

Supplemental Material S3. Family story interview protocol.

Family Story Protocol

Purpose:

Story telling is a way for us to get to know a child and his/her family better. It provides a context for understanding who this child is. It allows the parent to "see" the child in the context of relationships that he/she has with him/her and with other family members. It helps both the parent and interviewer understand the critical events in the child and family's life. It provides another way for us to think together about the child's skills and emerging strategies for communication in the context of who the child is and how he/she functions in his/her everyday life. It helps us choose a good beginning point (skills and strategies) for language intervention.

The family story is a way for us to get to know the family and the child in a more holistic and deeper way than we could by simply looking at assessments. As the interviewer, your job is to create a safe space for the parent to share this very personal story and let them know that you care and are listening intently.

Before the session with the family:

1. Review the child's assessment data and the family file. Be familiar with the child's testing information and the family's history.
2. Be sure to review the demographic form (if possible).
3. Know where the child is developmentally and what skills come next. It is helpful to review the testing information item by item and determine specific next skills.
4. Come prepared with knowledge of some positive characteristics of the child and the family. List skills the child already has. Consider the child's strengths as a learner and a communicator.
5. Make an appointment at a convenient time for about 1 hour. Choose a time when both you and the parent can be relaxed and focused on the interview.
6. Get the needed equipment together for the interview: video recorder, child's assessment file and any notes you need for talking with the parent about the child's developing skills.

Steps in the family story:

1. Explain to the parent the purpose of the family story.
 - a. To learn about your life with (child's name) and how he/she has developed thus far.
 - b. To talk about strengths, needs, skills, challenges
 - c. To make communication goals.
 - d. To make a plan about how to best work on the child's communication goals.
2. Explain that this is an informal conversation designed to share information and that they can choose what information they are willing to share, that their information will be treated with respect and confidentiality, and they can ask you to turn off the camera at any point.

3. Ask the parent to walk you through the child's life starting from pregnancy. Try to cover all developmental milestones (motor, language, feeding) and social relationships, as well as ways the child communicates now. Cover the following topics using the following guiding questions or similar questions that address the same topics.
 - a. "What was life like before (child's name)?"
 - b. "How did life change when (child's name) was born?"
 - c. "Tell me about your pregnancy" OR "Were there any significant events during your pregnancy?"
 - d. "How did your child first communicate? How has this changed over the last year or so?" Did (child's name) babble? "Tell me about some of the significant life events for (child's name)?" "Any feeding difficulties?"
 - e. Tell me about how (child's name) communicates with you now.
 - f. What are some fun activities that you and (child's name) like to do together?
4. Ask: "What are 3 things you love about your child just as she is?" Be prepared to offer some ideas or general comments to support the parent if she is hesitant (e.g., who could not love that sweet smile when you play with her, or the way her eyes light up when you come into the room).
5. Next ask, "What are 3 things you are doing really well in terms of parenting right now?" Be prepared to help the parent make this list if they are all hesitant (e.g., you are obviously very loving and caring, very responsive, thoughtful in your decisions about your child, really good at arranging supports for your child, etc.).
6. Towards the end of the story move to goal setting. Let the parent know you have heard what she has said and let her know that you are shifting focus. You may need to summarize a little about where the child is developmentally before you ask the next questions.
 - Ask: What are 3 things you wish your child could do in terms of communication? If needed help the parent place her wishes for communication in the context of the child's development and try to find a realistic and possible way to address these wishes. Reframing and support to find a good place to begin may be needed.
 - Ask: What are 3 things the parents wish they could do as parents to better support their child's communication. Be prepared to offer some broad based suggestions or ask questions that support the parent (e.g. Do you always understand what she says? What do you think might help you better understand? What do you think helps your child communicate with you?)
7. Summarize the story in a supportive way. Emphasize the positives and the plans for the communication intervention (child goals, parent goals)
8. Thank the parent for sharing his/her story.

Skills to facilitate a family story:

You will use encouraging, reflecting, reframing, and goal setting skills to facilitate the family story.

Encouraging questions/Statements

Encouraging questions are open-ended questions that allow for the parent to expand on their story and take the lead in sharing what he/she thinks is important to share. These questions will get more information and are less direct. Avoid asking closed or yes or no questions. Yes or no questions do not give very much information and can be very directive.

- For example, instead of asking "has family been supportive?" (a yes/no question), try "what has been/was supportive during this time?" (this question will give the parent an opportunity to share much richer information). This second question also uses a reframing technique (more later).
- Avoid asking "why" questions, the parent may not know why, and "why" may not be helpful. For example, think about the question, "why was family not supportive?" The parent likely does not know "why" and even if he/she does it is not an important aspect of the story.

Encouraging statements are short statements that convey to the parent that you are attentively listening and care about their story. These statements can be very simple statements such as "I see", "yes", "right", "hmm", or a non-verbal head nod. If you pick up on something important that the parent has said and would like more information, another encouraging statement would be, "say more about that."

Reflecting Statements

Reflecting back to the parent is a great way to let the parent know that you are really listening to their story, and will help them feel comfortable giving more information. Avoid responding to the parent by sharing personal stories. When we talk about personal experiences it takes the focus away from the parent's story and makes it about us. There are two types of reflecting statements that you will use, reflection of content and reflection of feeling. Reflecting statements are wonderful tools because they allow you to actively listen to the parent's story without attempting to fix problems.

Reflection of content: By reflecting content, you allow the parent to know you are listening, and give him/her an opportunity to confirm or correct the impression they are giving. You are serving as a mirror to them. Listen and give a condensed and nonjudgmental version of facts and thoughts the parent has communicated to you to reflect content (examples to follow).

Reflection of feeling: Another way to use reflection is to reflect feeling. To do this you will have to identify the parent's feelings, and articulate the emotion back to him/her. If you can use a reflection of feeling, this is often a more powerful reflection, because it will take the story to a deeper level. Furthermore, when the parent uses a feeling or emotion in their statement, it is much more appropriate to reflect back a feeling.

Examples: The following are examples of statements taken from family stories that might be difficult to hear and know how to respond to. Following each statement is an example reflection that would be an appropriate response:

- “When I’d go in for a checkup the nurse would give me a sheet of all the things that she was supposed to be doing and I finally said please stop giving me these because she’s not doing any of it and it upsets me, it just reminds me of what she’s not doing”
 - a. **Reflection of content:** “You kept being given information on developmental milestones that she wasn’t hitting”
 - b. **Reflection of feeling:** “It was frustrating to be given all this information and know your child wasn’t doing it”
- “All these people came in, geneticists, counselors, social workers, case workers, and every person had all this paper work... and to be honest I didn’t read any of it”
 - a. **Reflection of content:** “There were a lot of people coming in with an abundance of information, and you couldn’t get to it all”
 - b. **Reflection of feeling:** “You felt overwhelmed by the sheer amount of people and all the information they had to give”
- “I didn’t know what I was doing anyway this being our first child and then you throw in a special need that I know nothing about and it was just overwhelming”
 - a. **Reflection of content:** “It was especially difficult knowing what to do with a child with special need”
 - b. **Reflection of feeling:** “You felt unprepared and it was overwhelming”
- “I was crying because I was scared and trying to process all the things I needed to do for her”
 - a. **Reflection of feeling:** “You felt terrified not knowing everything you needed to do.”

Note: The parent used the feeling “scared” in her statement; therefore a reflection of feeling is more appropriate.

Tip: When the parent gives you a feeling word, it is appropriate to use a deeper more powerful word that conveys the same feeling in your reflection. In the above example the word “scared” is replaced with “terrified.”
- “I worry about when he gets older, because you know kids can be really mean. As a mom that really concerns me.”
 - a. **Reflection of feeling:** “You feel distressed thinking about his future relationships with peers”

Reframing

To Reframe, listen for and comment on parents’ strengths. Frame questions in a way to get parents to talk about positives. Example questions with a positive reframe include:

- “How is your child communicating right now?”

- “What are some things you enjoy doing with your child?”
- “How do you feel supported in meeting your child’s needs?”
- “How do you feel empowered to meet your child’s needs?”

Using reframing techniques allows the parent to think about their child and experiences in positive terms. This will also give us valuable information to work with the family.

Goal Setting

Four important things when thinking about goals are (1) goals should be specific, (2) parents should be involved in the goal setting process, (3) goals should be stated in positive terms, (4) goals should be realistic.

1. **Creating specific goals:** When we simplify a goal, we make it more specific. You may need to help guide the parent by asking the right questions to make goals more specific. For example, the parent states the goal is to have their child communicate more. This is a very broad goal. The following are questions you can use to help specify/ guide the goal making process:

- “What activities will help your child communicate/give them motivation?”
- “What does communication look like for your child?” (You will have this knowledge and knowledge of developmentally what will come next in order to help guide the parent)
- “How often/how many times a day would you like for your child to (use mode/targets)?”
- “Looking at how (child’s name) is communicating NOW, what would represent an improvement/ increase in communication?”

Note: be able to clarify and reframe for parents things that they might not see about their child.

2. **Goals should be important to the parents:** (Follow their lead) It will increase motivation! Ask, “How important is this goal to you?” or “If we accomplished this what difference would it make in your life?”
3. **State goals in positive terms:** Phrase goals in terms of what the parent or child **WILL** do instead of will not do. If the parent gives you a negative behavior that they would like to stop, find out what the positive replacement behavior would be.
4. **Goals should be realistic:** This is where your knowledge of where the child is now and what comes next will be extremely important. Parents might need help looking at one thing at a time. It is likely they have several different goals around communication and other aspects of the child’s development/life. When the parent’s goals seem overwhelming or all over the place, you can help bring them back in by focusing on a few more specific goals. Because our project centers around communication, you can start there. First acknowledge everything that the parent has named as concerns that could lead to goals. “You are concerned that _____ is not walking yet, does not seem interested in peer interactions, is not eating solid

foods, has both gross and fine motor issues, and can’t tell you what is wrong when they are upset or tell you things he enjoys.” After summarizing the parent’s concerns you can say something like “Which of these concerns are the most critical to you RIGHT NOW and that you think we could work on in our intervention sessions?”

Think of using our “responsive interactions” with parents:

Following the Lead	<ul style="list-style-type: none"> • Ask open ended questions (avoid yes or no questions) • Avoid irrelevant filler questions • Don’t be directive—let the parent guide the interview
Balanced Turn Taking	<ul style="list-style-type: none"> • Reflect and use encouraging statements. • Pause and be comfortable with silence to allow parent to gather their thoughts.
Responding with Intent	<ul style="list-style-type: none"> • Reflect back to parents accurately the message they are trying to convey
Mirroring and Mapping	<ul style="list-style-type: none"> • Use reflection skills to be a mirror to the parent of their stories • “Map” feelings on to your reflective statements when appropriate.