

# Transition to Adulthood For Individuals with Neurodevelopmental Disabilities

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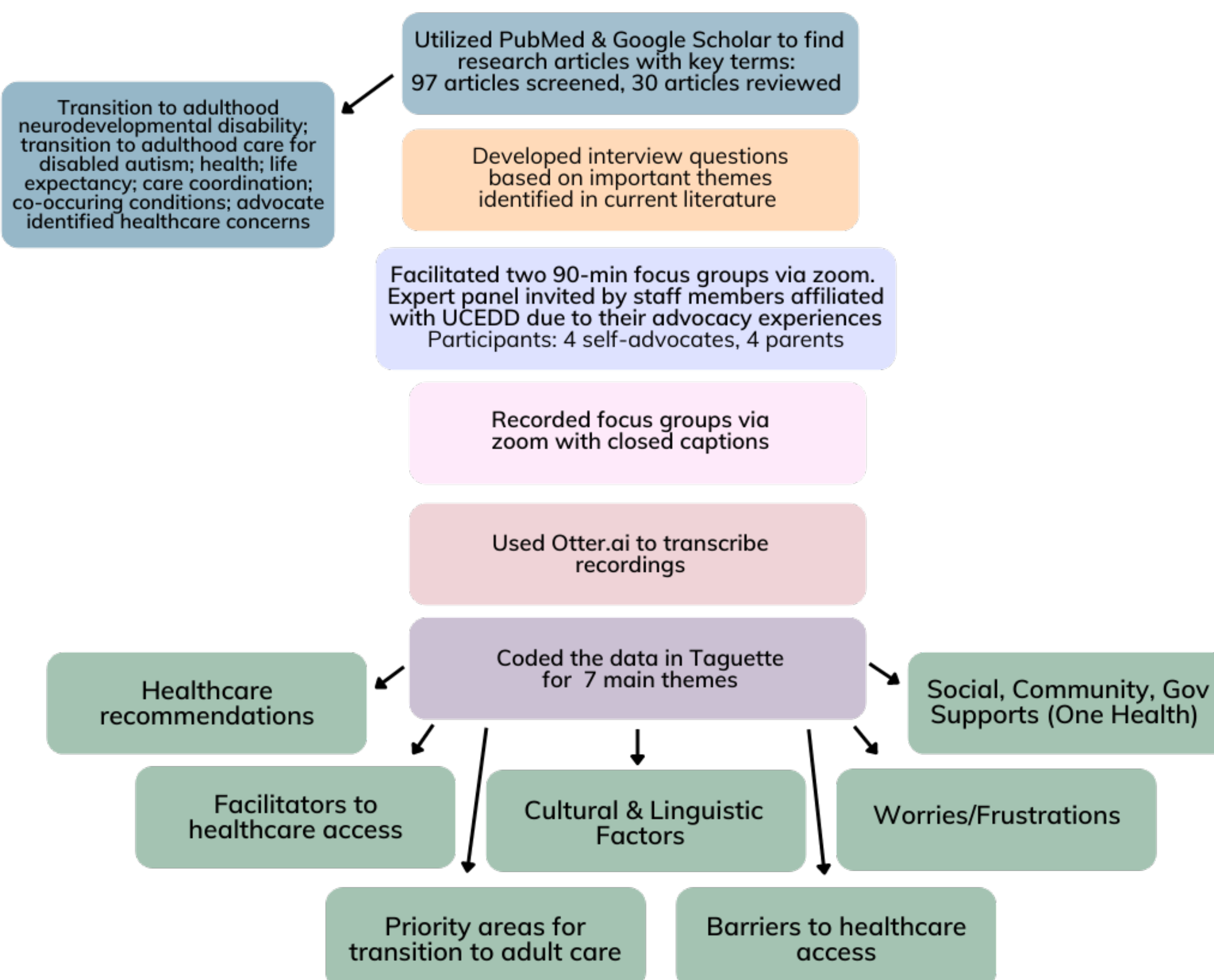
## INTRODUCTION

- There are many determinants of health for individuals with neurodevelopmental disabilities (NDD) when transitioning from pediatric to adult care. Transition goes beyond primary and specialty switching. It includes different aspects of life such as education, work, social, financial, and legal (Nugent et al., 2018)
  - Previous studies have found gaps in healthcare transition and access: healthcare advocacy, open communication, living away from home, supported jobs, continuing education/ programs
- Self-advocate and family perspectives are necessary for inclusive care. The MIND Transition to Adulthood Clinic strives to include the voices of self-advocates and family members.

## OBJECTIVES

- Understand personal healthcare experiences related to NDD transition.
- Identify priority areas of need for transition with self-advocates & family members.
- Consider results for MIND's Transition Clinic to address community identified areas of need.

## METHODS



## RESULTS

Figure 1. Data of 7 Main Theme Takeaways

Healthcare Recommendations		
Parent	Shared Values	Self-advocate
Comprehensive care- more time getting to know the patient & their capabilities	Accommodations- sharing personal information, shorter waiting room times, access to user friendly technology Communication- directly with the provider, structured appointments, speaking in plain language	Supported decision making- inclusion in healthcare conversations, providers listening to self-advocates
Barriers to Healthcare Access		
Parent	Shared Values	Self-advocate
Inclusive care & understanding- ineffective communication & transition plans, lack of support tools, lack of provider experience with NDD	Access- accommodations, inconsistent providers & specialists, low quality healthcare	---
Facilitators to Healthcare Access		
Parent	Shared Values	Self-advocate
Parent support/advocating- being able to self-advocate for their child and encouraging their child to do the same	Provider understanding- giving compassionate care Healthcare access- coordination/collaboration between providers & patients Insurance transition plan	Healthcare supports & access- technology, support staff, healthcare coordination of accommodations
Priority areas for transition to adult care		
Parent	Shared Values	Self-advocate
Transition: starting earlier, plan for speciality providers, full range of care & accommodations Provider quality- more training and education about NDD, collaboration between providers	Supports- communication tools, independent activities, disability services, awareness of determinants to health	Person centered care- control of medications, appointments, and direct communication with providers
Worries/Frustrations		
Parent	Shared Values	Self-advocate
Faulty healthcare system- difficulty changing providers, inconsistency, late transition age, Lack of communication- rushing appointments, having to seek services	Negative mental health- anxiety, low quality mental health care NDD understanding- not included in conversations, no compassion, no access to accommodation	Stigma- bias and ableism Inconsistency with services
Cultural and Linguistic Factors		
Parent	Shared Values	Self-advocate
Communication- creating community, having dialogues within groups	Advocating for yourself- learning to speak up for yourself & community	Understand Autism culture- bias, ableism, knowledge
Social/Community/Gov. supports (One health)		
Parent	Shared Values	Self-advocate
--	Positive supports- close circles, services Social determinants- transportation, education, cultural background, personal lives	Meaningful community experiences- connecting, networking, mental health care Autonomy within capabilities- healthcare advocacy, support programs/assistance

## DISCUSSION

Both self-advocates and parents expressed need for:

- Accommodations, communication, access
- Provider understanding of NDD
- Positive supports
- Awareness of social determinants of health

Self-advocates identified need for

- Supported decision making, autonomy within capabilities
- Meaningful community experiences, Understanding Autism culture
- Healthcare supports & access, consistency with services
- Person centered care

Parents identified need for

- Comprehensive & Inclusive care
- Faulty healthcare system, Transition process
- Creating community, Parent support/advocating

## CONCLUSIONS

- Recommend providers take into consideration these specific areas identified by this expert panel.
  - Healthcare services can be improved to bridge the gap between transition priority areas of need.

Implications & Future Direction

- Communication supports should be used in healthcare settings. Understand the self-advocates' capabilities for communication and supplementing that will foster positive healthcare experiences.
- Future work should include the self-advocate and supporter perspectives with a larger sample size and random selection.

## STRENGTHS & LIMITATIONS

Strengths

- Qualitative approach
- Focus group questions developed from previous literature
- Expert panels identified unique areas of need

Limitations

- Selection bias, not a random sample
- Small sample size, not representative
- Time constraints of data collection and analysis

## ACKNOWLEDGEMENTS

Special thanks to Dr. Janice Enriquez, Steve Ruder, Dr. Jonathan Bystrinski, the participants, and my colleagues.



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"I really make sure when I set the appointment to tell the receptionist the situation about my son...If they understand good, if they don't understand, I'm not going to go with them and I'm going to start again...Some experiences are successful, some are not. And it's very stressful to not get the doctor that you need, at the first attempt to do it." Parent

"One of the first initial things that you need to do is create a circle for support. And I think that's key for anyone living, going to college, having a job is needing a good support system around you. That isn't just your family and people that are paid to help you." Self-advocate

"I know she can't hold a conversation with you the way you want other adults to but that doesn't mean that you then immediately talk to her like she's two years old either...Treat her like she's the age you see her, involve her in the process and just look to me for guidance. And obviously, if she's not able to have decision making, I still want her involved at every step." Parent

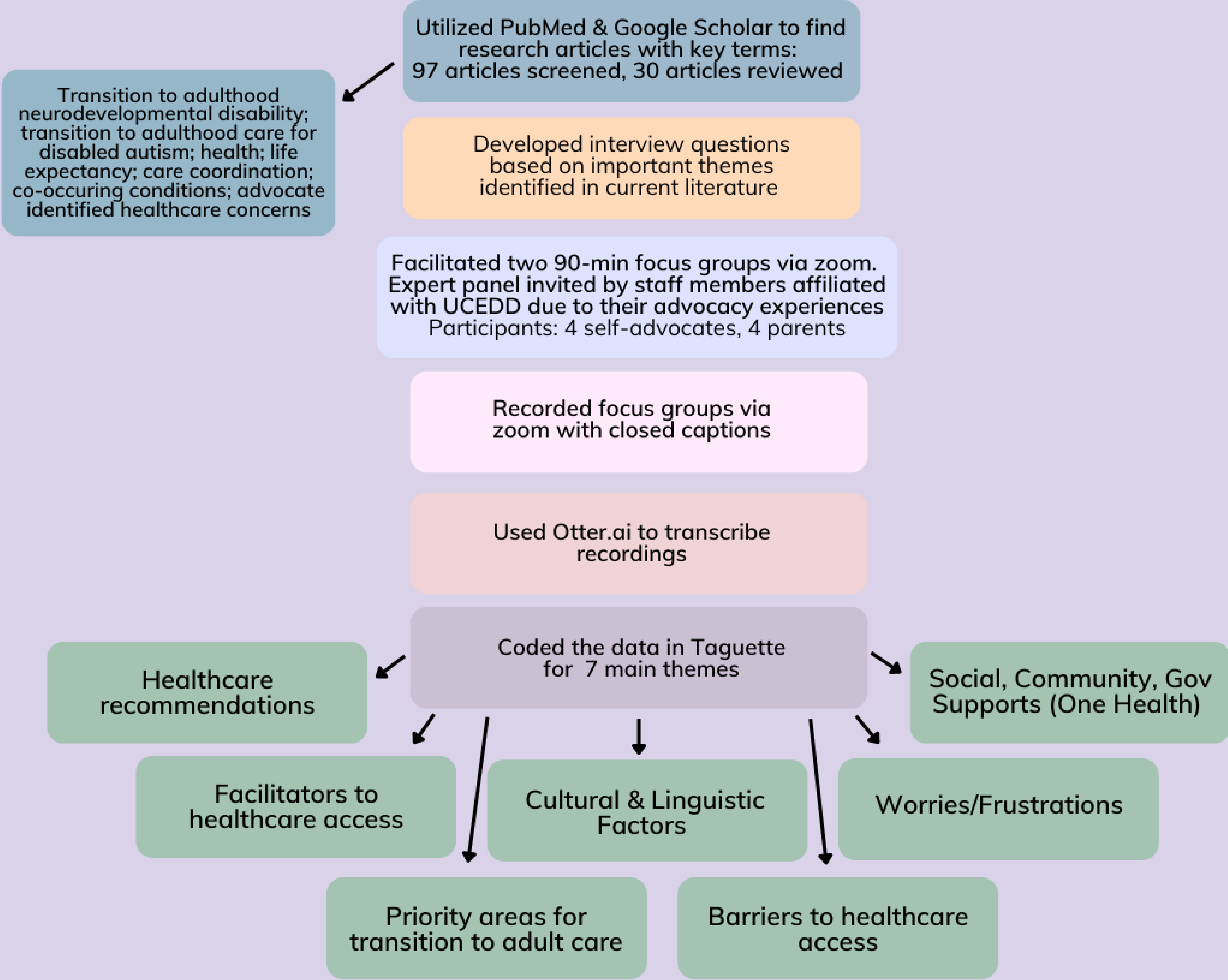
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  - Transition goes beyond primary and specialty switching. It includes different aspects of life such as education, work, social, financial, and legal (Nugent et al., 2018)
  - Previous studies have found gaps in healthcare transition and access:
    - Healthcare advocacy
    - Open communication
    - Living away from home, supported jobs, continuing education/ programs
  - Successful and inclusive transition to adulthood healthcare requires the voices of individuals with NDD and their family members

# OBJECTIVES

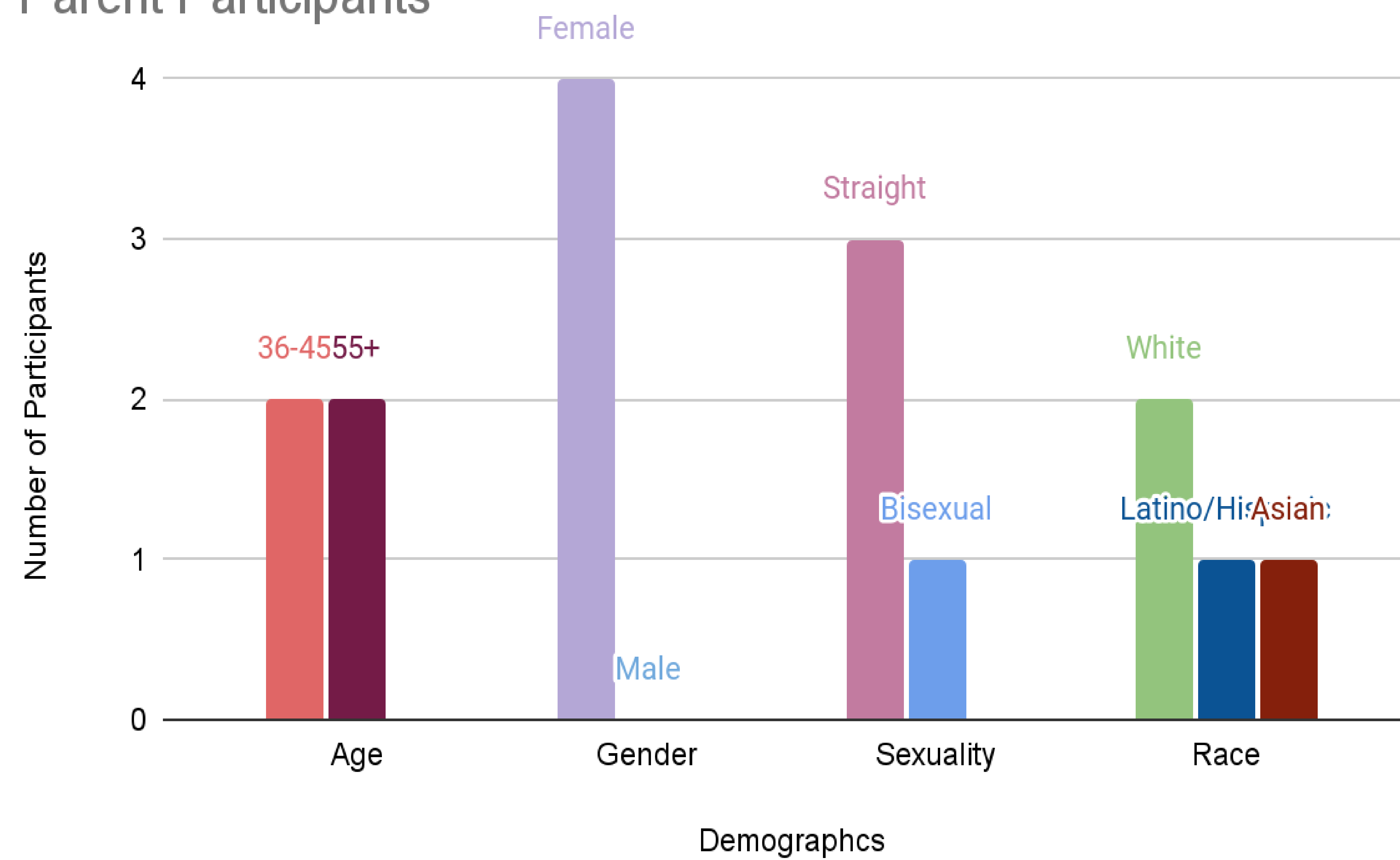
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2. Identify priority areas of need for transition with self-advocates & family members.
3. Consider results for MIND's Transition to Adulthood Clinic to address community identified areas of need.

# METHODS

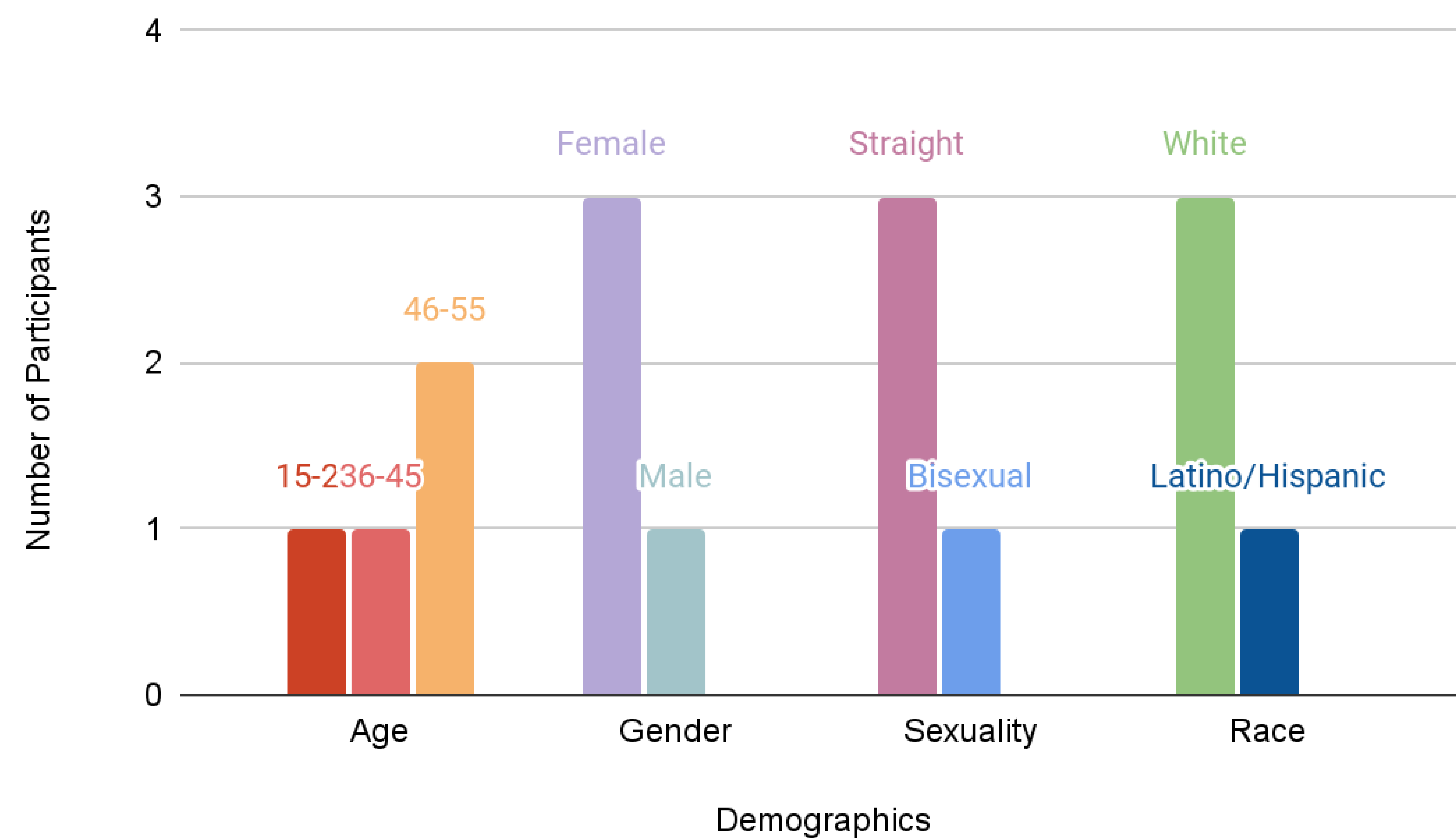


# PARTICIPANTS

## Parent Participants



## Self-advocate Participants



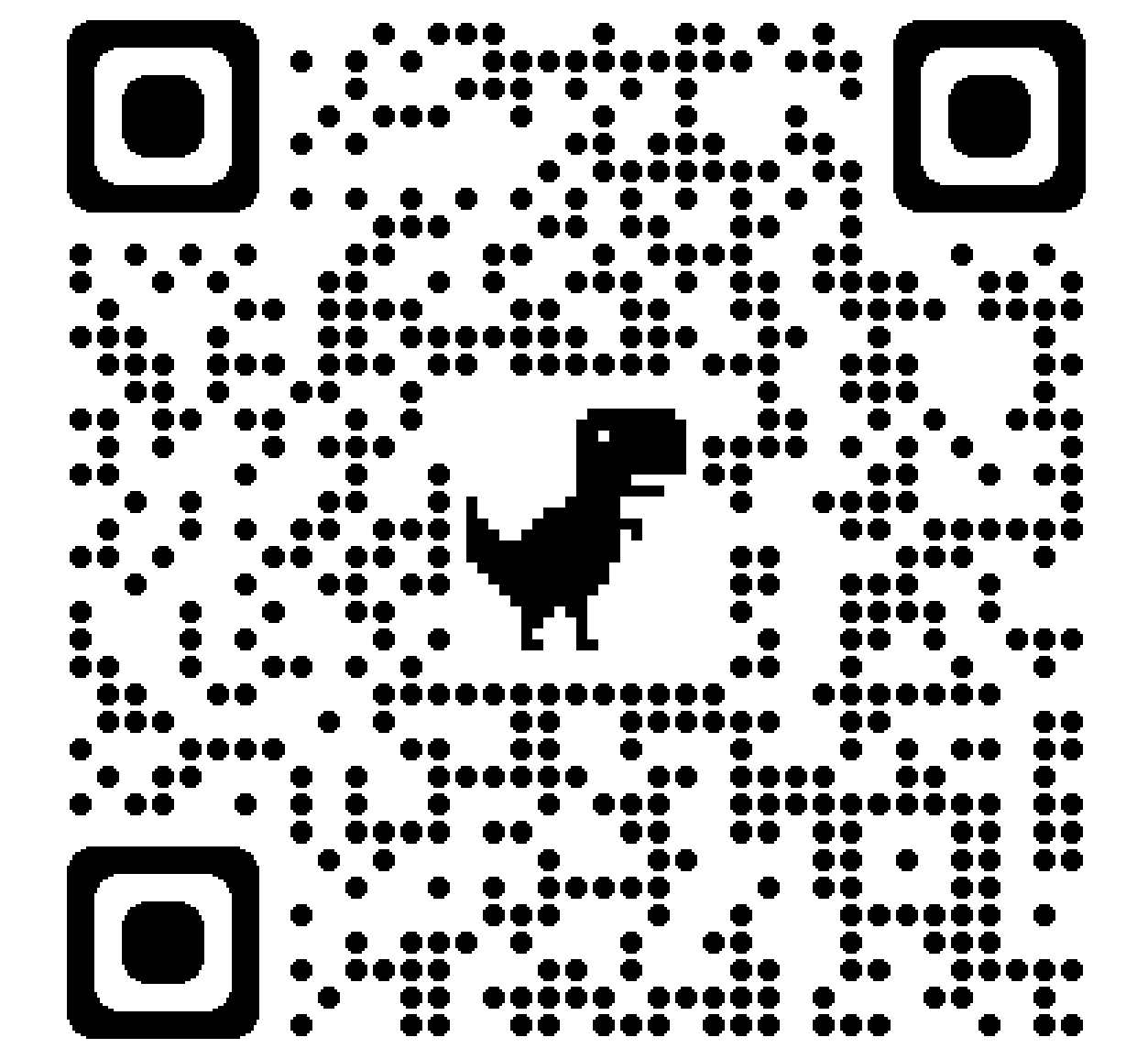
# RESULTS

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# RESULTS

- 1) Relationship development
- 2) Addressing personal stigma
- 3) Communication
- 4) Supported Decision making
- 5) Parent support and advocacy
- 6) Care coordination
- 7) Insurance Transition Plan
- 8) System supports
- 9) Timing of transition occurring earlier
- 10) Integrate communication tools and accommodations
- 11) Mental health care
- 12) Meaningful community activities
- 13) Quality provider training related to NDD and transitions

# RESULTS



“I know she can't hold a conversation with you the way you want other adults to but that doesn't mean that you then immediately talk to her like she's two years old either...Treat her like she's the age you see her, involve her in the process and just look to me for guidance. And obviously, if she's not able to have decision making, I still want her involved at every step.” Parent

## Communication

“As a strong advocate for the Autistic community, and for myself. Autism has its own culture. I've had some professionals, one in the mental health, where I pick it in my stim objects, the fidgets I have, and I was in a group, and he pulled me aside and he said, You need to get rid of that. Don't bring a little toy in with you that these people won't socialize. You're supposed to learn to socialize. Well, I want people to see me as me and what I do. And I see that as part of my culture.” - Self-advocate

## Bias & Ableism

“To be in an environment where your behavior is not judged. My child may be having a hard day, but we're going to push through it because we need an answer to whatever medical question we're there for. That just makes it for me, you know, I might cry in the car on the way home wishing it could have been different. But we get through and we get what we need. So those accommodations are really important to me.” - Parent

## Accommodation and understanding of NDD from provider

“We need to instill youth and adults with disabilities that hit 18. You know you got to sit down and understand, what your healthcare needs are, what your medications are, how you want to present that. I think you know there needs to be some education in some way of teaching you how to advocate for yourself.” Self-advocate

## Self-advocacy



# DISCUSSION

## **Both self-advocates and parents expressed need for**

- *Accommodations, communication, access*<sup>2</sup>
- *Provider understanding of NDD*<sup>1</sup>
- Positive supports: community & program assistance
- Awareness of social determinants of health

## **Self-advocates identified need for**

- Supported decision making, autonomy within capabilities
- Meaningful community experiences, *Understanding Autism culture*<sup>1</sup>
- *Healthcare supports & access*<sup>2</sup>, consistency with services
- Person centered care

## **Parents identified need for**

- Comprehensive & Inclusive care
- Improved healthcare system, Transition process
- *Creating community, Parent support/advocating*<sup>3</sup>

<sup>1</sup>Kripke, C. (2018, 10 01). Adults with Developmental Disabilities: A Comprehensive Approach to Medical Care. *American Family Physician*, 97(10).

<sup>2</sup>Nicolaidis, C., Raymaker, D. M., Ashkenazy, E., McDonald, K. E., Dern, S., Baggs, A. E., Kapp, S. K., Weiner, M., & Boisclair, W. C. (2015). "Respect the way I need to communicate with you": Healthcare experiences of adults on the autism spectrum. *Autism*, 19(7), 824–831. <https://doi.org/10.1177/1362361315576221>

<sup>3</sup>Bruder, M.B., Kerins, G., Mazzarella, C. et al. Brief Report: The Medical Care of Adults with Autism Spectrum Disorders: Identifying the Needs. *J Autism Dev Disord* 42, 2498–2504 (2012). <https://doi.org/10.1007/s10803-012-1496-x>

# CONCLUSION

- Common themes emerged: communication, provider understanding of NDD, and access to healthcare, are consistent with regional community perspectives
- Recommend providers take into consideration these specific areas identified by this expert panel to improve healthcare services for transition aged youth

## **Implications & Future Direction**

- Communication supports, compassionate/ person centered care, addressing bias and ableism, meaningful community experiences should be used in healthcare settings.
- Future work should include the self-advocate and supporter perspectives with a larger sample size and random selection

# STRENGTHS & LIMITATIONS

## **Strengths**

- Qualitative approach
- Focus group questions developed from previous literature
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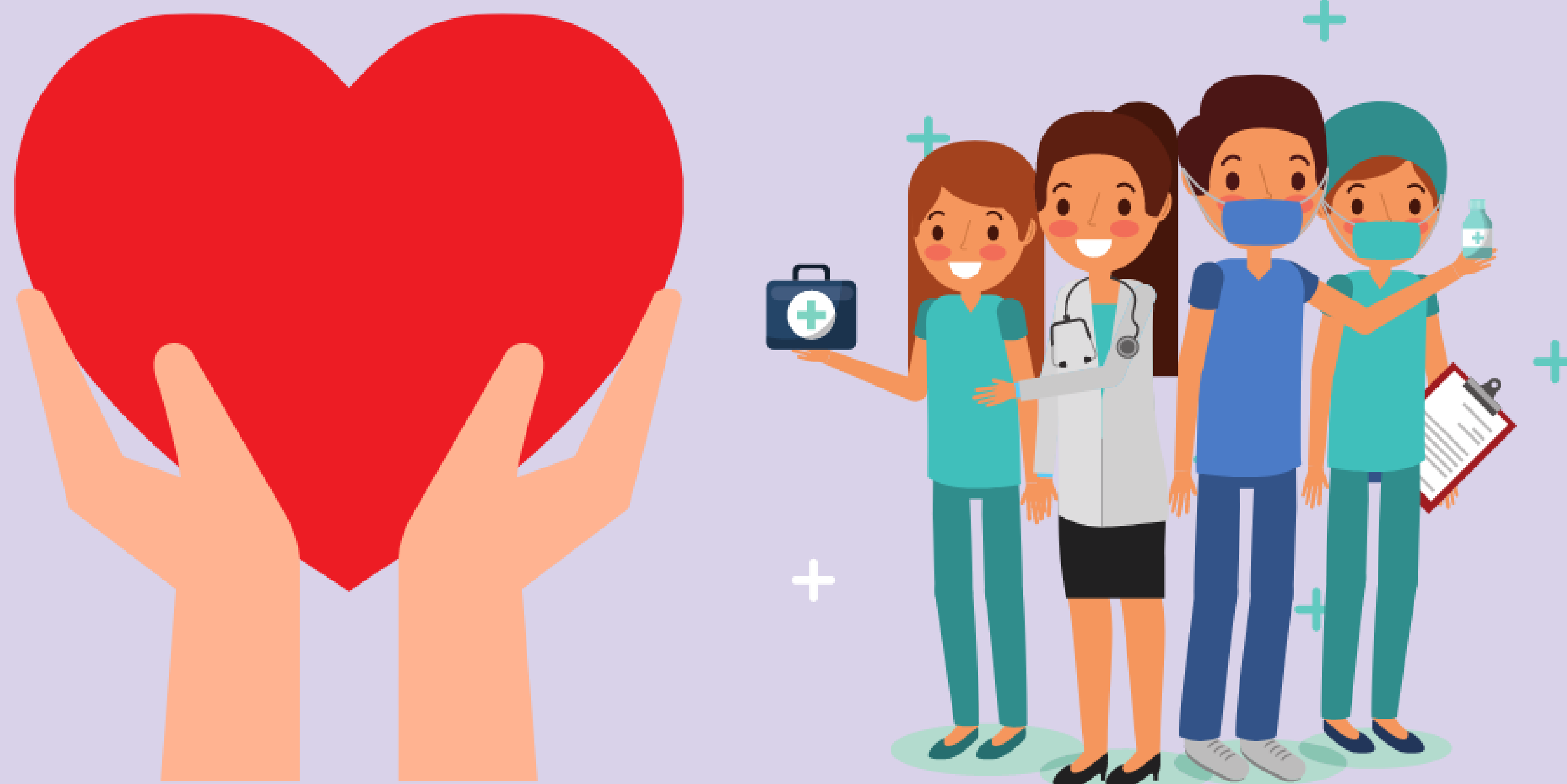
## **Limitations**

- Selection bias
  - Participants invited, were not found through a random selection
- Small sample size
  - Not representative of larger population
- Time constraints of data collection and analysis

# ACKNOWLEDGEMENTS

This project would not have been possible without the help and guidance of Dr. Janice Enriquez, Steve Ruder, and Dr. Jonathan Bystrynski. The amazing focus group participants that were able to share their personal experiences. I'd also like to acknowledge KKI for the opportunity to do this work with the UC Davis MIND Institute.

Special thanks to my colleagues for their advice and community.  
Excited to see the health professionals you all become.



# REFERENCES

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