

Home

Assessing Early Development



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- The Complexity of Developmental Assessment and Early Intervention
- Risk Factors for Developmental <u>Delays</u>
- Co-occurring Conditions
- Developmental Assessment Tools

- Best Practices in Early Childhood Assessment
- Equity in Early Childhood Assessment
- Building Effective Parent Partnerships in El

Our society's collective well-being hinges on the healthy development of babies and toddlers—which is why families, educators, health professionals, and policymakers spend so much time talking about the care and education of young children. And it's why we all work so hard to spot developmental differences and delays as early as possible.

In the first year of life, an infant's brain doubles in size. By the time a child is two, the brain will have reached nearly 80% of the size it will be in adulthood. During this period of intense growth, neurons are expanding, migrating, and becoming more complex. Hubs and networks are connecting. Slick sheaths are forming around nerves so signals can travel at greater and greater speed.

The whole body is optimizing so the baby can learn, and learn quickly (Gilmore et al., 2018).

That much is predictable. In fact, experts have created a variety of timelines to help families, educators, and health professionals know what to expect. Yet human development is always individual. Brains differ. So do bodies. And the environments that surround growing individuals also vary. What is considered developmentally appropriate in one culture may be different in another. Differences and delays are not uncommon—and while some resolve on their own, others may need to be evaluated.

Sometimes a delay is a clue to an underlying health issue. Sometimes a delay suggests there is a developmental disability, which is a condition that affects physical, behavioral, learning, or language development. Identifying a developmental disability early, and providing effective intervention, may lower the risk of more significant difficulties later.

The <u>Centers for Disease Control and Prevention (CDC)</u> estimates that 1 of every 6 children will have at least one developmental disability (CDC, 2023).

>	Research and Resources:		
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The Complexity of Developmental Assessment and Early Intervention









Development is an intricate, interactive growth process.

What someone experiences as an infant or toddler can change how the brain develops. In the same way, the brain can influence the way a person experiences and responds to their environment. Brain development and early life experiences are interconnected, shaping outcomes for many years to come.

Because early development has such wide-ranging and lifelong effects, it's very important to identify delays and start interventions as soon as possible.

A Multi-Faceted Developmental Evaluation Protocol

Tracking the development of an infant or toddler (often using milestone checklists) is known as developmental *surveillance* or *monitoring*. Parents and caregivers are often frontline developmental monitoring experts—interacting with their children, carefully studying what they are learning to do. They may use formal checklists or apps, or they may keep a less informal watch on development—by noticing and comparing one child's growth patterns to another, for example. For families with access to health care, developmental tracking can also take place in pediatric primary care settings.

Developmental *screening* refers to the structured process of assessing for certain developmental conditions, even if there are no noticeable symptoms or delays. The American Academy of Pediatrics recommends developmental screening at 9, 18, and 30 months, with an autism screening recommended at 18 and 24 months.

When health experts evaluate developmental milestones, they are typically looking at markers in five areas:

- Gross motor skills such as sitting and standing without support, taking steps, and moving from one spot to another
- Fine motor skills such as holding things and handing an object to someone
- Language skills such as making and responding to sounds, gesturing, and learning words
- Cognitive skills such as following movement, using objects, and exploring the environment
- Social-emotional/behavioral skills such as showing emotion, mimicking facial expressions, and showing preference for certain people or objects

Developmental differences or delays may appear in physical, cognitive, social—emotional, adaptive, or communication domains. Sometimes a single delay is present; sometimes delays are present in more than one area. When delays exist in more than two areas, developmental delay is considered global.

Developmental Cascade

Developmental cascade is a framework for understanding how events that happen in one developmental stage can impact skills that are supposed to develop later. The basic principle is this: The brain's structures develop in a sequence that supports whatever skills a baby or toddler is learning at a particular stage. Each new skill depends on the brain structures that have already developed, just as each new skill depends on the abilities that have previously been learned.

When an event interrupts development (whether the event is physical, like an injury or a nutritional deficit, or environmental, like stress or trauma), the skills a baby is learning at that moment will be affected. But so will all the related skills that are supposed to come afterward. In that way, a developmental interruption cascades or—to use another watery image—has ripple effects.

As you're conducting a developmental assessment, it's important to consider which skills a person is likely to be learning in the developmental stage when an interruption occurs. It's equally important to anticipate which other skills could be impacted moving forward (Oakes & Rakison, 2019).

A Multi-System Early Intervention Process

When a child has developmental differences, services are available through at least two different governmental systems: Early Intervention (EI) and Early Childhood Special Education (ECSE). Which system is involved in serving a particular child depends largely on the child's age.

Early Intervention (EI) generally refers to programs and services that support infants and toddlers ages 0 to 3 years who have developmental delays or disabilities. Very often, early intervention programs are operated by health departments in individual states. The law that governs early intervention is Part C of the Individuals with Disability Education Act (IDEA).

You can help parents and caregivers locate the Part C program in their area by guiding them here.

Early Childhood Special Education (ECSE) typically refers to educational services and supports available to children ages 3 to 22 years with specific disabilities. ECSE programs usually operate through school systems, guided by legal requirements. The law that governs early childhood special education is <u>Part B of IDEA.</u>

Both EI and ECSE programs provide services and supports to families, including care from practitioners like these:

- Speech-language pathologists
- Occupational therapists
- Physical therapists
- School psychologists
- Nutritionists and dieticians

- Audiologists
- Mental health counselors
- Social workers
- Health care providers
- Infant/toddler development specialists

Even though states differ on many aspects of the early intervention process, some factors are alike across all states. For example, under Part C of IDEA, families in all states don't have to pay for the following:

- Services to identify children who need early intervention (known as Child Find programs)
- Assessments and evaluations
- Writing and reviewing the Individualized Family Service Plan (IFSP)
- Service coordination

Learn more: What to Do in the Meantime—Helping Families Navigate Early Intervention

The law requires each state to:

- provide a Child Find program;
- define "developmental delay" in a rigorous way;
- make available a central directory that informs people about available early intervention services, providers, and other resources; and
- promote the professional development and preparation of early intervention professionals and service coordinators.

To learn more about the legal responsibilities of state early intervention systems, you can explore <u>Section 1435 of IDEA Subchapter III (Part C)</u>. To learn more about assessment and individualized family service plan requirements, you may want to explore <u>Section 1436 of IDEA Subchapter III</u> (Part C).

To learn more about the legal responsibilities of state educational agencies in evaluating children who may need early childhood special education, you can explore <u>Section 1414 of IDEA Subchapter II (Part B).</u>

The state where you practice is likely to have additional requirements. You can find out more about state IDEA agencies and requirements <u>here</u>.

A Comprehensive, Multi-Disciplinary Approach to Assessing Development

The complexity of development calls for an evaluation process that is holistic and sensitive to individual variations. For that reason, the IDEA, the Division of Early Childhood (DEC), the National Association for the Education of Young Children (NAEYC), and many developmental specialists recommend that evaluations be conducted by a multi-disciplinary team of experts, including family members.

A transdisciplinary evaluation team may enable you to widen the lens, so that your team can:

- consider co-occurring conditions and how they may overlap or interact;
- integrate family concerns and priorities from the start;
- balance a variety of personal, cultural, and professional perspectives;
- problem-solve more effectively using varied expertise;
- understand patterns of strength and need across all developmental domains; and
- create an intervention plan that addresses a more complete developmental profile.

IDEA and DEC also recommend using a variety of tools and measures in an initial eligibility evaluation. Assessing comprehensively can help your team to:

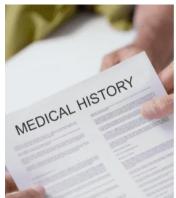
avoid relying on a single data source;

- identify or rule out co-occurring conditions;
- contextualize data from standardized assessments; and
- capture the fullness of a child's lived experience.

It's considered best practice to include a thorough review of available developmental and health histories; a range of validated developmental assessment tools; interviews with parents, caregivers, educators, and health professionals; and observation of play, daily routines, and social interactions in natural settings (Stein & Steed, 2023).

Research and Resources:

Risk Factors for Developmental Delays









It's not always possible to pinpoint the cause of a developmental delay; in most cases, several factors contribute. Still, understanding a child's risk factors may help you decide which developmental areas and co-occurring conditions to investigate. It may also aid you as you design an intervention plan to address as many needs as possible.

Social Factors

As you plan an evaluation, you may want to consider the following societal circumstances and factors which can increase the risk of developmental delays for infants and toddlers:

- Lower family income/poverty
- Limited educational opportunities for parents
- Child neglect and maltreatment
- Exposure to domestic violence

Developmental delays and disabilities occur in babies and toddlers of all backgrounds. Even so, it's important to be aware of health care disparities that affect people in marginalized groups. Research shows that pediatric health care providers are less likely to identify developmental delays in Black children, Asian children, those whose primary language is not English, and those without health insurance. Children in these groups are also less likely to receive services for diagnosed developmental delays (<u>Gallegos</u> et al., 2021).

In a study that explored the experiences of Black families in early intervention systems, parents said their concerns about developmental delays were often overlooked in pediatric care settings. Some parents said their children were not referred for evaluation until pediatric providers eventually became concerned about delays that had been reported earlier (Weitlauf et al., 2022). Other studies have shown that an average of 42 months elapsed from the time a Black parent first communicated a developmental concern and the time autism was identified (Constantino et al., 2020).

Health Conditions

When an infant or a birth parent experiences illness, excessive stress, or injury, the chances of a developmental delay increase. It's a good idea to discuss medical history and to review medical records if possible during a developmental evaluation.

These events can raise the risk of a developmental delay or disorder:

- Genetic/family history of developmental disorders
- Birth parent infections during pregnancy
- Exposure to toxins, including alcohol, during pregnancy
- Meningitis, encephalitis, and other infections in infancy

- Injury during infancy, especially head trauma
- Illness during infancy, including jaundice and malaria
- Metabolic conditions such as phenylketonuria (PKU)

Nutrition

In studies, infants with lower levels of certain vitamins and minerals were more likely to experience developmental delays. Delays have been linked to these deficiencies:

- Zinc
- Vitamin B12
- Iron
- Vitamin D
- Folate

Breastfeeding is an excellent source of developmentally important nutrients—but breastfeeding isn't an option for all families. The Centers for Disease Control and Prevention (CDC) reports that 24.9% of babies received breast milk exclusively in the first 6 months, and 55.8% had received some breast milk during that period (CDC, 2022). Some researchers note that developmental delays in socio-emotional and fine motor skills are more common in children who were never breastfed (Sánchez-Vincitore et al., 2023).

In a study involving Ethiopian children under 5 years of age, those whose food intake was not sufficient to support their growth had a risk of developmental delay 2.6 times higher than children with adequate nutrition (Wondemagnen & Mulu et al., 2022).

Pregnancy and Birth

Maternal health, pregnancy, and childbirth differ around the world, and even state to state in the US. Depending on access to care, the following factors can also affect the risk for delays:

- Premature delivery
- Low birth weight
- Complicated labor and delivery
- Asphyxia (loss of oxygen) during delivery
- Aspirating meconium during pregnancy or delivery

- Medications during pregnancy
- Birth parent malnutrition during pregnancy
- Birth parent injury or fall during pregnancy
- High levels of birth parent psychological distress

Most developmental delays resolve on their own in time. Knowing the risk factors for developmental delays and disabilities can equip you to help families better protect infants and toddlers during critical developmental periods.

▶ Research and Resources:

Co-occurring Conditions









Developmental delays often resolve on their own; however, in some cases delays can progres s, becoming disorders or disabilities. Developmental disorders and disabilities can exist on their own, or they may co-occur with other conditions. When disabilities co-occur, the symptoms of one condition may worsen, mask, or mitigate the symptoms of another condition, making it harder to correctly identify them and to plan the right interventions.

Neurodevelopmental Conditions

Approximately 1 in 6 U.S. children between the ages of 3-17 years old has been diagnosed with a developmental disability, according to parent reports in the 2018-2021 National Health Interview Survey (<u>Li et al.</u>, 2023). Data from the survey show a high degree of overlap between these conditions:

- ADHD & learning disabilities
- Autism & learning disabilities
- ADHD, autism & learning disabilities
- ADHD, learning disabilities & intellectual disability
- Learning disabilities, autism & intellectual disability

Overlap of Delays in Different Domains

Exploring the intersection of developmental delays in multiple domains may yield important clues about the possibility of a neurodevelopmental disorder.

For example, if the child you are evaluating has a delay in motor skill development, you may also want to assess speech and language development. That's because developmental coordination disorder, which affects 5-6% of young children, commonly co-occurs with childhood apraxia of speech and other language difficulties. Motor skill developmental differences can also overlap with ADHD and anxiety (Tamplain et al., 2024).

There's further evidence of an overlap between speech development, motor skill development, and later diagnosis of a neurodevelopmental condition. Some researchers say there may be an "integrated speech-gesture communication system." Studies have shown that lower skill in the pointing gesture at 18 months may predict later language delays in children with certain risk factors, such as preterm birth (Sansavini et al., 2021).

At least one study showed that at 12 months, pointing with the index finger rather than the whole hand predicted more advanced verbal skills at 3 years (<u>Lüke</u> et al., 2020). Other studies have found differences in the ability to coordinate gestures and signs in children with developmental language disorder (DLD) (Factor & Goffman, 2022; Goffman et al., 2023).

As you are analyzing data from developmental assessments, you may also want to consider symptoms like these, which have been linked with neurodevelopmental disorders and with developmental delay across multiple domains:

- Irritability (Yu et al., 2023)
- Sleep difficulties (<u>Shelton & Malow</u>, 2021)
- Feeding issues (<u>Putnick</u> et al., 2022)
- Eyesight differences (<u>Kavitha</u> et al., 2023)
- Hearing loss (<u>Trudeau</u> et al., 2021)

Learn more: Is it Autism, Trauma, or Both? Understanding the Overlap

Mental Health Conditions

It's also important to consider anxiety and depression symptoms in a developmental evaluation. Researchers say there is a higher need for mental health services among children with learning disabilities, speech difficulties, ADHD, and developmental coordination disorders because of the challenges associated with these conditions (<u>Heslon</u> et al., 2024).

In studies, caregivers and health professionals say young children with mental health conditions may experience internalizing symptoms like these:

- Words or actions that demonstrate low self-esteem
- Low energy
- General discouragement
- Ongoing intense stress
- Words that show distress and unhappiness
- Unrealistic body perceptions

- Attachment difficulties
- A view of the world that is out of sync with reality
- Social withdrawal
- Academic difficulties
- Loss of motivation in school

It can be difficult to detect anxiety and depression in very young children because their vocabularies may not yet be extensive enough to describe what they're experiencing. You may gain insight from asking open-ended questions and observing interactions at home and at school. You may also find it helpful to use assessments that rely on illustrations and pictures to communicate feelings (Patra, 2019).

Developmental differences and delays have also been associated with externalizing symptoms (those that show up as behavior difficulties). For example, when the development of executive function is delayed, neurodiverse children are more likely to demonstrate externalizing symptoms. These symptoms have also been linked to anxiety and depression (All et al., 2024).

Learn more: WPS Guide to Assessing Anxiety and WPS Guide to Assessing Depression in Children and Teens

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Developmental Assessment Tools



WPS is pleased to provide a full complement of assessments to help you and your team create a holistic, balanced picture of the young children in your care. WPS <u>Assessment Consultants</u> can help you select the appropriate tools for each situation, whether you are determining eligibility for services, assessing skills and functional capabilities, or measuring progress.

Developmental Assessments

- Developmental Profile 4 (DP™-4)
- Developmental Assessment of Young Children, Second Edition (DAYC-2)
- Adaptive Behavior Assessment System,
 Third Edition (ABAS®-3) Infant and
 Preschool Kit
- Stages Questionnaires, Third Edition
- Sensory Processing Measure, Second
 Edition (SPM™-2) and SPM-2 Quick Tips™

Cognitive Development

- Early Sociocognitive Battery (ESB)
- Woodcock-Johnson IV Tests of Early Cognitive and Academic Development (ECAD)
- Bracken School Readiness Assessment, 4th Edition
- Behavior Rating Inventory of Executive Function, Second Edition (BRIEF-2)

Language Development

- Arizona Articulation and Phonology Scale, Fourth Revision (Arizona™-4)
- Comprehensive Assessment of Spoken Language, Second Edition (CASL-2)
- Oral and Written Language Scales,
 Second Edition (OWLS™-II)
- Bracken Basic Concept Scale, Fourth Edition: Receptive (BBCS-4:R)

- Phonological and Print Awareness Scale (PPS Scale)
- Oral Passage Understanding Scale (OPUS)
- Tests of Dyslexia-Early (TOD-E™)

Social Development

- Social Responsiveness Scale, Second Edition (SRS™-2)
- Social Communication Questionnaire (SCQ™)

Motor Development

Peabody Developmental Motor Scales,
 Third Edition (PDMS-3)

Neurodevelopmental Conditions

- Autism Diagnostic Observation Schedule, Second Edition (ADOS®-2)
- Monteiro Interview Guidelines for Diagnosing the Autism Spectrum, Second Edition (MIGDAS™-2)
- Autism Diagnostic Interview-Revised (ADI™-R)

- Childhood Autism Rating Scale[™], Second Edition (CARS[™]2)
- Autism Spectrum Rating Scales (ASRS®)
- Conners, Fourth Edition (Conners 4)

Best Practices in Early Childhood Assessment







The Council of Exceptional Children's Division for Early Childhood (DEC) has identified practices that lead to more effective and equitable developmental assessments. Here's a brief overview of those recommendations:

- Work with the family to find how they feel and emphasize their importance during the assessment process.
- Build a team to gather information, working with families, educators, and health professionals.
- Match your assessment tools and strategies to the characteristics of the individual child their age and abilities, their communication skills, their social and emotional needs, and their cultural background.
- Measure all areas of development so you can form a holistic picture of the child.
- Conduct assessments in the child's primary language, supplementing with other languages as appropriate.
- Vary your assessment methods, being sure to gather information from multiple sources, including the people closest to the child.
- Explore the child's skills in natural settings and in routines that are typical for the child.
- Use your clinical reasoning and the assessment results in all phases of the early intervention process.
- Monitor progress toward the goals you and the family have established and evaluate those goals as you continue the journey.
- Ensure that the assessments you select can detect even small changes in a child's progress.

• Communicate with families in a way that is helpful and useful to them, including in your written reports (McLean et al., 2020).

Best practices are always evolving. New research is being published all the time, and your team is becoming more knowledgeable with each evaluation you conduct and each professional development course you take. You may want to consider a periodic audit of your screening and assessment practices as a means of continuous improvement.

Clinicians in a 25-group practice in Wisconsin undertook such an audit. Providers worked with a children's hospital and medical college to learn more about how patients saw their developmental screening experiences. Project leaders interviewed pediatricians, nurses, and staff to find out more about how they used screening tools. Practice managers looked closely at demographic data to identify gaps in family participation.

After their audit, they implemented several new strategies, including these:

- Appointing "clinic champions" to promote developmental screening
- Training staff on roles and responsibilities in the screening process
- Using electronic health record prompts and standardized tools
- Offering financial incentives

Over a two-year period, screening rates went from 60% to 95%, affecting close to 30,000 children (Meurer, 2022).

Learn more: Strengthen Your Early Intervention Process with Evidence-Based Best Practices

>	Research and Resources:		

Equity in Early Childhood Assessment



Every eligible child has a right to early intervention and an appropriate education. That right is safeguarded by the Individuals with Disabilities Education Improvement Act (IDEA). Even though the law protects the rights of children and families, in practice there are still large disparities in access to early intervention and special education services.

Just 34.2% of infants and toddlers between 9 and 35 months had a developmental screening using a parent-completed screening tool in the last year, and 6.8% of babies and toddlers received IDEA Part C services during that timeframe (State of Babies, 2023).

The 2023 State of Babies Yearbook, published by Zero to Three, an early childhood advocacy organization, has identified racial, geographic, and economic disparities with a direct impact on infant and toddler development. They include wide differences in:

- Maternal and baby health
- Mental health in infancy and early childhood
- Mental health of early childhood educators

- Access to high-quality childcare and early education
- Availability of safe housing
- Economic well-being and security

The development of the brain—and consequently, the development of cognitive, social, and emotional abilities—is deeply intertwined with each of the factors cited above.

Some disparities are rooted in systems that take time, effort, and collaboration to change—often at the institutional, state, or national policy level (<u>Love & Beneke</u>, 2021). Other opportunities for change may be within your sphere of direct influence as an individual educator or clinician.

For example, you might try these tactics:

- Seek out professional development in cultural sensitivity, trauma sensitivity, disability inclusion, and equitable assessment practices.
- Create safe, welcoming educational or clinical environments for all children.
- Offer multiple ways of participating in activities and showing achievement.
- Encourage the acceptance of diversity, including disability, within the spaces where you practice.
- Provide plenty of opportunities for children to connect and interact with one another.
- Ensure that your curriculum and assessments are developmentally and culturally appropriate for your individual students.
- Educate families about the early intervention services available where you are.
- Communicate warmly and collaborate regularly with families (Rad et al., 2022).

These are a few of the many questions you and your team might ask to figure out the daily practicalities of these larger goals:

- How can we make space for children and families to have more choice, decision-making power, and agency as we move through this process?
- As we plan interventions, are we focused on changing the child or changing the environment to meet the needs of the child?
- When we assist a child with a disability, is our goal to help that child follow through on our initiatives or on the child's own initiatives?
- Do our classroom practices show that we value cultural variations in verbal turn-taking, physical movement, and self-expression?
- Is our view of a child shaped more by deficits or by strengths and assets?
- How can we express the family's values and expectations in our goal-setting?
- Have we collected and analyzed our data to see which groups, if any, are disproportionately represented or under-represented?
- Have we collected and analyzed our data to see which groups, if any, are disproportionately subjected to harsh disciplinary tactics like corporal punishment, restraint, seclusion, suspension, and expulsion?
- Do our planned interventions remove children from environments where they would experience rich learning opportunities and place them in more isolated spaces?

- Do we automatically equate "at risk" with lower family income, race, or home language?
- How can we honor the many different ways families engage, including parenting in a culturally meaningful way or resisting a disability label? (<u>Love & Beneke</u>, 2021; <u>Park</u> et al., 2021)
- How can we increase access to multilingual learning opportunities for children who are learning in more than one language? (Meek et al., 2020)
- How do our own identities influence our perspectives and actions?

Working toward equity in early intervention and early childhood education is a collective responsibility with many individual opportunities for advocacy and action. For further professional development in this area, visit WPS ProLearn.

Research and Resources:

Building Effective Parent Partnerships in El



Genuine partnerships between practitioners and families are essential to achieving good outcomes for children. To understand the factors that hinder or encourage family engagement, researchers have interviewed parents who have been through the early intervention process. In a meta-synthesis conducted by Batz & Yadav in 2023, parents told researchers about some of the barriers and supports they encountered in the assessment journey.

 Some parents perceived racism in their interactions with early intervention providers. For example, one parent said her child's doctor assumed that because she was Black, she had Medicaid insurance and had no spouse.

- Some families said they were worried that their children would be regarded as "dumb" because of the stigma associated with developmental delays and disabilities. One researcher noted that a parent said he was uncomfortable with a diagnosis because "he doesn't want anyone to judge his son."
- In some instances, families said the way a practitioner treated them created roadblocks. For example, when practitioners frequently arrived late to scheduled sessions, parents felt disrespected. One parent said respite care had been available to her for a long time—but she learned about the opportunity from a third party, not her own case manager. She felt the case manager had not been aware of or sensitive to her family's needs.
- Sometimes parents felt that their opinions and concerns were minimized or ignored by practitioners, resulting in wasted time, delayed referrals, poor eligibility decisions, and a lack of services.
- Another barrier arose when parents felt exhausted by the early intervention process itself too much information or not enough. One parent said practitioners gave her "piles and piles of pamphlets and paperwork" that left her feeling utterly overwhelmed. Another shared that her child's doctor didn't explain "what El does or how to obtain services," so she felt lost from the beginning.
- Practical difficulties often limited participation. For example, families living in rural areas
 had limited access to services because there were often fewer providers and programs in
 those locations. Many parents said they want home-based activities they could do with their
 children when a therapist is not available.
- Some parents and caregivers felt empowered by disability advocates, parent groups, faith groups, and extended family during the early intervention process. They used their social capital to learn more about services, navigate the systems involved, and cope with emotional impacts.
- Another source of empowerment for parents was their own ability to speak up effectively on behalf of their children. Researchers said the growth of "parental voice and a sense of power" happened gradually as parents gained experience.
- Many parents said they valued practitioners who viewed parents as experts on their own children. When providers regarded parents this way, it helped families to make decisions and advocate for their children more effectively. One parent said, "I expected the teacher to trust that I, as a parent, am an expert in her. I'm not an expert in anything else, so when I tell you that she can do something...believe me."
- Parents said certain practitioners made it easier for them to stay connected throughout the intervention process. They particularly appreciated practitioners who offered flexible services and those who provided encouragement, guidance, compassion, and respect during the process. One parent described her sense of relief when a practitioner continued

to meet with them after they moved to a homeless shelter. "It made me feel so good because I had left everybody else behind...she's the little angel who stayed with us."

How parents see their child's developmental differences is different from person to person. Feeling guilt is not uncommon among parents whose children receive early intervention services. Some parents wonder whether they caused a delay or disability; some say they wish they had noticed signs earlier (Scherr et al., 2022).

For some parents, developmental disabilities are a socially isolating experience. In a study conducted in Ethiopia, parents said they had separated from their families because taking care of their child's needs was their priority, or because their families did not understand the needs of the child. "Even in your family a normal child and a child with disability will not be considered in the same way," one mother reported. "That is because they do not have the understanding. They see it as an illness..."

For other parents, a child with a developmental disability was a challenge, but one that they interpreted in a positive light. "I think it helped me to be stronger," one mother said. "If other challenges come, I think I can handle them." Another mother said other people had greater respect for her because she parented a child with a developmental disability. "To be honest, lots of people know me. They respect me," she pointed out. "I have lots of respect because of my child. My child is my jewel" (<u>Tekola</u> et al., 2023).

Given these experiences, what steps can practitioners take to build stronger, more collaborative partnerships?

- 1. Recognize that power imbalances may exist, and work toward a two-way dialogue between equals. In some settings, practitioners are considered experts because they are paid professionals. This type of power imbalance may feel more intense if differences in income, race, disability status, education level, or immigration status exist. In a genuine partnership, parents and practitioners both have expert information and insights to share. Their values, beliefs, and expectations are equally important. To help offset any perceived power differences, it may be a good idea to meet in inclusive, neutral spaces where everyone can feel welcomed.
- 2. Consider asking families about their needs and expectations in several different ways. Studies have shown that practitioners tend to use face-to-face meetings to find out about what families need—but some parents prefer to express their expectations and priorities in anonymous or indirect forms of communication such as surveys or informal chats (Kambouri et al., 2022). Allowing for this confidential kind of information exchange is especially important early in the relationship when trust is being established.
- 3. Pay special attention to communication during the transition from early intervention programs to school settings. Several studies have confirmed that parents may "get lost in transition" as their children move from one system to the other. Discontinuity between the programs and fewer choices for parents left families feeling less supported, researchers pointed out (Chang et al., 2023). At least one study recommended guidelines for transition

teams that could help parents and educators plan the transition and provide equipment and teaching strategies in the interim (<u>Tollan</u> et al., 2023).

4. Adopt a strengths-based approach that incorporates the child's and the family's positive characteristics, abilities, and resources. While it is important not to minimize or discount challenges and deficits, it's important to see them in context—part of the whole, multi-dimensional family system. Researchers think this perspective may "increase caregiver confidence and engagement by recognizing their efforts and affirming their capacity in caring for their infant" (Peyton et al., 2022). An added advantage is that a strengths-based approach may help to counteract power imbalances, since practitioners don't have to take on the role of problem-solver.

Learn more: How to Communicate with Families to Build Trust, Connection, and Engagement

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