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Partnering with Families to Support Inclusion: Part 1

Viewer's Guide

This viewer's guide will help you find more information and capture your ideas as you engage with the webinar content. During this webinar we will focus on the importance of partnering with families of children with disabilities or suspected delays to have supportive conversations about their child's development. We will explore potential family reactions to learning about a developmental concern. We will share responsive engagement strategies that program staff can use to have ongoing conversations with families that support them to learn more about or act on a developmental concern. Helpful resources can be found in the Resources section of this guide.

A Family's Journey



Many parents of children with disabilities have described the series of experiences they encounter and evolution of feelings over time as a "journey". No family experiences their child's disability or delay in the same way. The emotions that families experience, while overwhelming and intense at times, are also normal and acceptable. Learning that a child has a disability, seeking services, navigating systems, and managing transitions are part of the ongoing journey for many families. When program staff engage families to understand their journey, they can walk alongside the family to build mutual respect, trust, and a sense of belonging.

"My experience following receipt of the diagnosis, was affirming in part, devastating in whole. I felt, even with my husband and my mother's presence, very alone. No one could understand the loss that I felt for a child that was visibly present. I felt unsupported and angry. Mad, extremely so...unrealistically so. How dare God? I am a good person... Why me?! Later would come depression, embarrassment, and hopelessness. Her father went through a bit of denial. I can't say I ever denied or distrusted her diagnosis. The strain on my relationships was overwhelming. Every day was a different experience. Some good, some bad, each one needed to progress to where we are today."- Mother, reflecting on her family's journey

"I have learned, and grown, more since Dylan's birth than any other time in my life. You learn patience, and you get to witness miracles that you otherwise would have been too busy to have noticed...You learn acceptance, you realize you have been wrong to judge, and you learn that there is a thing called unconditional love."- Lori Hickman



National Center on

Early Childhood Development, Teaching, and Learning

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Sharing Developmental Concerns

Talking with families about developmental concerns should be a collaborative process, grounded in relationship-based practices. Sharing concerns is more than having an initial conversation, a meeting, or completing the necessary screening forms. It's an on-going process that requires building meaningful relationships over time. When a relationship built on mutual trust and partnership has been established, it allows space for difficult conversations to occur.

Even in the context of a trusting relationship, conversations about developmental concerns can be difficult and take some thoughtful planning. Here are six relationship-based practices to build and maintain positive relationships with families. Consider these practices when engaging families in collaborative conversations about developmental concerns.



Describe observations of the child's behavior: Start with the positive - share positive and neutral observations without assigning meaning to the behavior and allow the family space to reflect and respond with their observations. The family's response to your observation can guide you in what to say next.



Focus on the family-child relationship: As you prepare to have challenging conversations with families, it's critical to recognize and highlight that the family-child relationship is the primary one in the child's life. The power of the emotional connection is a protective factor for a family as they cope with a challenging conversation.



Value a family's passion: Parents may have different reactions and strong feelings during the initial conversations about their child's development. Their emotions and reactions, while they may make us feel uncomfortable, indicate their desire to protect their child and that they want the very best for their child. Try to understand their point of view and what might be driving their response.



Support parental competence: Parents' perceptions about their child's development should always be taken seriously. Supporting a parent's competence means listening for the observations and concerns before you tell them about your understanding of the challenges. This reinforces the parent's expertise and makes it more likely that you can share your observations effectively.



Actively reflect on the family's perspective: Invite parents to share their own observations and goals about their child and the family. Although you will be there to support them, it is necessary to hear and consider the family's views before coming up with a collaborative plan of action. Reflect back to parents what you have heard, and to say it in a way that shows you value their perspective.



Reflect on your own perspective: As you talk with a family about *your* concerns, reflect on your perspective to identify your own emotions so you can set aside any unhelpful judgments and biases, and better manage any feelings of discomfort. Try looking for common ground between you and the family to strengthen your partnership.

The National Center on Parent, Family, and Community Engagement has developed a series of resources to support education staff to learn and use relationship-based practices when having sensitive conversations with families. Check out [Talking with Families About Developmental Concerns](#), [Starting with Strengths in Challenging Times](#), and [Engaging with Families in Conversations About Sensitive Topics](#)

What is Family Readiness?



When faced with concerns about their child’s development or behaviors, families may experience a variety of reactions. Some families may feel worried, concerned, or hesitant. They may disagree with the concerns and be resistant to following through with a recommendation for further evaluation. In these cases, it may be tempting to feel that the family is “in denial” about their child’s development and feel unsure how to move forward. It can be helpful to reframe family hesitance as family readiness – whether a family is emotionally or psychologically ready to act on developmental concerns.

Readiness is a process that can take time and vary based on family characteristics. As families become more ready to act on developmental concern, the support they seek, type of information needed, and urgency to move forward develop in predictable ways (Gentles et al., 2020). Education staff may see families move through various stages of readiness related to concern about their child’s development. They may show more motivation and readiness to:

- Ask questions and learn more about developmental milestones and how their child’s development compares
- Ask questions and learn more about specialized services
- Engage in further screening or evaluation
- Consent to referral for evaluation
- Engage in and complete the initial eligibility evaluation process
- Access specialized services, treatment, and support for their child and family

Is the concept of family readiness familiar to you? Is this something you use in your work? What information or resources would be helpful in your work with families?

What Might Impact Family Readiness?

How ready a family is to act on developmental concern will depend on that family's individual characteristics and circumstances. There are many factors that might influence family readiness.

- **Family knowledge and beliefs**

- What a family knows and believes about child development, disability, and specialized services may impact their readiness. Many families feel like they don't have enough or the right type of information about developmental milestones and don't understand why acting early when there are potential delays is so important (Raspa et al., 2015). Families who have knowledge of developmental milestones, the benefits of screening, and the benefits of services for children with disabilities or delays are more likely to follow through with referrals (Jennings, 2012).
- Family beliefs about the role of parents in children's development may also influence their readiness. Families have unique perspective on how a child learns new skills and the roles of different adults and environments in the developmental process (Keels, 2009).
- Language can also influence how ready a family may be to act on developmental concern, particularly if the family speaks a language in which there is no word or concept for the disability or delay.

- **Family concern**

- How concerned a family is about their child's development or behavior will impact their readiness. Many families will attempt to make meaning of the concern about their child's development – they may try to determine how much of a delay is present, whether the delay will resolve on its own, and, ultimately, how worried they are about the concern. If a family perceives the delay as more severe or worrisome, they are more likely to be ready to act on the concern (Marshall, Coulter, Gorski, 2016).
- At the same time, a family, a family may also attempt to make sense of the benefits of acting on the developmental concern. If the family perceives that the benefits of further action, such as consenting to a referral or accepting services, outweigh their concerns they are more likely to be ready to move forward (Marshall, Coulter, Gorski, 2016).

- **Child and family characteristics**

- The type of concern present about a child's development may also impact family readiness. When there are concerns about a child's physical development, language delays, or behavior, families are more likely to follow through with referral. Parents who have a family history of developmental delays are also more likely to follow through with referral (Marshall, Coulter, Gorski, 2016).

- **Other's perceptions**

- When presented with a concern about their child's development, many parents look to others for feedback regarding the concern. They may look to a partner or spouse or extended family. Parents report that they look to friends and other parents most often to learn more or gain perspective on their child's development or behavior (Marshall, Coulter, Gorski, 2016). Parents will often watch to see how other same-age children interact, engage, or behave to make sense

of their child's own development. What they see or hear may influence their own readiness to act on a concern about their child.

- Many families will also seek feedback about their child's development from a medical professional. However, it's been reported that nearly 50% of pediatricians don't regularly conduct developmental screening referral (Marshall, Coulter, Gorski, 2016). Many parents report that, when they brought up a concern with their doctor, they were encouraged to take a "wait and see" approach (Raspa et al., 2015). Not having a developmental concern validated by a medical professional may impact a family's readiness.

- **Family culture**

- When presented with a recommendation for an assessment, a family's cultural background and identity may influence how they respond to the concerns presented and influence their readiness to act on concern.
- Culture can shape a person's understanding of disability and its "cause", whether to seek treatment and who to seek or accept help from, treatment options or preferences, and their relationships with professionals.
- Some cultures views on disability may include considering a child with a disability to be a gift from God, a punishment, or a condition caused by illness or vaccines (Ennis-Cole, Durodoye, & Harris, 2013). A family's perception of the cause of a disability may influence how they choose to intervene or seek treatment. For example, if a family believes that a child's disability was caused by an environmental factor, such as vaccines or processed foods, they may be likely to seek out treatment methods including diet and detoxification. However, if a family believes their child's disability is the will of God, they may be less likely to seek intervention, considering the presence and course of the disorder to be from a higher power (Ravindran & Myers, 2012).
- Education staff can partner with families to understand how the disability is approached or understood in their culture. They ask questions to understand a family's beliefs about education, disability, and intervention (Levy et al., 2003). Useful questions might include:
 - "How do you describe your child's behavior or delay?"
 - "What do you think this disability/a disability does? How does it work?"
 - "What kind of help/treatment do you think your child should receive?"
 - "What do you expect from a treatment?"

Family Perspective Videos: Reflections

Listen and reflect as these parents describe what was helpful to them, or what they wish would have happened, during ongoing conversations about their child's development.

What stands out to you? How might you use this perspective as you partner with families?

Reflect on Conversations and Perspectives



When there's a developmental concern and are engaging with families in ongoing conversations, reflection is critical. Education staff should **actively reflect on the family's perspective**. Invite parents to share their own observations and goals about their child and the family.

It's also important to **reflect on your own perspective** as you talk with parents about your concerns. Your expertise, of course, is valuable. But your role is to provide support and guidance rather than telling a parent what you think they should do in their child's

best interest. Determination to help may easily backfire and be off-putting to a parent, disrupting the collaborative process.

Reflecting on your own perspective helps you identify your own emotions so you can set aside any unhelpful judgments and biases, and better manage any feelings of discomfort. Try looking for common ground between you and the family to strengthen your partnership.

You may reflect on questions such as how:

- How did I begin the conversation from a strengths-based perspective? How have I shared observations about the child's strengths and things I see the child do that I know the parents have seen too.
- How have I invited the family to share reflections or responses to my observation of the child's behavior? How have I invited them to share their own observations of the child's behavior?

- How have I invited the family to share their goals for their child and family?
- How have I listened to family perspectives and concerns before sharing my own understanding or interpretation of the behavior?
- How have I shown the family through my words and actions that I value their perspective and role as the expert on their child?
- How have I used their observations and expertise to further the conversation?
- How have I reflected on my own perspectives on my concerns about this child's development or behavior?
- How am I providing support and guidance, rather than telling the family what I think they should do?
- How have I looked for common ground between myself and the family?

Helpful Resources

Online Resources

ECLKC

- Engaging Families of Children with Disabilities
 - <https://eclkc.ohs.acf.hhs.gov/family-engagement/article/engaging-families-children-disabilities>
- Building Partnerships: Guide to Developing Relationships with Families
 - <https://eclkc.ohs.acf.hhs.gov/family-engagement/building-partnerships-guide-developing-relationships-families/tools>
- Disability Services Coordinator Orientation Guide: Screening Children
 - <https://eclkc.ohs.acf.hhs.gov/children-disabilities/disability-services-coordinator-orientation-guide/screening-children>
- Disabilities Services Coordinator Foundations
 - <https://eclkc.ohs.acf.hhs.gov/professional-development/individualized-professional-development-ipd-portfolio/course-catalog>
- Medical Home and Head Start Acting Together
 - <https://eclkc.ohs.acf.hhs.gov/publication/medical-home-head-start-working-together>
- Head Start Early Learning Outcomes Framework (ELOF)
 - <https://eclkc.ohs.acf.hhs.gov/school-readiness/article/head-start-early-learning-outcomes-framework>

CDC 'Learn the Signs. Act Early'

- Why Act Early?
 - <https://www.cdc.gov/ncbddd/actearly/whyActEarly.html>

- Tips for Talking with Parents About Developmental Concerns
 - https://www.cdc.gov/ncbddd/actearly/pdf/CDC_LTSAE_TipsForTalkingWithParents_AppBadge-508.pdf
 - <https://www.cdc.gov/ncbddd/actearly/pdf/tipstalkingparents-spanish-P.pdf>

Center for Parent Information & Resources

- The Unplanned Journey
 - <https://www.parentcenterhub.org/journey/>
- You Are Not Alone
 - <https://www.parentcenterhub.org/notalone/>

National Center for Pyramid Model Innovations

- Response Strategies When Parents Share Hard Things
 - <https://challengingbehavior.org/document/response-strategies-when-families-share-hard-things/>

Online Communities

Head Start Disabilities-Inclusion Network MyPeers Community

<https://eclkc.ohs.acf.hhs.gov/about-us/article/mypeers-collaborative-platform-early-care-education-community>