature

I hereby certify that I have given an explanation to the above individual of the contemplated study and its risks and potential complications.

______________________________  4/20/17  
Principal Investigator
Instrument Title: The Family Quality of Life Scale (FQOL)
Instrument Author: Beach Center on Disability
Cite instrument as: Beach Center on Disability. (2012). The Family Quality of Life Scale (FQOL). Measurement Instrument Database for the Social Science.
Retrieved from www.midss.ie
FAMILY QUALITY
OF LIFE SURVEY

Developed by the Beach Center on Disability
The University of Kansas
in partnership with families, service providers and researchers.

For information, contact:
Jean Ann Summers, Ph.D.
Research Director, Beach Center on Disability
jsummers@ku.edu

Suggested reference for reports utilizing this instrument:
Assessing family outcomes: Psychometric evaluation of the beach center

Beach Center on Disability
Making a Sustainable Difference in Quality of Life
Survey Information and Instructions

All the information you give us is confidential. Your name will not be attached to any of the information you give us. It is important that you answer as many questions as you can, but please feel free to skip those questions that make you feel uncomfortable.

Answering questions: Please use a pencil to check your answers. Use a check Mark ☑ or “X” – please do NOT shade in the whole box. If you change any answers, please completely erase any previous answers or any extra pencil marks on the page. Please do not make any stray marks, including comments, on the form. If you have comments to share, you may e-mail them to Jean Ann Summers (jsummers@ku.edu).

Thank you so much for sharing your opinion with us!

By completing this survey, you indicate that you have been informed of the important aspects of this study.
Thank you for agreeing to complete this survey. The survey is about how you feel about your life together as a family. We will use what we learn from families to inform policy makers and service providers for children and families.

Your "family" may include many people - mother, father, partners, children, aunts, uncles, grandparents, etc.

For this survey, please consider your family as those people

✓ Who think of themselves as part of your family (even though they may or may not be related by blood or marriage), and

✓ Who support and care for each other on a regular basis.

For this survey, please DO NOT think about relatives (extended family) who are only involved with your family every once in a while. Please think about your family life over the past 12 months.

The items below are things that hundreds of families have said are important for a good family quality of life. We want to know how Satisfied you are with these things in your family. Please check the boxes on the following pages that reflect your level of satisfaction with each item.

✓ Checking the first square means you are very dissatisfied.

✓ Checking the fifth square means you are very satisfied.

Thank you so much for sharing your opinion with us!
<table>
<thead>
<tr>
<th>How satisfied am I that...</th>
<th>Very Dissatisfied</th>
<th>Dissatisfied</th>
<th>Neither</th>
<th>Satisfied</th>
<th>Very Satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My family enjoys spending time together.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. My family members help the children learn to be independent.</td>
<td></td>
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<tr>
<td>3. My family has the support we need to relieve stress.</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>4. My family members have friends or others who provide support.</td>
<td></td>
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<tr>
<td>5. My family members help the children with schoolwork and activities.</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>6. My family members have transportation to get to the places they need to be.</td>
<td></td>
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</tr>
<tr>
<td>7. My family members talk openly with each other.</td>
<td></td>
<td></td>
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<tr>
<td>8. My family members teach the children how to get along with others.</td>
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</tr>
<tr>
<td>9. My family members have some time to pursue our own interests.</td>
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<tr>
<td>10. Our family solves problems together.</td>
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<td></td>
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<tr>
<td>11. My family members support each other to accomplish goals.</td>
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<td></td>
</tr>
<tr>
<td>12. My family members show that they love and care for each other.</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>13. My family has outside help available to us to take care of special needs of all family members.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Adults in our family teach the children to make good decisions.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
# FAMILY QUALITY OF LIFE (cont.)

<table>
<thead>
<tr>
<th>How satisfied am I that...</th>
<th>Very Disatisfied</th>
<th>Dissatisfied</th>
<th>Neither</th>
<th>Satisfied</th>
<th>Very Satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>15. My family gets medical care when needed.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. My family has a way to take care of our expenses.</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>17. Adults in my family know other people in the children’s lives (friends, teachers, etc.).</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>18. My family is able to handle life's ups and downs.</td>
<td></td>
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</tr>
<tr>
<td>19. Adults in my family have time to take care of the individual needs of every child.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. My family gets dental care when needed.</td>
<td></td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>21. My family feels safe at home, work, school, and in our neighborhood.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>22. My family member with a disability has support to accomplish goals at school or at workplace.</td>
<td></td>
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</tr>
<tr>
<td>23. My family member with a disability has support to accomplish goals at home.</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>24. My family member with a disability has support to make friends.</td>
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<td></td>
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<td></td>
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<tr>
<td>25. My family has good relationships with the service providers who provide services and support to our family member with a disability.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Thank you! You have finished completing this survey. Please make sure you erase any extra marks and have answered all the questions.
This research was conducted in collaboration with the Beach Center on Disability. It was funded by the Rehabilitation Research and Training Center on Families of Children with Disabilities of the National Institute on Disability Rehabilitation and Research (H133B30070) and private endowments. Permission granted to reproduce and distribute this research tool.

Beach Center on Disability  
The University of Kansas  
1200 Sunnyside Avenue, 3136 Haworth Hall  
Lawrence, Kansas 66045  
Telephone: 785.864.7600  
TTY: 785.864.3434  
www.beachcenter.org  
beachcenter@ku.edu
Potential Interview Questions

**These may change based on participant answers on the FQOL survey and how the natural conversation flows during the interview process**

Family Experiences:

1. How many siblings do you have?
2. Are they older or younger?
3. Do you get along with them?
4. Can you provide an example of a time where your disability affected your relationship with a sibling?
5. Has your sibling(s) aided you a lot with your disability? Are you reliant on them?
6. Are your parents together?
7. Have they mostly assisted you?
8. How many hours a day do you spend time with your parents/siblings?
9. Do you get along with your parents?
10. Are you closer with your mom or dad? Why?

Peer Interactions:

1. How often do you interact with friends?
2. Are you able to hang out alone or is someone else there?
3. What sort of activities do you and your friends participate in?
4. How difficult has it been to make friends?
5. Do your friends have disabilities?
6. Have your friends assisted you? If so, how often?
7. Do you and your friends get along?
8. Would you say they understand your situation or is unknown do them? (Are they knowledgeable about your disability?)
9. Have you felt accepted by your peers?
10. If not, why is that?
11. Have your found the majority of your friends at school or in different settings?

School/Early Intervention:

1. When did early intervention begin?
2. What has early intervention looked like for you? Your family?
3. Has it been helpful?
4. Has it continued on throughout your school career?
5. Has each of your classroom settings been adaptable?
6. If not, what has been the issue?
7. Do you have examples of your IEP's?
8. How do you think the classroom could have been more helpful with your disability?
9. Have your teachers been accommodating?
10. Were you in a mainstream classroom or in a resource room?
11. If you could change one thing about your school career—what would it be and why?
COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI PROGRAM)
COMPLETION REPORT - PART I OF 2
COURSEWORK REQUIREMENTS*

* NOTE: Scores on this Requirements Report reflect quiz completions at the time all requirements for the course were met. See list below for details. See separate Transcript Report for more recent quiz scores, including those on optional (supplemental) course elements.

- Name: Madison Adrian (ID: 5980834)
- Institution Affiliation: Western Oregon University (ID: 2993)
- Institution Email: madrian14@wou.edu
- Institution Unit: Honors Thesis

- Curriculum Group: Group 1: All WOU Researchers
- Course Learner Group: Same as Curriculum Group
- Stage: Stage 1 - Basic Course
- Description: Choose this group to satisfy CITI training requirements for investigators and staff involved primarily in biomedical research with human subjects.

- Record ID: 21571891
- Completion Date: 17-Apr-2017
- Expiration Date: 16-Apr-2020
- Minimum Passing: 80
- Reported Score*: 99

REQUIRED AND ELECTIVE MODULES ONLY

<table>
<thead>
<tr>
<th>Module Description</th>
<th>Date Completed</th>
<th>Score</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>History and Ethical Principles - SBE (ID: 490)</td>
<td>16-Apr-2017</td>
<td>5/5</td>
<td>100%</td>
</tr>
<tr>
<td>Defining Research with Human Subjects - SBE (ID: 491)</td>
<td>17-Apr-2017</td>
<td>5/5</td>
<td>100%</td>
</tr>
<tr>
<td>The Federal Regulations - SBE (ID: 502)</td>
<td>17-Apr-2017</td>
<td>5/5</td>
<td>100%</td>
</tr>
<tr>
<td>Assessing Risk - SBE (ID: 503)</td>
<td>17-Apr-2017</td>
<td>5/5</td>
<td>100%</td>
</tr>
<tr>
<td>Informed Consent - SBE (ID: 504)</td>
<td>17-Apr-2017</td>
<td>5/5</td>
<td>100%</td>
</tr>
<tr>
<td>Privacy and Confidentiality - SBE (ID: 505)</td>
<td>17-Apr-2017</td>
<td>5/5</td>
<td>100%</td>
</tr>
<tr>
<td>Research with Prisoners - SBE (ID: 506)</td>
<td>17-Apr-2017</td>
<td>5/5</td>
<td>100%</td>
</tr>
<tr>
<td>Research with Children - SBE (ID: 507)</td>
<td>17-Apr-2017</td>
<td>5/5</td>
<td>100%</td>
</tr>
<tr>
<td>Research in Public Elementary and Secondary Schools - SBE (ID: 508)</td>
<td>17-Apr-2017</td>
<td>5/5</td>
<td>100%</td>
</tr>
<tr>
<td>International Research - SBE (ID: 509)</td>
<td>17-Apr-2017</td>
<td>5/5</td>
<td>100%</td>
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<tr>
<td>Internet-Based Research - SBE (ID: 510)</td>
<td>17-Apr-2017</td>
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<td>100%</td>
</tr>
<tr>
<td>Unanticipated Problems and Reporting Requirements in Social and Behavioral Research (ID: 14928)</td>
<td>17-Apr-2017</td>
<td>5/5</td>
<td>100%</td>
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<tr>
<td>Belmont Report and CITI Course Introduction (ID: 1127)</td>
<td>17-Apr-2017</td>
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<td>Conflicts of Interest in Research Involving Human Subjects (ID: 488)</td>
<td>17-Apr-2017</td>
<td>5/5</td>
<td>100%</td>
</tr>
<tr>
<td>Cultural Competence in Research (ID: 15166)</td>
<td>17-Apr-2017</td>
<td>4/5</td>
<td>80%</td>
</tr>
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</table>

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COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI PROGRAM)
COMPLETION REPORT - PART 2 OF 2
COURSEWORK TRANSCRIPT**

** NOTE: Scores on this Transcript Report reflect the most current quiz completions, including quizzes on optional (supplemental) elements of the course. See list below for details. See separate Requirements Report for the reported scores at the time all requirements for the course were met.

- Name: Madison Adrian (ID: 5909934)
- Institution Affiliation: Western Oregon University (ID: 2993)
- Institution Email: madrian14@wou.edu
- Institution Unit: Honors Thesis

- Curriculum Group: Group 1: All WOU Researchers
- Course Learner Group: Same as Curriculum Group
- Stage: Stage 1 - Basic Course
- Description: Choose this group to satisfy CITI training requirements for Investigators and staff involved primarily in biomedical research with human subjects.

- Record ID: 21571891
- Report Date: 20-Apr-2017
- Current Score**: 96

REQUIRE, ELECTIVE, AND SUPPLEMENTAL MODULES

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<tr>
<th>Module</th>
<th>MOST RECENT</th>
<th>SCORE</th>
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<tbody>
<tr>
<td>History and Ethical Principles - SBE (ID: 493)</td>
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<tr>
<td>Defining Research with Human Subjects - SBE (ID: 491)</td>
<td>17-Apr-2017</td>
<td>5/5 (100%)</td>
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<tr>
<td>Belmont Report and CITI Course Introduction (ID: 1127)</td>
<td>17-Apr-2017</td>
<td>3/3 (100%)</td>
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<tr>
<td>The Federal Regulations - SBE (ID: 502)</td>
<td>17-Apr-2017</td>
<td>5/5 (100%)</td>
</tr>
<tr>
<td>Assessing Risk - SBE (ID: 503)</td>
<td>17-Apr-2017</td>
<td>5/5 (100%)</td>
</tr>
<tr>
<td>Informed Consent - SBE (ID: 504)</td>
<td>17-Apr-2017</td>
<td>5/5 (100%)</td>
</tr>
<tr>
<td>Privacy and Confidentiality - SBE (ID: 505)</td>
<td>17-Apr-2017</td>
<td>5/5 (100%)</td>
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<tr>
<td>Research with Prisoners - SBE (ID: 506)</td>
<td>17-Apr-2017</td>
<td>5/5 (100%)</td>
</tr>
<tr>
<td>Research with Children - SBE (ID: 507)</td>
<td>17-Apr-2017</td>
<td>5/5 (100%)</td>
</tr>
<tr>
<td>Research in Public Elementary and Secondary Schools - SBE (ID: 509)</td>
<td>17-Apr-2017</td>
<td>5/5 (100%)</td>
</tr>
<tr>
<td>International Research - SBE (ID: 509)</td>
<td>17-Apr-2017</td>
<td>5/5 (100%)</td>
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<tr>
<td>Internet-Based Research - SBE (ID: 510)</td>
<td>17-Apr-2017</td>
<td>5/5 (100%)</td>
</tr>
<tr>
<td>Unanticipated Problems and Reporting Requirements in Social and Behavioral Research (ID: 14928)</td>
<td>17-Apr-2017</td>
<td>5/5 (100%)</td>
</tr>
<tr>
<td>Conflicts of Interest in Research Involving Human Subjects (ID: 488)</td>
<td>17-Apr-2017</td>
<td>5/5 (100%)</td>
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<tr>
<td>Cultural Competence in Research (ID: 15166)</td>
<td>17-Apr-2017</td>
<td>4/5 (80%)</td>
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</tbody>
</table>

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Email: support@citiprogram.org
Phone: 888-523-5929
Web: https://www.citiprogram.org
This is to certify that:

Madison Adrian

Has completed the following CITI Program course:

Group 1: All WOU Researchers  (Curriculum Group)
Group 1: All WOU Researchers  (Course Learner Group)
1 - Basic Course  (Stage)

Under requirements set by:

Western Oregon University

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COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI PROGRAM)
COMPLETION REPORT - PART 1 OF 2
COURSEWORK REQUIREMENTS*

* NOTE: Scores on this Requirements Report reflect quiz completions at the time all requirements for the course were met. See list below for details. See separate Transcript Report for more recent quiz scores, including those on optional (supplemental) course elements.

- Name: Maria Peterson-Ahmad (ID: 3392014)
- Email: petersonahmadm@wou.edu
- Institution Affiliation: Western Oregon University (ID: 2993)
- Institution Unit: Education
- Curriculum Group: Group 1: All WOU Researchers
- Course Learner Group: Same as Curriculum Group
- Stage: Stage 1 - Basic Course
- Description: Choose this group to satisfy CITI training requirements for Investigators and staff involved primarily in biomedical research with human subjects.
- Report ID: 19777500
- Completion Date: 14-Aug-2016
- Expiration Date: 14-Aug-2019
- Minimum Passing: 80
- Reported Score*: 88

REQUIRED AND ELECTIVE MODULES ONLY

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<th>Module</th>
<th>Date Completed</th>
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<td>History and Ethical Principles - SBE (ID: 490)</td>
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<td>4/5 (80%)</td>
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<tr>
<td>Defining Research with Human Subjects - SBE (ID: 491)</td>
<td>14-Aug-2016</td>
<td>5/5 (100%)</td>
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<td>The Federal Regulations - SBE (ID: 502)</td>
<td>31-Aug-2014</td>
<td>4/5 (80%)</td>
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<td>Assessing Risk - SBE (ID: 503)</td>
<td>31-Aug-2014</td>
<td>5/5 (100%)</td>
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<td>Informed Consent - SBE (ID: 504)</td>
<td>31-Aug-2014</td>
<td>5/5 (100%)</td>
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<td>Privacy and Confidentiality - SBE (ID: 505)</td>
<td>31-Aug-2014</td>
<td>5/5 (100%)</td>
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<tr>
<td>Research with Prisoners - SBE (ID: 506)</td>
<td>14-Aug-2016</td>
<td>4/5 (80%)</td>
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<td>Research with Children - SBE (ID: 507)</td>
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<td>4/5 (80%)</td>
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<tr>
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<td>Internet-Based Research - SBE (ID: 510)</td>
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<td>Conflicts of Interest in Research Involving Human Subjects (ID: 488)</td>
<td>31-Aug-2014</td>
<td>4/5 (80%)</td>
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<tr>
<td>Cultural Competence in Research (ID: 15166)</td>
<td>14-Aug-2016</td>
<td>4/5 (80%)</td>
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**NOTE. Scores on the Transcript Report reflect the most current quiz completions, including quizzes on optional (supplemental) elements of the course. See list below for details. See separate Requirements Report for the reported scores at the time all requirements for the course were met.**

- **Name:** Maria Peterson-Ahmad (ID: 3392914)
- **Email:** petersonahmadm@wou.edu
- **Institution Affiliation:** Western Oregon University (ID: 2993)
- **Institution Unit:** Education
- **Curriculum Group:** Group 1: All WOU Researchers
- **Course Learner Group:** Same as Curriculum Group
- **Stage:** Stage 1 - Basic Course
- **Description:** Choose this group to satisfy CITI training requirements for Investigators and staff involved primarily in biomedical research with human subjects.

- **Report ID:** 19777500
- **Report Date:** 17-Oct-2016
- **Current Score**

### REQUIRED, ELECTIVE, AND SUPPLEMENTAL MODULES

<table>
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<tr>
<th>Module</th>
<th>Most Recent Score</th>
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<tr>
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<td>14-Aug-2016</td>
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<tr>
<td>Belmont Report and CITI Course Introduction (ID: 1127)</td>
<td>5/5 (100%)</td>
</tr>
<tr>
<td>The Federal Regulations - SBE (ID: 502)</td>
<td>14-Aug-2016</td>
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<tr>
<td>Assessing Risk - SBE (ID: 503)</td>
<td>5/5 (100%)</td>
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<tr>
<td>Informed Consent - SBE (ID: 504)</td>
<td>14-Aug-2016</td>
</tr>
<tr>
<td>Privacy and Confidentiality - SBE (ID: 505)</td>
<td>5/5 (100%)</td>
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<tr>
<td>Research with Prisoners - SBE (ID: 506)</td>
<td>14-Aug-2016</td>
</tr>
<tr>
<td>Research with Children - SBE (ID: 507)</td>
<td>5/5 (100%)</td>
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<tr>
<td>Research in Public Elementary and Secondary Schools - SBE (ID: 508)</td>
<td>14-Aug-2016</td>
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<tr>
<td>International Research - SBE (ID: 509)</td>
<td>5/5 (100%)</td>
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<tr>
<td>The IRB Member Module - What Every New IRB Member Needs to Know (ID: 816)</td>
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