

Supplemental Information

SCRIPTED CAREGIVER SCREENING TOOL TO ASSESS FOR EXPERIENCES IN DISABILITY-BASED DISCRIMINATION

Initial Screening Tool

I am going to ask a couple different questions to help us determine your eligibility for this study. I am asking these questions because we are hoping to engage families who are interested in sharing their experiences with us from all types of different backgrounds. To ensure our study represents a breadth of experiences, we are recruiting subjects with diverse but frequent experiences with a health care system. The following questions will help us understand what experiences your family has had within the health care system.

How old is your child?

If <1 or >18 years old, excluded from study.

On average, how many health care visits has your child needed within the past year? Visits can include inpatient, outpatient, and emergency department visits.

If <4, excluded from study.

How many physicians/providers has your child seen in the past year?

If <3, excluded from study.

Regarding Discrimination

Have you ever felt your child was treated unfairly or inappropriately in a health care setting because of their disability?

Have you ever felt your child was treated unfairly or inappropriately in a health care setting because of their medical condition?

Have you ever felt your child was treated unfairly or inappropriately in a health care setting because of their race?

Have you ever felt your child was treated unfairly or inappropriately in a health care setting because of their ethnicity?

If answer no to all questions, excluded from study: Thank you for taking the time to answer these questions. We really appreciate your interest in the study, but you are not eligible.

If screen positive with an affirmative answer to discrimination because of disability or medical condition: Thank you for taking the time to answer these questions. You are eligible for participation in our study. Are you interested in learning more about the study now?

DISABILITY-BASED DISCRIMINATION IN HEALTH CARE INTERVIEW GUIDE

Questions are meant to open discussion and can be followed up with more probing questions as appropriate. Some questions may be redundant on the basis of the

interviewee responses and may not be necessary. Interview questions are semistructured and can be adapted on the basis of the interview. This interview guide will be iterative and build upon previous interviews for further questions.

Thank you for agreeing to participate in this research study involving disability-based discrimination in health care. Today, I will be asking you some general questions about your experience with discrimination related to your child's disability that you or your child have experienced or perceived in the health care system. We hope that you will feel comfortable sharing your experiences. If at any time you feel uncomfortable, you can simply say that you do not wish to answer the question. Participation in this study is voluntary.

Also, I (we) anticipate our talk today could last up to 60 minutes. If you would like to take a break at any point, just let me know. I will be audio-recording our discussion today so that I can review it later, and if you would like to review the recording afterward, you are welcome to at any time. Do you have any questions about the audio-recording?

Are you ready to start the interview? I will begin audio-recording now.

Introduction to Parent

First, tell me a little bit about yourself and your child with a disability.

Prompts:

- Child's disability, medical condition(s), age at diagnosis, current age
- Length of time they have been interacting with a health care system
- Hospitalizations, emergency department visits, outpatient providers
- Family caregiving tasks, family structure, family in the home

Experiences in the Health Care System

Thank you for sharing that information. Now, I'd like to talk to you about the experiences your child has had in health care settings. As we know, children with medical complexities and disability can have many experiences in the health care system. Some of these experiences may be really excellent, whereas others may have left you with a feeling of mistreatment or loss of trust. I'd like to begin with some experiences you have had within the health care system that were good. Tell me about those times.

Prompts:

- Tell me about any experiences you have had where you felt empowered by your health care team.

- What have experiences with health care providers, such as nurses, doctors, or therapists, been like for your child who has a disability?
- What kinds of systems and supports have contributed to good experiences?
- What experiences have you had that helped your child in the health care system?
- Tell me about your experiences with communicating with your child's medical team. Tell me about a time when the team was communicating effectively.

Now, I would like to shift a bit from positive experiences. From our initial conversation, you answered yes to having experienced discrimination in health care on the basis of your child's disability. Can you talk about any time where you felt that your child was not treated fairly or appropriately because of their disability?

- Tell me about any challenges you have faced in the health care system because of your child's disability.
- What perceptions do you think health care providers have related to your child's disability? Do you think these perceptions affected the quality of care your child received?
- Tell me about an experience where you felt health care providers made assumptions about your child just because of their medical conditions and disability.
- Tell me about your experiences when your thoughts on your child's condition or a treatment plan differed from the medical teams plan because of their disability.
- Tell me about your experiences with communicating with your child's medical team. What experiences have you had with differences in expected goals or treatment plans.
- Tell me about your experiences with doctors' or nurses' perceptions of your child's quality of life because of their disability.
- Tell me about any experiences you have had where you lost trust in your doctor.
- Have you ever had an encounter in health care where you felt like the health care personnel felt you or your child were a burden because of your child's disability? Tell me about that experience.

Thank you for sharing your experiences with your child in the health care system. I now want to ask you, with these experiences in mind, how do you feel these experiences have impacted your or your child's life?

Outcomes

Tell me how your experiences in health care because of your child's disability have impacted you.

How have these negative experiences impacted your child's health?

How have these experiences impacted your access to high quality health care?

How have these experiences in health care because of your child's disability impacted your well-being?

Thank you for sharing your perspectives on this difficult subject. I am going to shift the conversation a little bit now to talk about your experiences with systems of care and how the way our health care system is designed may impact you or your child because of their disability.

Systematic Discrimination

Tell me about any times you may have had trouble in accessing the care your child needs because of their disability.

Have you had experiences with limited access to care because of other factors outside of disability in your community?

What are your thoughts about how children with disability are prioritized in the health care system?

Global Assessment

- How do you think children with disabilities are treated differently compared with children without disabilities in health care settings?
- [If appropriate] As a parent of a child who identifies as [Black, Hispanic, etc] with a disability, how do you think your experience in health care is different from a child who is white and has a disability?
- How do you think children of different races are treated in health care? How does that compare with the experiences on the basis of disability?

Closing

If you were able to tell us 1 thing that would help to make the health care system better for you and your child with a disability, what would you want us to know?

Thank you for all the valuable information you have shared and your time today. Is there anything else you'd like to share before we end?

Probes

Clarifying their response:

- It sounds like you are saying, "...". Is that a fair summary?
- When you say "...", what do you mean by that?
- What you're saying now is very important, and I want to make sure that I understand exactly what you mean: Please explain some more.

Probing for detail:

- Tell me more about that.
- Would you elaborate more on that?

- That's helpful, could you provide more detail?
 - What you are sharing (or have said) is important. Can you say more?
 - How so?
 - Can you give me an example?
 - If you could change anything about that experience, what would it be?
 - How do you do that?
 - Can you tell me more about that?
 - Is there anything else?
- Can you say something about why this issue generated so much emotion?
 - What aspects of this issue do you think prompted such strong emotions?
 - How do you feel about that?
 - Why is that important to you?
 - Why does that stand out in your memory?
 - Why do you think you noticed that?
 - What was significant about this to you?
 - Tell me about the last time this happened.