

Evaluating Experiences of Invisible Disabilities: A Spectrum

UNM LEND Capstone 2021-2022

Seriana Gutierrez

NMSU MSW Student



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Outline



Problem Framing



Research Process



Product



Dissemination



References

LEND Competencies

Competency 1:
Leadership Skills

Competency 3:
Knowledge of
Neurodevelopmental
and Related Disabilities,
with a Focus on ASD

Competency 4: Cultural
and Linguistic
Responsiveness and
Diversity

Competency 5: Person
and Family Centered
Care

Competency 6:
Research, Quality
Improvement, and
Evidence Based
Practice

Problem Framing



Increasing concern that individuals with invisible disabilities are not heard in the community and within research.

Prevalence

- About 42 million individuals have a disability
- Approximately 96% of these individuals have an invisible disability

Research

Creating Interview Questions
Connections through social media
Podcast creation and implementation

Interview Questions

- What does invisible disability mean to you?
- Why do you identify yourself with an invisible disability?
- On the day-to-day basis, what are some challenges of having an invisible disability?
 - How does the invisible disability impact your day-to-day routine? Are you in school or work or both?
- What are some positive aspects of having an invisible disability that you have experienced?
- When starting a new job, how can your employer better accommodate you?
 - This can help listeners who are starting a new job know what to ask for or request.
- What are some of the experiences that you have with an invisible disability that are similar to physical/visible disabilities?
- How do you go about the misconceptions made about those with an invisible disability?
- How can the community aid in better understanding invisible disabilities?
 - Family and loved ones
 - Healthcare professionals

Social Media

- Facebook Group
 - Not Wasting My Twenties
 - Ages from 20-29
 - 14 participants

Synthesizing Information

I sat down with each participant via Zoom from between 10-45 minutes having a casual conversation discussing the questions and their experiences

Diagnosis

- ASD
- Bipolar Disorder 2
- MS
- Depression
- Fibromyalgia
- Arthritis
- Asthma
- Epilepsy
- Possible IBS
- Chronic Migraines
- Anxiety
- Tourette's
- Hearing disability
- JDMS (Juvenile Dermatomyositis)
- Celiac

Common Themes

School and Workplace Accommodations - 9

Online communities - 8

Family Supports - 8

Becoming your own self advocate - 7

Product



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Behind the Invisible Podcast

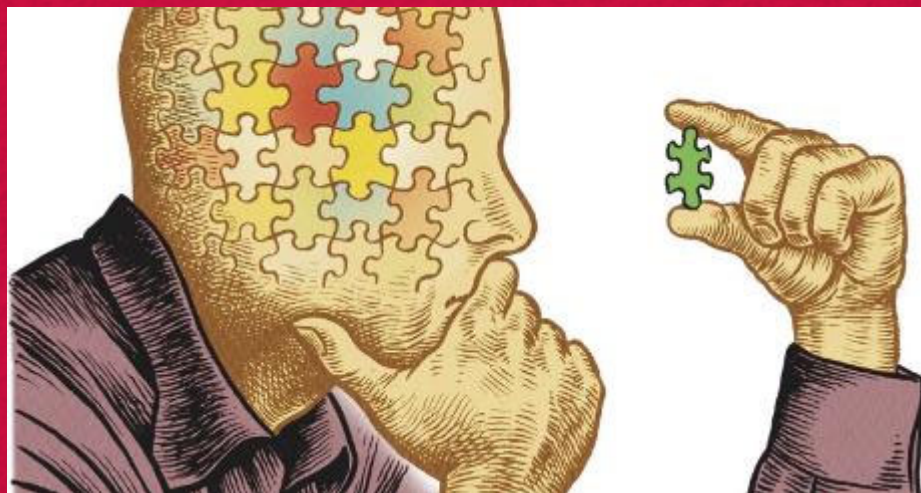
- Including questions, personal experiences, what the participants want others to know

Dissemination



- 
- Post on YouTube, Spotify, Apple Podcasts, etc.

Implications



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Scheduling

Consent

- Received verbal consent, but not written consent

Conclusion

What I learned

- Developing networking and interviewing skills
- Scheduling in different time zones is another stressor on its own
- You won't always get a 100% participant response rate
- Technology is not always your friend
- It is okay to have implications

Special Thanks

- Nanette Concotelli-Fisk, LEND Mentor
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- Leslie Cook, Professor at NMSU



References

- Hendry, G., Wilson, C., Orr, M., & Scullion, R. (2022). "I just stay in the house so I don't need to explain": A qualitative investigation of persons with Invisible Disabilities. *Disabilities*, 2(1), 145–163.
<https://doi.org/10.3390/disabilities2010012>
- Morgan, P. (2020, March 20). *Invisible disabilities: Break down the barriers*. Forbes. Retrieved April 1, 2022, from <https://www.forbes.com/sites/paulamorgan/2020/03/20/invisible-disabilities-break-down-the-barriers/?sh=11147594fa50>

Questions

