



program to enhance the
Health & Development
OF INFANTS AND CHILDREN

Parent feedback regarding developmental surveillance and screening

Introduction

The clinical report and algorithm [Motor Delays: Early Identification and Evaluation](#) (*Pediatrics*, June 2013) includes recommendations for engaging parents in the gathering of a detailed family history and incorporation of parental concerns regarding identification of developmental delays that may not be evident in a clinical setting.

Recognizing that in a family focused approach it is incumbent upon the parent/family to communicate their concerns and observations the American Academy of Pediatrics has engaged Parent Project Muscular Dystrophy and the consulting firm CommunicateHealth to develop plain language educational materials and tools for parents and families about global motor delay and development.

To better understand the informational needs of the target audiences and to inform the development of the materials and tools, CommunicateHealth conducted five focus groups with parents. Specifically, we wanted to learn:

1. What do parents understand about developmental milestones, developmental screening, and global motor delay?
2. What are parents' experiences with global motor delay?
3. What are parents' educational needs regarding child growth and development, particularly related to global motor delay?
4. What are parents' opinions of existing materials about global motor delay?
5. What qualities do parents want to see in educational materials and resources about global motor delay? What qualities do they not want to see in educational materials and resources?

Participants

Five focus groups were conducted with a total of 25 participants. Participants were either parents of typically developing children (groups 1 to 3) or parents of affected children (groups 4 and 5):

- Group 1: Parents of typically developing infants age 0 to 12 months (n=6)

- Group 2: Parents of typically developing young children age 13 to 48 months (n=6)
- Group 3: Parents of children age 0 to 7 years who have ever been concerned about their child’s motor development (n=7)
- Group 4: Parents who have a child age 0 to 7 years with a neuromuscular diagnosis (n=3)
- Group 5: Parents who have a child age 0 to 7 years with a neuromuscular diagnosis (n=3)

CommunicateHealth enlisted a recruitment firm in the Washington, D.C. metro area to recruit participants for groups one through three. A standard screener was used to ensure that participants represented a range of ethnicities, ages, and income levels. To recruit participants for groups four and five, Communicate Health worked with AAP and PPMD to identify affected parents from their respective networks. Participants were offered a \$75 gift for their participation.

Methods

Each focus group lasted approximately 90 minutes in which the moderator implemented a discussion protocol to solicit a greater understanding of parents understanding of physical (motor) development, physical (motor) delay, developmental screening and early intervention. Parents were also asked to share their experience with screening for their child’s development through their pediatrician.

To give participants something to react to and discuss, a educational materials from the Centers for Disease Control and Prevention (CDC) program “Learn the Signs. Act Early” was shared. The stimulus material was used to help participants think about physical (motor) development resources for families with young children.

To gain insights regarding parents need for any future materials, a standard set of 30 collaging images was used. Participants were asked to select two images that represented qualities they would like to see in materials about motor delay and development, and two images that represented qualities the would not like to see in materials. The images varied widely and were intended to be symbolic and evocative.

Findings

Overall, the focus groups provided valuable insights into parents’ perceptions and understanding of motor delay, and their educational needs regarding child growth and development. Participants were generally enthusiastic about sharing their experiences in order to help improve educational materials for families.

Focus group highlights

- There is a general lack of information available to parents about physical (motor) development in children. Most parents reported that they hadn’t seen or been provided with anything as helpful as the CDC’s “Learn the Signs. Act Early.” materials.
- Many parents rely heavily on other family members for information about their child’s development and consider their family members a key resource.
- Parents mostly understand their child’s development through comparisons with other children, such as siblings or peers.

- Parents in all the groups shared that their initial concerns about their child’s development were often disregarded by pediatricians, leaving them to research their concerns on their own. Most parents would have liked their pediatrician to be more responsive to their concerns, especially those who had a child that was later diagnosed with a delay or developmental problem.
- Parents in all the groups said they generally needed to be highly proactive to successfully advocate for their child when they had a concern about a delay or developmental issue.
- Participants said that in addition to health care providers, they generally expect teachers, daycare providers, or others who frequently interact with their child to alert them that their child isn’t developing typically.

Parents’ Understanding of Developmental Milestones, Developmental Screening and Global Motor Delay

Parents of Typically Developing Children

In general, parents related milestones and motor development to specific activities like rolling over and walking by a certain age. Participants commented that milestones were like a deadline — it was “good” if their child passed, and “bad” if the child didn’t.

Although all parents understood the concept of milestones, parents of typically developing children generally did not understand the difference between physical, motor, or cognitive delays, or how those relate to milestones.

While most parents were aware that well-child visits involve developmental screening, there were several parents who were unsure of how these differed from prenatal screenings and screenings at birth.

“To me, milestones are almost like a test. It’s measurements — something is either good or bad. If it meets the milestone, it’s good, and if it doesn’t meet the milestone, it’s bad.”

Parents of Affected Children

All parents of affected children knew what milestones were, and generally understood motor and cognitive delays. These parents often understood milestones in terms of specific physical abilities and limitations particular to their child’s diagnosis.

Compared with parents of typically developing children, who saw milestones as something to strive for and achieve, parents of affected children tended to look at milestones regretfully — as a measure of their child’s declining physical abilities.

Most parents in these groups had a child with Duchenne muscular dystrophy. These parents expressed that their child experienced a unique set of developmental milestones that were characterized by *decreasing* (instead of increasing) abilities.

“Because my son has a disability, I tend to think about [milestones] more along those terms.”

“I think sometimes I look at other children who can run and jump and play, and I look at my son and think, ‘Wow, he has never experienced that.’ That’s how I think about physical abilities.”

Parent’s Experiences with Global Motor Delay

The parents of affected children expressed that there was a lack of information to help them recognize the early signs of their child’s diagnosis as well as a general lack of awareness on behalf of their pediatrician, which they thought had further delayed a diagnosis.

In general, all parents with an affected child said they or a family member knew intuitively that something wasn’t right — however, their pediatrician either recommended “waiting it out” for a few more months or dismissed their worries entirely.

“That’s kind of a downside — the pediatrician can’t test for [everything]... and with muscular dystrophy, they’re not always going to fit into those milestones. I think that from our experience, we just had that feeling inside that something wasn’t right. And I didn’t know it was muscular dystrophy — I didn’t even know what that was.”

“In our case, the pediatrician would say, ‘Let’s wait until the next visit.’ So you end up losing time and having negative consequences — ‘Let’s wait and see if he catches up with the normal schedule...’ But if there is a delay... and it’s not caught...”

Some parents of affected children said they experienced negative emotions — such as denial or regret — when faced with concerns of a possible delay, which they said might have prevented them from taking action sooner.

“He was 9 when he was diagnosed, but now I know that his CK levels were elevated the entire time because it was MD. I feel like I failed, and I feel like I was failed by doctors not explaining to me what those things meant.”

In several instances, parents said when their child failed to meet a milestone and was finally diagnosed, there was no further information or interaction from their regular provider. Parents expressed disappointment that their pediatricians were not a good source of information, and were generally not knowledgeable about their child's rare diagnosis.

"The pediatrician called us at midnight on a Saturday and said, 'I'm sorry I have to deliver this news to you.' There wasn't any follow up about where you can go — it was just business as usual [after that]."

Parents' Educational Needs Regarding Child Growth and Development

Parents of Typically Developing Children

Most parents of typically developing children said they rely heavily on child development or milestone mobile applications (apps), such as Baby Center and The Bump.

- Participants liked that information in this format is portable, engaging, and often delivered to them in a passive manner via "push" features on the app.
- Participants appreciated that these apps present information that's not overly scientific or complicated.

Participants also said they like hearing about development and milestones from the perspectives of other parents, which are often featured in apps in the form of message boards and forums.

"There's a Reddit forum that I subscribe to that's for autism, and you can talk to other parents, and it's really nice to talk to someone who's experiencing the same thing... It's nice to talk to someone without going to a doctor's office because [the doctors] don't deal with the day---in and day---out."

Parents of Affected Children

Parents of affected children wanted support and information relevant to their child's unique set of milestones, to help them understand and support their child throughout the course of the child's development. Participants expressed a need for the following:

- Clear explanations of qualification for and benefits of public assistance, such as Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), and Medicaid
- Better care coordination and access to personal care assistant (PCA) services
- Information on developmental delay---related research, clinical trials, and conferences
- Guidance on transitioning guardianship when their child becomes an adult

Parents' Opinions of Existing Educational Materials

Parents of Typically Developing Children

Parents of typically developing children generally liked the format of CDC's "Learn the Signs. Act Early." materials. In particular, they noted that:

- Clear, simple language is used throughout
- Headers and categories contain short lists of information
- Telephone numbers and links to other web resources are provided
- General milestones and "red flag" warning signs are clearly separated

Several parents noted that they found the materials somewhat alarming. They said that the materials seemed to communicate that if their child doesn't meet every milestone as described, the child may have a delay.

Parents of Affected Children

Almost all parents of affected children said that their child actually met the typical developmental milestones, and that CDC's "Learn the Signs. Act Early." checklist would not have necessarily helped them to identify warning signs. They said that the materials seemed more focused on cognitive warning signs but excluded the subtle, physical signs that could be early warning signs for conditions such as Duchenne muscular dystrophy.

Several parents mentioned that while their child was able to walk at the expected time, the child had a specific gait or waddle that they didn't recognize as an early warning sign at that time.

"We always thought Drew was so cute because he did this little waddle — but that was a symptom. He had these cute little cheeks, and his calves were so well---defined. Again, not knowing that that was a sign of Duchenne's — especially the doctors, who saw him and didn't pick up on it."

Desired Qualities for Educational Materials

To gain specific feedback from parents on their preferences for the tone, look, and feel of educational materials about motor delay and development, participants were asked to do a collaging exercise. In this activity, participants chose pictures to represent qualities that they would and would not like to see in educational materials regarding their child's development.

Collectively, participants chose images that were child---focused and evoked feelings of positivity, comfort, and warmth. The most frequently mentioned qualities participants would like to see represented in educational materials were: youth, warmth, happy relationships, closeness or togetherness, hope and optimism.

Recommended Next Steps

Based on the focus group results three primary areas of need for educational materials, tools, and outreach strategies have been identified for the following groups.

- New materials and communication strategies for concerned parents
- Improved materials and outreach strategies for parents of typically developing children
- New in-depth resources and support for parents of affected children

The project team prioritized focusing on new materials and communication strategies for concerned parents and exploring the possibility of doing a plain language refresh of select content and materials for affected parents.

Contact the project manager (PEHDIC@aap.org or 847/434-7863) for additional information about the focus groups or the materials developed as part of the recommended next steps.