

Focus Groups Protocol

(Focus group sessions will be held in Spanish, English, or both as preferred by the participants.

Preference will be obtained during the phone screening process)

(Focus groups will consist of parents/caregivers of autistic children, autistic adults, teachers and OT practitioners)

1. Welcome

- a. Main Introduction and Roles
 - i. Moderator and supports available (autistic adults and spaces for breaks)
 - ii. Team members
 - iii. Note taker/any other team member present
 - iv. Location guidance (bathroom, snacks, if child care is provided room and staff, location on where to take a break)
 - v. Participant introductions and warm-up

Engagement questions:

- Can you introduce yourself, your role, and share something about you, perhaps something you are good at, proud of, or anything? (everyone)

2. Stage 1: Introduction to the process

- a. Overview of the project
- b. Review of goals and participant selection (they were randomized to focus groups)
- c. Availability of English-to-Spanish translation/interpretation services
- d. Information on the recording of the sessions
- e. Format and ground rules
 - i. There are no right or wrong answers, just different points of view
 - ii. Respectful listening
 - iii. Needing a break *"We know from prior experience running groups like this one that talking about your experience can be emotionally overwhelming. We understand this and will do our best to support you. If the conversation feels overwhelming to you, please feel free to reach out to one of our designated assistants to step out of the room or ask us to take a pause if you need a moment to yourself. It is ok to do that at any time."*
- f. Responding to any questions the participants may have on the process.

3. Stage 2: Discussion

- a. Questions, probes, and/or elaboration of responses

Focus groups questions

Exploration questions: (Start recording here and inform participants about it)

Let's think about therapy services such as physical therapy (improve movement and pain), and speech therapy (improve communication), or occupational therapy (develop skills and manage symptoms for daily life routines) for a moment, think about the experiences you, your child, or

the families you serve have had trying to obtain those services, and if you received the services, think about them, if they were successful or not, and if there are specific positive and non-positive experiences you remember. Now, we are going to ask you some questions in a few moments.

- Can you tell us about successful experiences obtaining therapy services such as occupational therapy, physical therapy, or speech therapy?
- **(as needed)** How about clinicians? What positive experiences can you share working with the families? What went well?
- What positive experiences have you specifically had with Occupational therapy?
- Now, what specific efforts has your therapist made that helped you to feel supported?

Transition statement:

Thank you. We appreciate you sharing all the information. Now, we are going to shift a little bit and focus on the challenges. I want to reassure you that what you share with us today on any negative experiences is okay, as this is a safe place and is not going to affect you in any way.

- Can you tell us about the challenges in obtaining therapy services such as occupational therapy, physical therapy, or speech therapy for you, your child, or the families you serve?
 - **(as needed)** How about clinicians? What experiences accessing therapy services have you experienced/witnessed for the Hispanic/Latino clients you serve or the parents may have shared with you?
- What challenges have you had specific to accessing or using occupational therapy services?

Transition statement:

Thank you again for sharing all your experiences. We are going to transition a bit and ask some questions related to cultural preferences. This is for us to learn and support therapy practices that are sensitive to cultural preferences. Culture is defined as the way of life and it including beliefs, customs, manners, religion, dress, language, and arts of a population that are passed down from generation to generation.

Now, can you answer the following questions related to culture:

- Can you share any aspects of your culture that have influenced your decision to participate in therapy services?
- What thoughts do you have about whether the therapy sessions/interventions you received were culturally sensitive?
- Did you ever feel judged by your therapist based on your cultural values/traditions?

- Have you ever felt uncomfortable carrying out interventions at home because they may not go with your cultural beliefs?
- What would you like your therapist to know about you, your child, and/or your family regarding cultural values?
- Please share some suggestions on how to provide more culturally sensitive therapy services, including any cultural characteristics to include in interventions and/or services.

Transition statement:

Thank you for your answers. Now, we are going to talk about a specific occupational therapy intervention and ask some questions.

It is estimated that up to 90% of autistic individuals experience sensory differences that may present as hypo-reactivity to sensations (unaware of the sensations and stimuli in the environment such as not seeming aware of tactile, auditory, visual or other sensory cues), hyper-reactivity (being sensitive to noise, avoiding eye contact, disliking textures) or excessive seeking of sensory experiences (the need to seek sensory input such as frequently touching items, spinning, and jumping on different surfaces). In addition, they may have difficulty integrating sensory information, such as combining tactile and visual cues when figuring out how to put on a coat or pair of socks, or when figuring out how to play with a toy. Ayres Sensory Integration is an evidence-based intervention that addresses these sensory symptoms of autism through individually tailored activities, in a playful environment with opportunities for swinging, jumping, exploring ones body. The therapy is usually done in a large room with mats, large therapy balls, and other equipment that allows for active movement and exploration (e.g. carpeted barrels, scooter boards, or different kinds of swings). .

- Are you familiar with the intervention Ayres Sensory Integration?
 - If you are, has your child received/did you receive/have you provided ASI services?
 - Has your provider or therapist talked to you about this intervention?
 - Can you share any challenges or positive experiences accessing (or providing) these services?
 - Were they provided in a culturally sensitive way?

Transition statement:

Thank you. We appreciate all the information you shared. Now, we are going to ask for your wisdom to ensure we improve therapy services. Please feel free to share and be as specific as you can

- How can we improve access to therapy services for your family (clients)?
- How can we improve the use/utilization of therapy services for your family (clients)?

Exit questions:

- Finally, would you like to share any additional thoughts about your experiences accessing or receiving therapy services? These could be positive experiences, challenges, and/or any suggestions to improve therapy services.

4. Stage 3: Wrap up

- Final comments/discussions
- Next steps after the session (completion of surveys, payment, clincard)
- Closing the session.

Questions to use as needed:

- Can you give an example? Please describe what you mean
- Would you explain further?
- Would you say more?