

Quality of Life in Children with Vision Impairment Focus Group Script (Parents)

Welcome and Introduction

Hello! We're so glad you are here today! My name is (facilitator) and I will be your facilitator today. Let me also introduce...

Introduction of Subject of Group

The main reason we are here today is to talk about how you feel about your child's vision and how it affects everyday life.

Informed Consent; Oral Notification of Taping

Before we begin, I need to ask you to sign the informed consent document you have in front of you. Would anyone like me to read it out loud? Do you have any questions about it? *Read if needed and answer any questions. Have participants sign forms. Collect forms.*

We mentioned this before but just to remind you this session is being audiotaped. We will be using these only for making the transcripts, which will not contain your last names. After that, the tapes will be destroyed. Does anyone have any questions or objections?

Guidelines for Focus Group

Let me give you a few quick ground rules for the group. First, everyone's opinion is important and it's okay to disagree with each other or with me. We are very interested in hearing about all points of view. It's okay to talk to each other and not just to me. Since our time is limited I may need to ask you to stop and change topics from time to time. I'll give you the "Time out" sign if we need to do that. If you need to go to the restroom at any point, just raise your hand.

Introduction of Participants

Now I'd like to go around and let each one of you tell us your first name and one thing you did this week that was important or fun. I only need your first name.

***NOTE FOR ANY PROBLEM OR ISSUE MENTIONED BELOW, PROBE AS REQUIRED FOR:**

- ***How often is this a problem?***
- ***How serious or important is this to you?***
- ***How important is this compared to other aspects of your child's vision?***
- ***Have you had to stop doing an activity because of your child's vision?***
- ***Did your child perform an activity less often than you would like because of your vision?***
- ***Are you afraid to let your child do any activity because of his/her vision?***
- ***Does it take your child longer than you would like to perform the activity? Has this decreased their interest in doing the activity?***
- ***Do you feel your child is more dependent on others because of his/her vision?***
- ***Do you feel irritated or frustrated when your child has difficulty?***

General Vision

- Describe your child's vision.
- Is your child's vision different from his/her friends' vision? How is it different?

- Is your child's vision different from his/her brothers' or sisters' vision? How is it different?

Mobility

- How well can your child see to walk around inside your home?
- What kinds of problems or challenges does he/she have?
- Does your child have trouble getting up in the middle of the night to go to the bathroom?
- Are there certain areas in your home where it is harder for your child to move around?
- Does your child have any trouble walking around or playing outside of your house?
 - What types of problems does he/she have?
- Does your child have any trouble moving around in his/her classroom at school?
- Does your child have any trouble moving around the halls or in the gym or cafeteria at school?
 - What types of problems does he/she have?
- Are there certain areas in your child's school where it is harder for him/her to move around?
- Does your child have any trouble playing outside at school?
- Does your child have any trouble moving around somewhere he/she has never been before?
 - Does your child have any trouble moving around at his/her friends' homes?
- What types of problems does he/she have?
- Does your child have any trouble using a white cane?
 - What kinds of problems does he/she have?

School Functioning

- Does your child have any trouble reading school materials?
 - What kinds of problems does he/she have?
- How do you think your child feels about the size print he/she is using?
- How do you think your child feels about using large print materials?
- Does your child have any trouble with the assistive devices he/she uses?
 - What kinds of problems does he/she have?
- How do you think your child feels about using assistive devices?
- How do you feel about your child using assistive devices?
- How well does your child see to read?
- Are there situations when your child has difficulty reading?
- Does your child have any trouble reading the teacher's handwriting?
- Does your child have any trouble reading his/her classmates' handwriting?

Social Relations & Activities

- Has there ever been a sport or activity your child would have liked to do that he/she didn't do or that he/she had to stop doing because of his/her vision?
- Does your child's vision make any sport or activity less safe or enjoyable for him/her?
- Can your child do all the activities he/she would like to do or does his/her vision make it too difficult?
- Does your child's vision make it difficult for him/her to watch TV, going to movies, or go to friends' homes to play?
- Does your child have any trouble making friends because of his/her vision?
 - What kinds of problems does he/she have?
- Does your child have any trouble recognizing his/her friends or family members because of trouble seeing their faces?
 - What kind of problems does he/she have?
- How does your child's vision affect his/her self esteem?

Self-care Activities

- Does your child have any trouble getting dressed, brushing his/her teeth, or taking a bath because of his/her vision?
- Does your child have any trouble pouring a drink?
- Does your child have any trouble identifying coins?
 - What kinds of problems does he/she have?

Treatment

- How does your child feel about any medications he/she is taking?
- How do you feel about any medications your child is taking?
- How does your child feel about any eye surgeries he/she has had?
- How do you feel about any eye surgeries your child has had?
- Does your family have any hopes for future treatments?
- How does your child feel about wearing glasses?
- How do you feel about your child wearing glasses?
- Does wearing glasses ever make it more difficult for your child to do certain activities?

Family Impact

- Do you ever worry about your child's vision?
- Do you feel that you spend a lot of time at the doctor because of your child's vision?
- Do you feel frustrated about your child's behavior because of his/her vision?
- What expectations do you think your family has about your child's vision in the future?
- Are you ever surprised at certain things your child is able to do in spite of his/her vision impairment?
 - If so, what sorts of things surprise you?

Wrap-up

Is there anything we did not talk about that you think is important for us to know about how your vision affects how you feel or interact with others?

Questions to Facilitator

Do you have any questions about this group or why we are all here today it? Are there any comments you'd like to make?

Thank you

We're so glad you spent time with us today. We learned a lot and it was so much fun talking with all of you. Thank you for sharing your thoughts.