

Sharing Concerns- If you suspect a Developmental Delay or Autism, Speak Up!

For most parents, family members, friends, and physicians, sharing concerns about a child's development can be a challenging and daunting task. Here, we hope to provide the words and encouragement to help get the conversation started. With caring support, and open communication, parents can begin to take action.

Drawing on the experience of parents, this essay also provides a list of Do's and Don'ts, such as:

- *Listen to the child's parent, start with their observations or concerns*
- *Always be supportive, never judgmental*
- *Avoid jargon, labels, and terminology*
- *Keep it positive; emphasize 'ruling out' anything serious*

If you are concerned about a child's development, and want to bring it to the attention of the child's parent, here are a few Do's and Don'ts:

DO:

1. Set the stage for a successful conversation.

"My mother invited me to go for a long walk to tell me what was concerning her about my child. It confirmed my own suspicions. After, we had a long cry for ourselves over it."

Choosing the right time and place for a conversation to share your concerns is very important. Try to speak in person at a time when there will be no interruptions. Arrange to meet in a private setting. Dedicate as much time as you need to have a full conversation. Understand that emotions may be unpredictable. Be ready to offer help.

2. Start with the observations, questions, or concerns of the child's parent:

"It is critical to respect a parent's perspective; begin with a clear understanding of whether or not they may have concerns, and what those might be."

It's important to assess where a parent stands in relation to understanding his/her child's development before sharing your own concerns. The parent may already sense a problem and just not have the words to articulate it. Gently probe and ask questions that will allow a parent to share their own observations, questions, or concerns first. Then share your own observations. By doing so, you will open an exchange and may even validate a parent's hidden concerns and fears.

3. Put yourself in the parent's shoes. Be supportive, not judgmental.

"If you want to talk to a parent, please say it in a loving way. It might be good to begin by making a positive comment about the child's strengths and by reinforcing the parent's skills, love, and dedication to the child."

Some of the most memorable conversations that parents of children with special needs report are those that take place at the critical moment a first concern is expressed. An empathetic approach goes much further in establishing trust and understanding than a judgmental or emotionally-closed or -charged one. Your tone and manner should be open and available. Whatever the outcome, in the long run, the parent will remember and appreciate your discussion if it is framed in a caring way.

4. Focus on milestones, absolute indicators, and the need to "rule out" anything serious.

"It is such an emotional subject, with so little that made sense. Milestones made sense to me."

Give the parent something positive to read (see our developmental checklist of hallmark milestones and red flags). The checklist gives parents something to think about and consider, but never puts a label on it. It gets the conversation started with the child's physician and provides specific information about strengths and areas of challenge.

5. Refer parents and caregivers to other resources. Some parents need to come to this understanding on their own.

"I remember seeing a Web site that seemed to describe many of my son's unique and, frankly, troubling behaviors. As much as I wanted it to be wrong, the more I read the better I understood that something was going on."

Seeing developmental disorders described in writing, whether through literature or on the Web, allows a parent to make the match with his/her own child's behaviors and needs. It provides an objective description of common features and allows the parent to come into recognizing developmental concerns at their own pace.

6. Emphasize the importance of early identification and intervention.

"Early intervention is the key. Tell the parent that the earlier you catch a child, the easier it is to help the child...if you let it go too long, it just takes that much longer for the child to gain ground."

One way to look at developmental concerns is that if a child had signs of a serious and persistent physical illness, like asthma, you would want to get it checked out as soon as possible to rule it out. If there really were a problem, it would only make it worse by not doing so. Developmental delays are no different. By not receiving timely interventions for concerns around language, behavior, and social connectedness, the problems will not go away, but will worsen over time. And what's most hopeful is that early intervention works,

improving life in the long and short term for both the child and the family. So life will get better once interventions are underway.

7. Be confident that sharing your concerns is always the right thing to do. The hardest part is finding the right words and getting started.

“When my son was 18 months old with no language, a friend said that I should march him right down to the pediatrician’s office. I have to admit I was a bit offended but when I found out her advice was right, I thanked her. Most people would just sit back on their hands and not say anything. Her delivery lacked some tact, but she got me going.”

Try role playing what you will say first. Express what you have observed that gives you concern in a caring, supportive way. By doing so, it may lower your own anxiety and give you the confidence to have a heart-to-heart with a positive outcome.

8. By sharing your concerns, you may help to validate what a parent is afraid or unable to express.

“I felt comfortable in my denial. I just thought ‘oh, this too shall pass.’ But when my sister expressed her concern, it articulated what I was too afraid to say. Every now and then I need someone to shake me out of my comfort zone and get me moving.”

Often a parent may have a nagging and persistent subliminal fear that something is indeed wrong developmentally, but they may be afraid to say it out loud. All they may need is to hear the same concern from someone else to confirm their suspicions. These outcomes are usually described by parents as bringing them relief. Now they don’t feel so alone. It provides the impetus to take the next step for their child.

DON’T:

1. Don’t dismiss a parent’s concerns.

“Just listen and observe. Take the time to listen to the parent and observe the child before you do, or say, anything.”

If a parent shares concerns with you directly, you have a unique opportunity to help them. Listening is often all that is needed to help parents channel their concerns into words and actions.

2. Don’t compare one child to another. Each is unique.

“I’ve heard the story about how a child had no language and then one day, started to speak in volumes, almost miraculously. I’ve heard about Einstein being a late talker as another way to comfort me. Although well-meaning tales, they did nothing to help me move forward to help my child. They only prolonged my self-doubt.”

Often family and friends will share a story meant to give comfort to a parent that gives an anecdote of someone else who struggled with early developmental concerns, only to outgrow them in a dramatic or famous way. Instead of having the intended effect of providing comfort and ruling out concerns, parents often sense that they do not address

their child's unique concerns and dismiss them. Or they may provide more insecurity to a first time parent who is already experiencing self-doubt. Either way, anecdotes are not useful. It is more important to think about the particular child in question.

3. Don't use labels, technical jargon, or loaded terminology.

"When the teacher at my son's preschool said that he 'needed Special Education,' I thought she meant that she thought he was mentally retarded; I just shut down. Similarly, when my doctor told me she'd 'Seen kids like him before', I stopped listening."

It's probably too scary to mention a specific disorder to a parent right out of the gate. Many disorders are misunderstood and just the mention of them can bring up great fear in parents who may shut down. Sometimes giving a parent an article or book to read is enough to make the connection.

4. Don't scare a parent: keep it positive.

"I told my doctor that my daughter's daycare provider had some concerns about her, but I disagreed. 'Wasn't it OK for a child to be a little bit different? Why label?' I'll never forget my doctor's simple, steady words: 'Just get it checked out, just rule it out. You have nothing to lose.' She was right. If it hadn't been for the extra help my son got by being identified at such a young age, he—actually, WE—would never be doing as well today."

If a parent is encouraged to see their pediatrician with developmental concerns about their child, there will be one of two outcomes, but each will have its positive aspects. If concerns are ruled out, parents can rest easy. If there are indeed confirmed concerns, seeking help through evaluation and referral will eventually get the family back on a healthy developmental path.

No harm can be done by checking out concerns. Things can only get better.

This is a positive message that family and friends can share with parents to encourage them to seek help.

The above article is from www.firstsigns.org POAC is proud to be a supporter of First Signs and their great work.

