Developing Concerns: Developmental Milestones in Down Syndrome

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The American Academy of Pediatrics recommends that families of children and adolescents with Down syndrome receive anticipatory guidance regarding development and behavior, including reviewing "age-specific Down syndrome-related medical and developmental conditions." Yet, pediatricians do not have specific references to assist them in guiding families in what to expect. While it is clear that children and youth with Down Syndrome have developmental delays in many spheres of development, it is also true that there is wide variation between individuals and between different areas of development. So what is a pediatrician to use to guide families?

A recent article in Pediatrics (Baumer N, DePillis R, Pawlowski K, et al. Developmental Milestones for Children With Down Syndrome. Pediatrics. 2024;154(4):e2023065402) has tried to fill this gap by using the data collected about 842 children with Down Syndrome who are followed at Boston City Hospital's Down Syndrome Program whose caregivers were asked about developmental milestones. In the paper they report average age of acquisition for a variety of milestones, and compare the age to the CDC's average age of acquisition of the same milestone in typically developing children.

TABLE 3 Comparison of the Ages at Which 75% of Down Syndrome and Typically Developing Populations Accomplish Milestones

CDC		DSP	
Milestone	**Age (years)**	**Milestone**	**Age (years)**
Sits without support	0.75	Sits unsupported for at least 10 min	1.2
Tries to say 1 or 2 words besides mama or dada, like "ba" for ball or "da" for dog	1.25	Uses 1 or more word, sign, or picture	1.5
Walks without holding onto anyone or anything	1.5	Walks around home independently	4.5
Follows 1-step directions without any gestures, like giving you the toy when you say "Give it to me."	1.5	Follows 1-step directions	5.6
Drinks from a cup without a lid and may spill sometimes	1.5	Drinks from an open cup	12.3
Says at least two words together, like "more milk"	2	Uses 2-word phrases	7.7
Walks up stairs with or without help	2	Can use stairs independently	8.5
Runs	2	Runs	8.0
Follows 2-step instructions, for example, "put the toy down and close the door"	2.5	Follows 2-step directions	14.9
Says ~50 words	2.5	Uses 50+ words, signs, or pictures	15.8

However, some caveats should be considered when using the reported milestones. Most importantly, the information is not correlated with other diagnostic information, such as the level of intellectual disability in relation to developmental milestone achievement. The data was collected from a medical specialty center, which has

referrals of more medically or behaviorally complex patients, with limited data for children under 3 years of age. Caregiver report was used, which may at times not be accurate. In addition, because they collected data on skills present at the time of each clinical visit, the exact age at which milestones were first achieved was not available. Lastly, the demographics of the program were not representative of the state population, which may limit generalizability. However, the report does provide some guidance which is otherwise lacking for purposes of reassuring families that development continues even when delayed.



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