

Making “Mama’s Baby, Autism Maybe”: A Training Video for

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Background

This project was inspired by a training that was conducted by Building Bridges in December 2018. The training was called Difficult Conversations and it was designed to show healthcare professionals how to approach the topic of developmental delays and Autism with parents. I participated in the training by telling my story about my son, who has autism, and the obstacles and emotions we encountered in obtaining a diagnosis. I was surprised by the feedback from the physicians. They asked me a lot of follow-up questions and were eager to learn more about what parents experience outside of their office during the journey to a diagnosis. Before I left, one doctor suggested that I “take this show on the road” because he enjoyed hearing my story and thought it was important for other health care professionals as well. One thing I realize is that my story, while unique in minor details, is not really unique to me. It is common in the autism community to hear parents speak of diagnosis delays due to being ignored, discriminated against or having their concerns dismissed. I wanted to give a voice to these other parents. I wanted to acknowledge their struggle and validate their feelings of frustration. Since parents don’t always have time to “take this show on the road” I wanted to create this video so our stories could be told even if we weren’t there to do it.

There are many facets of discrimination on which I could have focused. I chose to pick some of the most prominent ones such as race, economic status and non-biological parents/guardians. According to Spectrum News, white children are about 19 percent more likely than black children and 65 percent more likely than Hispanic children to be diagnosed with autism. In addition, children who live in low socioeconomic areas are less likely to be diagnosed than children living in higher socioeconomic areas.

References

H. F. (2017, November 20). Race, class contribute to disparities in autism diagnoses. Retrieved July 9, 2019, from www.spectrum.org.

Walsh, F. (2011). Family resilience: A collaborative approach in response to stressful life challenges. *Resilience and Mental Health: Challenges Across the Lifespan*. 149-161. 10.1017/CBO9780511994791.012.

Methods

Recruitment- The process of finding participants started with a Facebook post to Autism, and other special needs, support groups. I also reached out to organizations such as Autism Delaware in order to find families that would be the right fit for the project. I received many responses from parents of children with autism who had very difficult experiences with identifying a problem. Narrowing down the pool of participants was difficult but I chose to highlight circumstances specific to race, economic status, and non-biological parent/guardian.

Participants



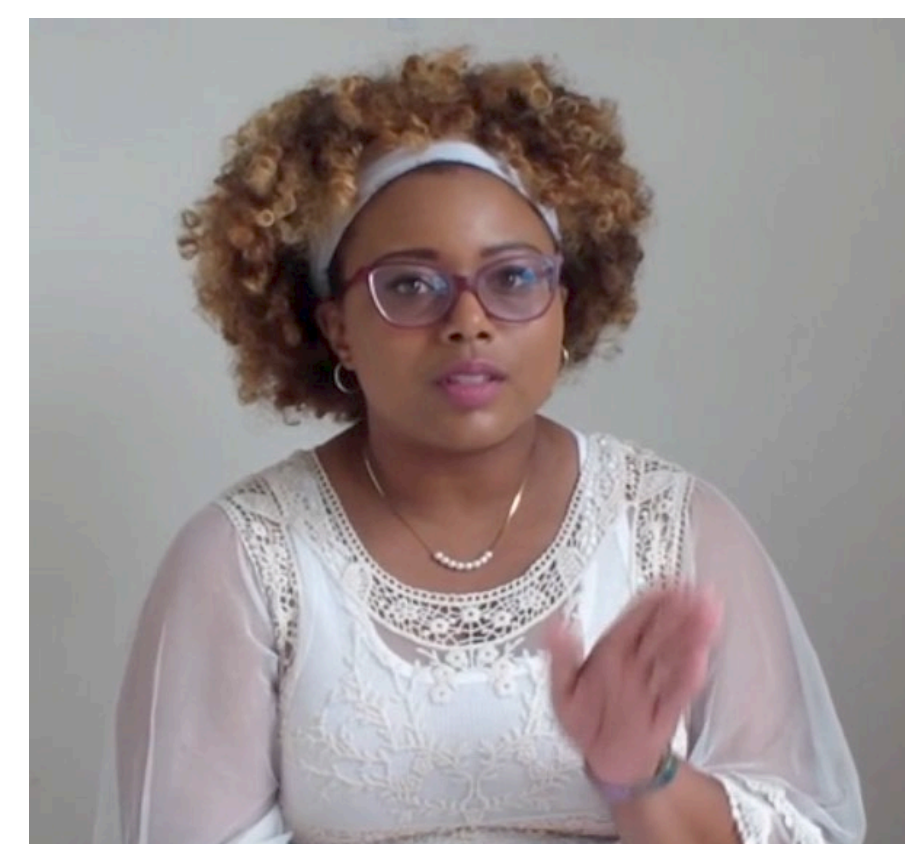
Stephanie Chase-Saunders

Her son (13) was diagnosed at age 5. Although she voiced her concerns about her son’s development, his symptoms were attributed to the family being homeless at the time.



Shirin Narimanian

She took custody of her nephew (2) and later adopted him. Shirin has struggled to get her nephew diagnosed while trying to be respected as a non-biological parent.



Angela Mitchell

Her concerns for her son (7), diagnosed at age 3, were dismissed as “new mom jitters.” He was a non-aggressive, African-American boy which made his symptoms easy to ignore.

Interviews- Information was gathered through semi-structured interviews. The interview included broad questions for all participants such as “How did your journey begin? What symptoms did you notice? What next steps did you take?” There are also questions which are specific to the participants’ circumstances, for example, Shirin is asked “what is it like to be a non-biological parent?”

Tools

Discussion Guide- The discussion guide was created to encourage reflection, conversation, exchange of ideas, and brainstorming for better protocol when developmental delays are identified.

Questions

- 1. What are some ways a professional can start the conversation about autism with a parent?** Some doctors are afraid to approach parents with possible developmental delays for fear of how they might react. This question is intended to help healthcare professionals to consider ways to start the conversation in a way that both parties can feel comfortable while clearly addressing the problem.
- 2. How do you currently start the conversation with a parent? After viewing this video, is there anything you would do differently?** The goal of this question is to have healthcare professionals look at their current methods and determine if there is anything that they can do differently to help their patients after listening to the experiences of the parents from the video.
- 3. All of the parents in the video discuss how scary the time around diagnosis is. In what ways can you support the family when they are not in your office, such as, between the time that a symptom is noticed and discussed and the time of formal evaluation or referral?** The hope is that this question will help healthcare professionals think about what they can do to support families outside of the office/hospital.
- 4. When you reflect on the obstacles these parents encountered, how can each parent’s experience have been improved?** The circumstances of the parents in the video are not uncommon. It is very possible that healthcare professionals will have patients, or have already had patients, who fit these demographics. This question should help one acknowledge the potential for implicit bias and generate ideas for best practices that can be applied to all families.

Recommendations

The video should be presented in conjunction with trainings for pediatricians, developmental pediatricians, psychologists, and other healthcare professionals responsible for providing an autism diagnosis or referral for evaluation. I recommend that organizations such as, Building Bridges, DNEA, Autism Delaware, etc. utilize the video when providing education to service providers.

Reflection

Cultural competence- Although there is research on this, the lived experience of women of color should be discussed explicitly, to help doctors consider life experiences, barriers and communication styles that may differ from their own. They are only three mothers, but through their interviews, despite minor details, they are telling my story and the story of so many other families. These interviews shed a light on the implicit bias of the healthcare profession. My hope is that this video can help practitioners to see their patients and their families not just as black, Hispanic, poor, uneducated, homeless, or adopted, but as people looking for help and answers.

Family Centered Care- Listen to parents and their concerns. Don’t dismiss them. Don’t withhold information or resources of which they may not be aware. For example, there are parents that don’t know about Child Watch. The ones that do, don’t know that they can make a referral without a doctor. Without knowing their options, families are stripped of their ability to make sound decisions.

Resilience- Family resilience has been defined as the family’s ability to “withstand and rebound from disruptive life challenges, strengthened and more resourceful.” (Walsh, 2011 p.149) These mothers represent the families who have had to grieve the loss of what they thought their child would be one day while simultaneously building a new life, including discovering resources for their child, support for themselves and becoming educated on this new diagnosis, all while being uncertain of what lies ahead in the future.