



Helping Parents Identify Signs of Physical Developmental Delays

CommunicateHealth: Sandra Williams Hilffker, MA; Xanthi Scrimgeour, MEd, MCHES; Ana Tellez, MA; Amy Behrens, MS; Jason Morris; Adam Moorman; Cozette Lehman
American Academy of Pediatrics: Rachel Daskalov, MHA; Michelle Esquivel, MPH
Parent Project Muscular Dystrophy: Holly Peay, MS CGC
Nationwide Children's Hospital: Garey Noritz, MD



Background

Signs of physical developmental delays (such as Duchenne muscular dystrophy) typically appear before age 5, but many children don't receive the diagnosis—and subsequent early intervention services they need—until after age 5. Children who receive services at a younger age tend to have better health outcomes.

Audience

Parents and primary caregivers of children 5 years of age and younger

Formative Research

CommunicateHealth (CH), in collaboration with the American Academy of Pediatrics (AAP) and with funding from the Centers for Disease Control and Prevention (CDC), conducted:

- » An environmental scan of existing materials on developmental milestones and delays
- » A content audit of the materials identified in the environmental scan
- » 5 focus groups with a total of 25 participants—participants were either parents of typically developing children or parents of children with motor delays

Focus groups revealed that:

- » Parents hesitate to raise potential signs with the pediatrician for fear of being told they're making a big deal out of nothing
- » Pediatricians sometimes advise parents to take the "wait and see" approach, which further delays diagnosis if not actively followed up on by both the pediatrician and parents

Creating the Tool

Based on findings from our formative research, CH and AAP created an interactive, plain language, web-based tool to help educate parents and caregivers of young children (ages 5 and under) who have concerns about their child's physical development.

The tool, titled "Physical Developmental Delays: What to look for," gives parents information about physical developmental delays (like early signs of Duchenne muscular dystrophy) and is meant to help them start a conversation with their child's pediatrician.

Identifying Milestones*

There are many milestones that pediatricians use in their assessment of child development, but this tool includes a smaller set of milestones that:

- » Parents can identify
- » Are highly correlated with motor delay

We narrowed the list down to 9 activities.

I'm worried about my child's ability to:

Hold his or her head up	Roll over
Bring things to his or her mouth	Grab, reach for, or hold toys
Sit up	Stand up
Walk	Go up and down stairs
Run	

From this list, parents can choose the activity they're worried about, identify their child's age and specific behavior, and learn recommended next steps.

Parents can also browse activities by age.

*The information and recommendations for all developmental delays are rooted in the clinical report Motor Delays: Early Identification and Evaluation (*Pediatrics*, June 2013)

Illustrating Developmental Milestones

Some milestones are difficult to describe using only words; therefore, we created animated examples to include alongside text for more complicated milestones.

Each example shows a child with typical development next to a child with a physical developmental delay trying to do the same activity. These illustrated animations allow parents to focus on the physical differences between typical and atypical behaviors without the emotional charge of watching a video of a real infant struggling.

My child is 4 months (or older) and can't support her head when sitting up. For example, if she's lying down on her back and I hold her hands to help her sit up, her head stays back (she doesn't stick her chin out).

Talk to your child's pediatrician about it at your child's next well-child visit. Children develop at different rates, so there may be nothing to worry about. But it's important to bring this up with your child's pediatrician.

Child with typical development

Child with a physical developmental delay

healthychildren.org

Get Started:

Choose an activity (like sit up or walk)

See all activities by age

Creating a Tailored List for the Doctor

Parents can select behaviors of concern and create a tailored list that they can bring to the pediatrician. The My List tool also allows parents to include notes about when they first noticed the behavior or if it's gotten better or worse over time. By using the My List language, parents may be more likely to ask their pediatrician about a potential missed milestone.

I will bring up these concerns with my child's pediatrician at the next well-child visit:

- My child is 4 months (or older). When I hold her by her chest with her feet on a hard surface, she can't support any of her weight. She can't push down or bounce on her legs. Remove
- My child is 6 months (or older) and when he tries to stand his muscles are very stiff and tight (hard to bend or move) or very loose and floppy (like a rag doll). Remove

Type specific information for the pediatrician in this space before printing.



To see the tool, visit: motordelay.aap.org

Usability Testing

After developing an initial version of the tool, we conducted 3 in-person usability sessions with parents concerned about their child's physical development. Parents were impressed.

"I like the 'trust your gut' message at the bottom of the pages."

"My absolute favorite were the animations."

"I'm not going to be self-diagnosing. It's very clear this is an aid, to take to my child's doctor."

"It's an easy site to go to, to read and review. I think it's very helpful to have a list to create for your pediatrician."

We used findings from usability testing to further tweak the design, functionality, navigation, and labels in the tool.

Potential Impact

Parents know their children best and often notice subtle signs that can't be identified in a well-child visit. With the aid of an easy-to-understand interactive tool, CH and AAP are hoping that parents will be able to identify signs of development delay early—and access intervention services as soon as possible, improving the long term outcomes for children with physical developmental delays.

