

Gathering Information from Families

This resource has quick tips on gathering the most useful information from families to make accommodations. Program Leaders can use this Tip Sheet as an outline for staff training. Program staff can use this Tip Sheet as a reminder about what information to gather from families.

Remember: **Protect Confidentiality**

- ✓ Keep medical and identifying information secure at all times.
- ✓ Share information among program staff only on a “need-to-know” basis.
- ✓ Avoid conversations in the presence of children, youth, and other families.
- ✓ Avoid disclosing a child’s diagnosis without permission.
- ✓ Communicate with parents about how you will keep information safe.

If a parent of a participant asks:

“What is wrong with Hayley?
Does she have a disability?”

You can respond:

“We maintain every child’s confidentiality. I can’t answer your question, but what I can tell you is we provide individual supports so that all children can be successful in our program.”

What is TOO MUCH information?

Asking for confidential or personal information that does not directly relate to caring for the child or youth is an example of “too much” information.

Why are some families hesitant to provide information?

They have been asked to share unnecessary information

- ✗ “Does it run in your family?”
- ✗ “What caused his disability?”
- ✗ “How did it happen?”

They have been asked personal questions that imply judgment

- ✗ “Did you have an amniocentesis?”
- ✗ “Did you drink alcohol when you were pregnant?”

They fear exclusion or rejection

- ✗ “I don’t know if we can handle that.”

What you need to know

Any Accommodations Needed

Accommodations may be required for a child or youth to fully participate in your program and activities.

- ✓ “Can you tell me what accommodations have worked for your son in the past?”
- ✓ “What support will your child need to be successful in the program?”

Behavior Supports

Understanding what motivates, upsets, or calms an individual can improve the way program staff responds to their behavior.

- ✓ “When she gets angry, what usually calms her?”
- ✓ “How do you encourage her at home?”

Individual Interests

Knowing the likes and dislikes of an individual can improve the success of program activity planning.

- ✓ “What kind of games does your daughter enjoy?”
- ✓ “What are your son’s interests?”

Unique Strengths & Challenges

Recognizing the abilities of individuals can improve readiness to offer support and plan learning activities that build on children and youth’s strengths.

- ✓ “Can you tell me what she is really good at.”
- ✓ “Can you tell me about the things that are difficult for him.”

What you DON'T need to know

- ✗ Diagnosis
- ✗ Developmental Age
- ✗ Family’s Personal Information
- ✗ Cause of Disability
- ✗ Medical History

Although some families may volunteer this information, it could possibly reinforce stereotypes. Labels derived from this information can interfere with the process of getting to know the individual child or youth.