



"Our mission: "To cultivate empathy and deepen understanding of one another through recognizing and celebrating neurodiversity"

Talking with children, adolescents and adults about FASD / Other Brain-Based Conditions

Should I tell my child about FA/NB? How do I introduce the idea of differences in brain function to clients? What if it makes things worse? I don't want to label, limit or stigmatize. When should I talk with him or her?

People with FASD and other Neurobehavioral Conditions (FA/NB) are often confused by how their brains work. Without information, there is no way of knowing that how their brain works is normal for them. One of the most basic human needs is the need to make sense to ourselves. Information about FA/NB provides this understanding and is usually described as "a gift" by people with FA/NB. Finally, things make sense. Understanding is a beginning, a point of liberation rather than limitation.

There is *No One Right Way* to introduce this potentially sensitive information. There are as many ways to introduce information as there are people doing so. Optimally, primary caregivers introduce and support ongoing discussions. Where a therapist is part of the process it is strongly recommended that this discussion happen with the family system, to support ongoing dialogue.

Experience has taught that discussing FA/NB is part of a broader process that involves the person facilitating the discussion as much as the people hearing the information. *This brief overview is not intended to address the intimate, powerful and vitally important emotions that may come up for parents, people with FASD or FA/NB or professionals while exploring these issues.* They include fear, grief, guilt, and shame and their resolution is central for healing.

The process may be thought of as having four parts:

1. Preparation of the person telling: Identification of personal feelings, needs and beliefs; developing information and a language for an ongoing dialogue.
2. Preparation for introducing the information: Know who the person is; establish a relationship and emotional safety. Understand learning strengths and plan accordingly.
3. Introduction: Choose the timing of the introduction of the information and develop an ongoing plan for continued exploration.
4. Follow-through: Continued awareness of the meaning of FA/NB in different settings – at home, school and community – and integration of the information into daily life; develop and advocate for accommodations in all settings.

Personal preparation

1. Gather information about FA/NB
2. Identify personal feelings, beliefs, hopes, fears, needs and concerns -- for example, discomfort may reflect beliefs about alcoholism
3. Find someone you are comfortable talking with to process feelings and beliefs
4. Clarify fears: What is the worst thing that could happen as a result of talking?
5. Clarify potentials: *How is identification helpful? What is the best thing that can happen as a result of having these discussions?*
6. Identify people who are knowledgeable and supportive.

Prepare for introduction

Evaluate for the timing of the introduction of information developmentally. An adolescent who wants only to be like everyone else and fears being seen as less than others first needs time to settle in order to be able to hear information about brain function. Use this time to observe, clarify, and prepare. There is often a sense of urgency around introducing the topic of FA/NB; resist the urge to rush.

1. Before initiating this discussion, if you are a professional, **establish a relationship**; if you are a parent, and if challenging patterns of behaviors exist, take time to reduce friction; spend time observing characteristics and identifying behavior patterns in children.
2. Look for and clarify strengths.
3. Identify primary and secondary behaviors; use the neurobehavioral screening tool to identify characteristics of FA/NB.
4. Identify the developmental level of the person with FA/NB, and tailor language and concepts so they are developmentally appropriate.
5. Plan to introduce information over time, in small pieces.

Introduction - a process

Choose a quiet time when there is no stress. Provide adequate time for processing and questions, and know that it is not uncommon for this information to "percolate," and come up later in different settings. An initial blasé response may belie the importance of ongoing discussions.

1. Suggestion: Use the draw-your-brain art exercise and talk about how all brains are different, how everyone has strengths and challenges. Normalize conversation about strengths, and how everyone's brain works differently. Talk about how we're just learning about how brains all work differently, not better or worse. Validate frustrations.



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2. Identify learning strengths, interests, and talents -- art, music, sports, mechanics, etc.
3. Plan to keep conversations concrete; story-telling and revisiting actual events helps.
4. Develop "picture language," referring to people, places and events familiar to the person. Find photos, use visual metaphors, e.g., "It's like a leaf being blown around."
5. Think about asking questions in a concrete way. Invite conversation, or use art to support exchanging information. Ask, "What's hard?" or "What works?" and then provide time for processing.
6. Explore the idea that we are all normal for ourselves. As appropriate, talk about your own strengths and "gaps." This takes the burden off the person, prevents finger-pointing, and keeps the conversation relational: "We" and "us," rather than "you."
7. If the person has a history of learning disabilities, know that the subject of brain dysfunction may rekindle trauma and discomfort. Reframe: learning disability does not mean "not smart," it just means that how a person learns may not be how they are being taught. Explore the many ways people learn. Some are visual, others learn by doing. This does not patronize; it is honest.
8. As appropriate, talk about how what we eat and drink may affect how we learn and develop, and may also affect pregnancies. The topic of alcohol is often not the first to be discussed and may come up over time. The discussion about how brains work differently is ongoing.
9. Again, be clear about your feelings about alcohol and FA/NB, whether you are a birth, adoptive or foster parent, or other caregiver or professional. Affirm that no one intentionally drinks or eats anything that might cause harm; usually lack of knowledge or trauma is the issue. Continue to give the message: I love/accept and respect you as you are.
10. All feelings are fair. Remember the stages of grief and remember that anger is a normal part of the healing process. Be honest, clear, and simple. Acknowledge, validate and listen. In many cases, grief is complicated by unresolved anger directed at others. There is healing beyond the pain.
11. Reduce fear around neurobehavioral symptoms and invite solutions.

Follow-through

1. Continue to explore how brains work.
2. Continue to clarify the fit between the person and environments, and work with the person to develop strategies and accommodations in order to prevent frustration.
3. Develop advocacy goals: Communicate and work with every person who lives or works with the person with FA/NB, in order to assure the goals are met.
4. Continue to educate any new person to assure ongoing collaboration and successful outcomes.