



Program Evaluation of a Research Engagement Curriculum and its Effectiveness on Research Knowledge and Health Advocacy for People with Intellectual and Developmental Disabilities

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Background:

- **People with IDD excluded from research engagement historically**
(Barnes, 2002)
- **IDD = increased health disparities**
 - Need to create more effective health outcomes → need to be engaged in research (Krahn, Hammond, and Turner, 2006).
- **The role of PAR and co-researchers**
 - sharing lived experiences is important
 - include people with IDD as co-researchers



Background:

- **Demonstrated benefits of having co-researchers**
 - Richer data collection tools created
 - More applicable outcomes (Barnes, 2002; Nind & Vinha, 2014; Bigby et. al., 2014).
 - Co-researchers have skills to identify and respect boundaries of interviewees in research; effectively relate to participants (St. John, Mihaila, Dorrance, DaWalt, & Ausderau, 2018).
- Creating specialized curriculums for research projects in order to include co-researchers has been found to **increase confidence and research knowledge for people with IDD** (Schwartz, et al., 2019; St. John, et al., 2018).
- **No curriculums currently exist to teach research knowledge and engagement for people with IDD → created a curriculum to pilot**



Purpose of Curriculum

 Research
Knowledge

Health
Advocacy





Research Engagement Curriculum

Modules 1-5

● **Module 1:**

- What is Health Research?

● **Module 2:**

- What is the Health Research Process and How Can I Get Involved?

● **Module 3:**

- Where is the Research Happening?

● **Module 4:**

- Think Like a Researcher

● **Module 5:**

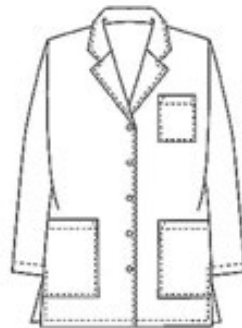
- Creating Your Own Health Story for Research and Care Advocacy



Preview of Curriculum

Health Research Participation: A Curriculum

A how-to guide to understand and get involved in research as a participant, researcher, and consumer for individuals with intellectual disabilities and their caregivers





What is research?

Research is the process of asking *meaningful* questions to better understand our world.

There are three important parts of research.



Ask a question



Find answers



Tell others



HEALTH STORY WORKSHEET

The steps to develop your health story

1 Complete the health worksheet to organize your ideas



2 Do an interview with a partner to dig deeper into your story

3 Write your story down



4 Review your story and make changes

5 Tell your story



Who is this story for?

Doctors



Researchers



Advocacy



Are there pictures that you have or would like to take that help explain your health?

My name is _____

I am _____ years old.



My favorite healthy activities are _____ and _____

Some important facts about my family's health history are

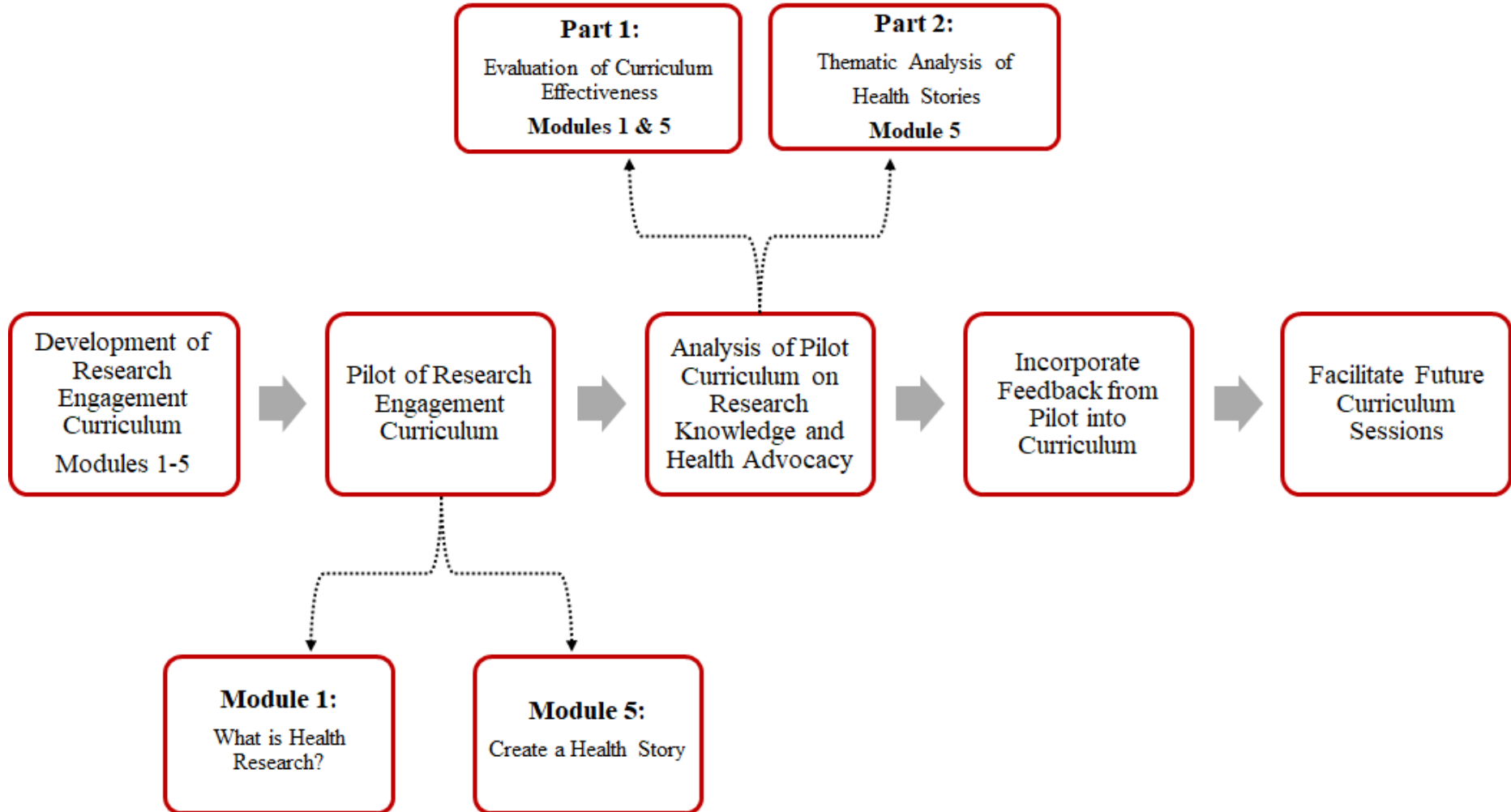


What is your diagnoses or some important health facts you should know about me from when I was younger are



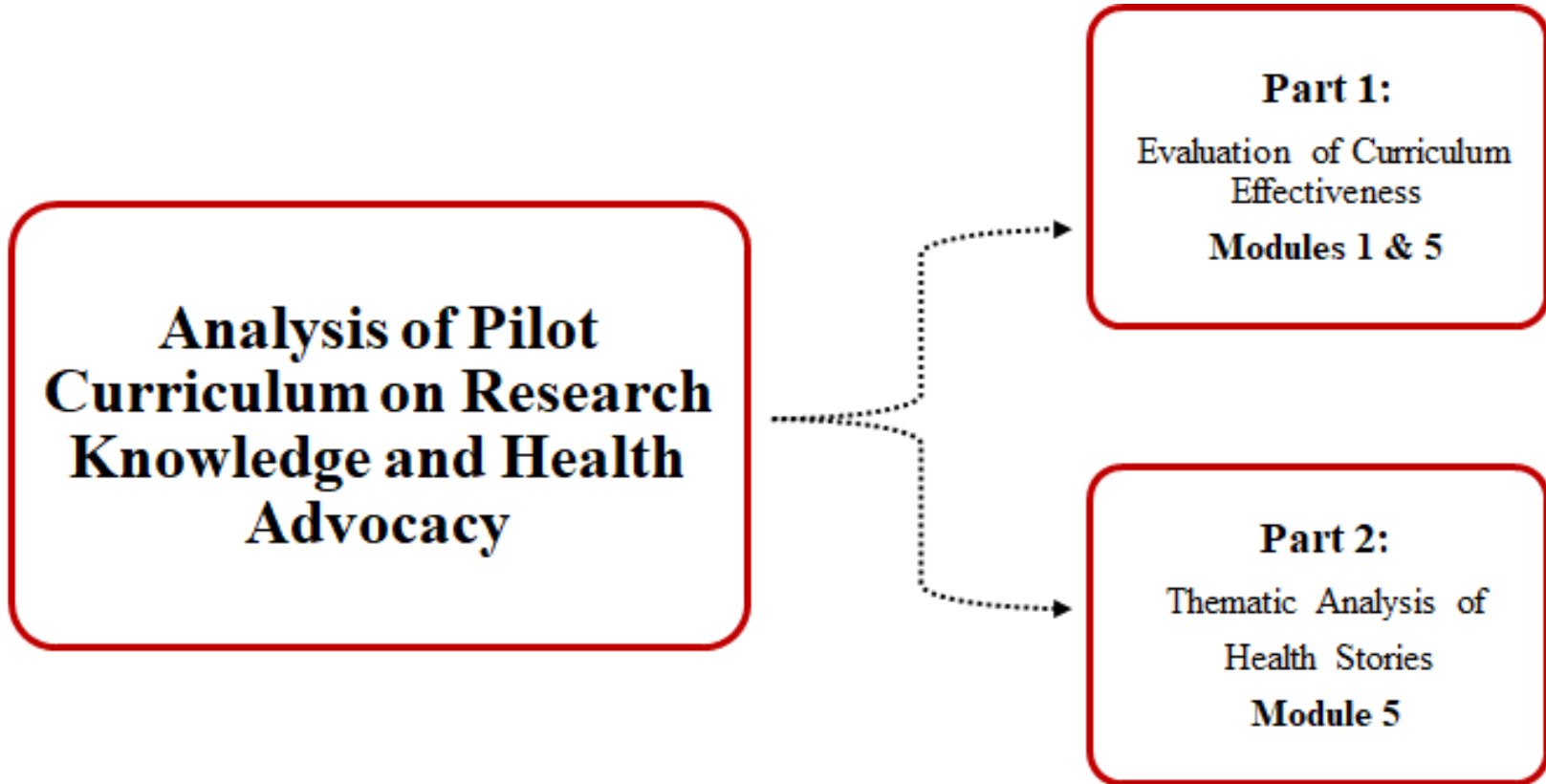


Methods





Results





Part 1 Findings: What went well?

General Feedback

- Adequate time and space for authentic conversation
- 1:1 ratio (partner to participant with IDD)
- Enough Breaks

Content-Specific Feedback

- Balance of words to pictures (PECs)
- Simplified language and key points
- Adequate amount of concrete examples
- Research Knowledge skills checks

Module 5: Health Story Feedback

- Sense of empowerment and confidence
- Accessible platforms and diverse adaptations



Part 1 Findings: Improvements for future sessions?

General Feedback

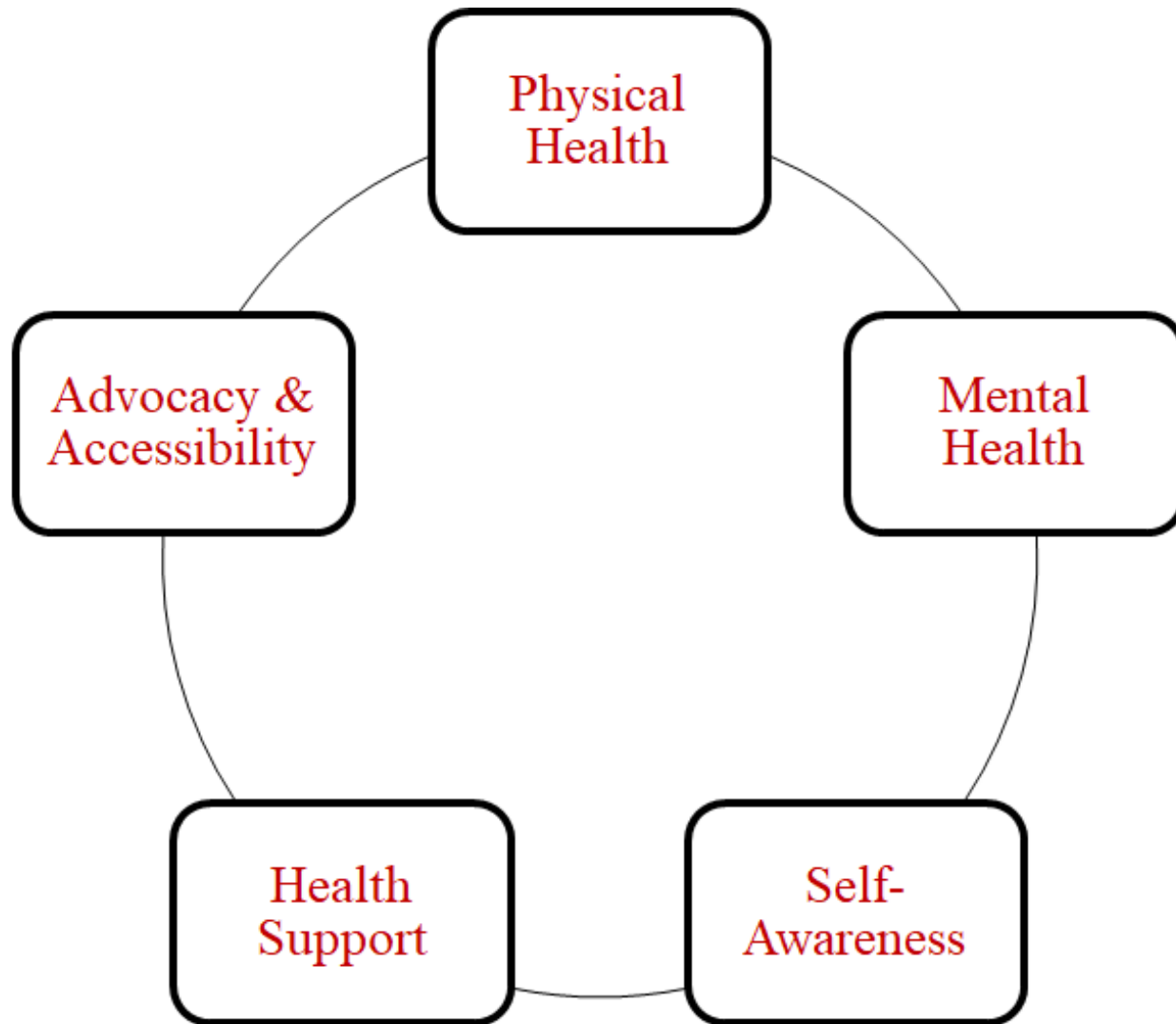
- Increase space and time for questions
- Add more rest and stretch breaks
- Condense wording/ 3rd grade reading level
- Add co-facilitator with IDD
- Combine PPT slides with similar content
- Time out slides to formalize curriculum

Module 5: Health Story Feedback

- Provide more education on appropriateness of sharing health story
 - When, where, and whom
- Increase scaffolding
- Provide more quiet space to think and write health story
- Increase picture use and simplified language on Health Story worksheet



Part 2 Findings: Health Story Themes





Physical Health Quotes

“I eat a lot of fruits and vegetables. I exercise more, and I walk as much as I can. I get a lot of sleep at night as well.” -Mariana

“I currently partake in Special Olympics where I bowl, practice basketball skills, and participate in track and field events.” -Gary



Mental Health Quotes

“I meditate to keep my body and mind healthy and I do mindfulness before I go to bed to keep my mind at peace.” -Brandy



Self-Awareness Quotes

“I worry that my anxiety will get worse as I get older, the cysts in my ovaries will return, or that my Fabry will get worse and I will need blood transfusions.” -Brandy

“I have autism. In my experience, autism means I have sensory sensitivity to loud noises. For this reason, I often wear noise-cancelling headphones so that the noises aren’t as loud.” -Ally



Health Support Quotes

“Having supportive friends, family, teachers, and caregivers aid in my understanding of my emotions helps decrease my anxiety.” - Ally

“I’m worried about getting cancer back in my brain. I had to take a lot of pills. One gave me a seizure and I fell down and my mom had to call 911. My mom was scared.” -Alex



Advocacy & Accessibility Quotes

“My disability does not make up who Brandy is, it is only the beginning.” -Brandy

“I want my doctor to know to talk to both my staff AND me during appointments.” - Darrel

“I believe that all dentists should need to accept patients like me and patients with all types of insurance. When this is not the case, it makes it very hard for me to see the dentist and keep my teeth clean.” -Ally



Discussion: Part 1

- **Participants valued authentic and meaningful conversation**
 - It is essential to provide space for this opportunity
 - Allows for deeper experiences that offers diverse perspectives
- **Importance of universal accessibility**
 - Picture Exchange Communication
 - Important feedback for designing accessible outcome measures which can help increase reliability and validity

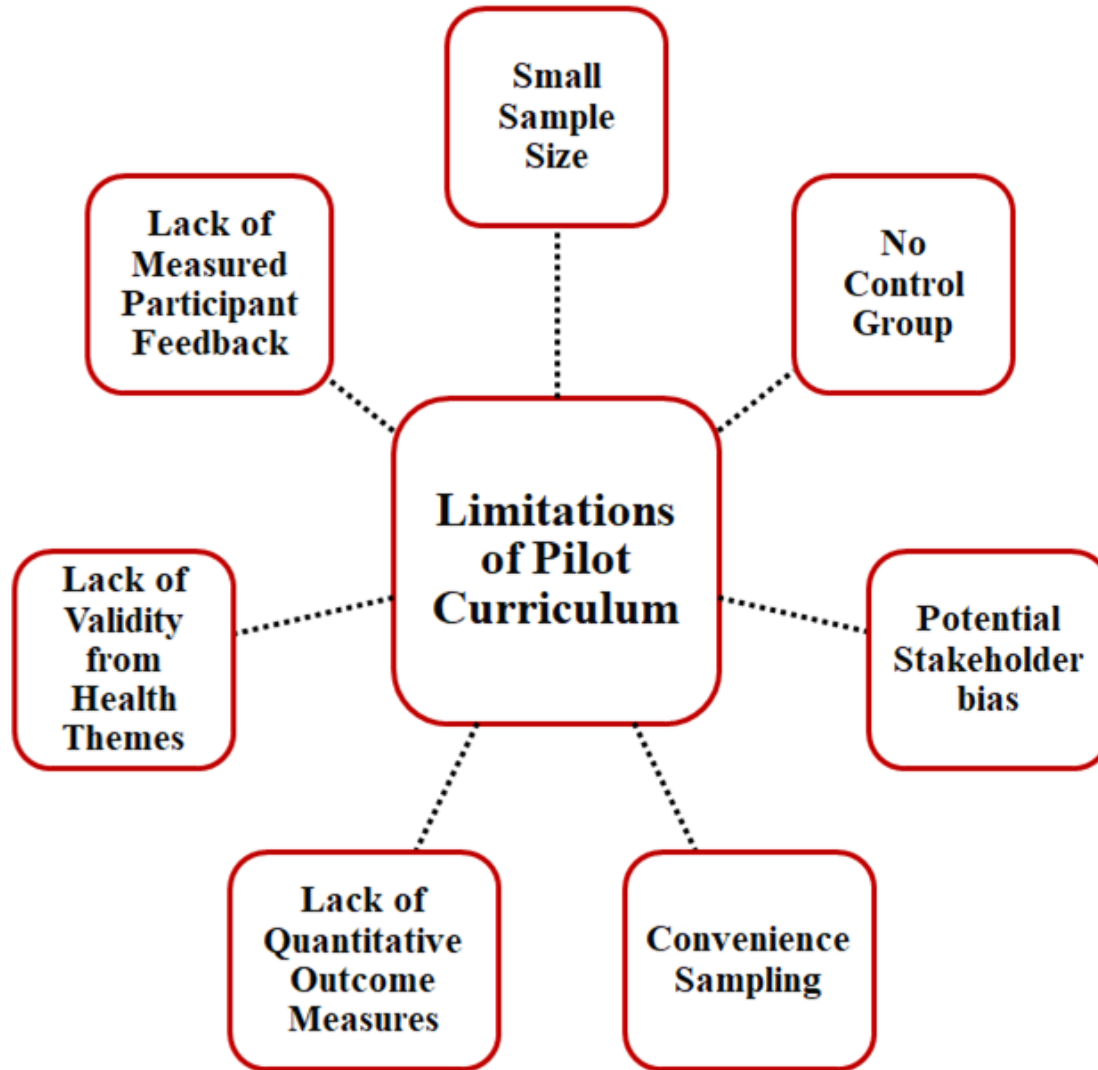


Discussion: Part 2

- Hypothesis: **increase in confidence in Health Advocacy**
 - more people shared their health story
- Address people with IDD appropriately
 - Doctor's office
 - Research (St. John, et. al., 2018)
- Curriculum further promotes “self-determination” (Coppersn, Nelis, & Shogren, 2015)
 - increased participation in research
 - increased sense of achievement



Limitations





Implications

Evoke Broader Systems Change

(healthcare, research, legislation, & education)

**Encourage Participation of People
with IDD as Collaborators**

**Develop Accessible and Enriching
Educational Resources that Promote
Understanding & Autonomy**

**Recruit and Encourage People with
IDD to Participate in Research
Engagement Curriculum**



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Questions?

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