



## Pediatrician Use of Down Syndrome Health Supervision Guidelines

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### Abstract

**Objective:** The primary care of children with Down syndrome (DS) requires close attention to specific medical vulnerabilities to maximize quality of life and prevent secondary disability. To help optimize adulthood outcomes for children with DS, the AAP Council on Genetics published health supervision guidelines to promote standardized care that adheres to the latest evidence based information. Our primary objective was to determine primary care pediatrician comfort, familiarity and frequency of referral to the 2011 AAP health supervision guidelines for children with DS. A secondary objective was to identify interventions that would improve compliance.

**Methods:** A voluntary, self-administered e-mail survey was distributed to Washington State AAP members using Survey Monkey. The questionnaire targeted information regarding demographics, guideline knowledge, perceived barriers to guideline utilization and interventions to improve use. General pediatricians living in Washington State with self-reported past, current or expected future experience with the pediatric DS population were included.

**Results:** Our response rate was 17% (N=161). Approximately 80% of pediatricians reported being comfortable using guidelines. About 20% of pediatricians were unfamiliar with the guidelines and do not refer to them. An additional 20% refer to the guidelines only sometimes. When asked a specific question regarding a guideline recommendation, 72% answered incorrectly. Over three-quarters of participants reported that electronic health record reminders would be the most beneficial.

**Conclusions:** Opportunities to improve general pediatrician awareness and utilization of the DS guidelines exist. The most beneficial perceived intervention among pediatricians is guideline integration into the electronic health record. Studies measuring compliance and awareness of guidelines with a variety of interventions will be necessary in the future.

### Introduction

Down syndrome (DS) is the most common genetic cause of intellectual disability and affects people across ethnicity, age, and gender. The prevalence of DS is estimated to be 400,000 in the United States alone [1]. However, with an increasing birth prevalence that parallels the advancing age trend of U.S. mothers, as well as improvements in survival among affected infants and children, the pediatric population of DS is increasing [2,3]. Children with DS are at increased risk for numerous health-related problems including hearing and vision impairments, hypothyroidism, obstructive sleep apnea, celiac disease, seizures and atlantoaxial instability. Untreated, these health problems can lead to an increase in behavioral problems, additional impairments in cognition/learning and decreased quality of life [4,5].

To maximize the adulthood outcomes of children with DS, the American Academy of Pediatrics (AAP) Council on Genetics has published health supervision guidelines since 1994 [6]. Recommended health maintenance and screening measures that address specific health vulnerabilities found in the DS population are included [7]. These guidelines target primary care providers and promote

standardized care that adheres to the latest evidence-based information [8,9].

The DS guidelines were restructured and republished in 2001 and subsequently re-affirmed in 2007 [10,11]. The most recent guidelines, published in 2011, introduced several important changes: obtaining a routine sleep study before the age of 4 years; removing the prior recommendation for routine cervical spine x-ray; emphasizing the importance and rationale for plotting weight and body mass index on the World Health Organization growth charts and increasing awareness of celiac disease, adult transition, sexuality and behavioral issues [12].

Insufficient adherence to DS health management and preventive care among pediatric providers has been identified across multiple studies, both internationally and in the United States. By self-report, physicians in the United Kingdom obtained regular thyroid screenings of their patients with DS every 2 years on average [13]. Conversely, a questionnaire sent to families of children with DS in Canada showed that many of the recommendations surrounding behavior issues, transition planning, diet, exercise and puberty/sexual health were followed infrequently in all age groups [14]. In Israel, a parent/guardian survey linked to a chart review demonstrated that a large proportion of the population with DS had not undergone

recommended diagnostic screenings, especially for thyroid function and sensory organ surveillance [5]. In England, a retrospective database analysis of 96 patients showed that more than 1/3 of children were not seen by ophthalmologists despite 96% having at least one ophthalmic abnormality [15]. In Finland, 137 case records were analyzed from the specialized and primary healthcare and disability services database. Several medical and surgical problems were described and records showed that health surveillance was insufficient with only 54% of affected individuals receiving thyroid screening in the previous five years [16]. Further, a retrospective database analysis of patients from Ireland determined not only that overall compliance with thyroid screening was only 53% but also that the compliance rate fell precipitously with increasing age [17].

In the United States, the trend continues. Cohen reports that during personal communication he learned that a majority of the referral population to an adult DS center had not been screened or evaluated for thyroid disorders. In a few instances, hypothyroidism was even incorrectly diagnosed as Alzheimer's disease [7]. Further, a chart review completed in Oklahoma and Nebraska using a 1994-2004 birth cohort investigated annual thyroid screen compliance measures. The rates of compliance were similar in Oklahoma and in Nebraska, just 13% and 14% of children, respectively [18]. To date, there has not been a primary care pediatrician survey study conducted in the United States to determine the comfort, familiarity and frequency of referral to all components of the AAP health supervision guidelines for children with DS.

Our overall objective was to describe comfort, familiarity and frequency of referral to the DS health supervision guidelines, to compare demographic characteristics of eligible respondents, and to identify barriers and/or possible helpful interventions to improve DS health supervision guideline use. Our hypothesis was that pediatricians would self-report relatively high rates of comfort and familiarity with the updated 2011 DS health supervision guidelines and less robust frequency of referral to the guidelines. Regarding their response to a specific content question lifted from a recommendation within the 2011 guidelines, we predicted that a majority of respondents would answer incorrectly.

## Methods

Data were collected using a cross-sectional survey design. Participants received an email cover letter explaining the voluntary

nature and goals of the study. The email also contained a link to a self-administered survey constructed in Survey Monkey®. The survey was designed to measure use, comfort, familiarity with and frequency of referral to the 2011 AAP Health Supervision Guidelines for Children with DS. Additional information regarding demographics, current/past experience with patients who have DS, information resources, possible barriers to compliance, and potential interventions to improve guideline use was also collected. Eligible participants included all members of the Washington Chapter of the AAP with available email contact (n=945). The questionnaire was constructed by a developmental-behavioral pediatrics fellow using recommended survey design strategies [19,20]. It was then pretested and revised for content and clarity by four developmental-behavioral pediatricians, one of whom has experience in survey development, two primary care physicians, a physical therapist and a research coordinator with experience in study design and data analysis. The survey contained 17 multiple-choice questions and 2 free-text questions. Multiple-choice response options were presented using a 5-point Likert scale. Data were collected between October and December 2013. Participants had up to 6 weeks to complete the questionnaire with one email reminder sent at 3 weeks. To be included in the analysis, respondents had to complete all demographic information, live in Washington State, have either current, past or expected future experience with patients who have DS, and be practicing primary care pediatrics.

In addition to the above, we also reviewed past studies of physician compliance to elucidate barriers that may be contributing to poor adherence to the DS health supervision guidelines, if observed. The study was approved by the Institutional Review Board at Seattle Children's Hospital.

## Results

The response rate was 17% (n=161). Eleven percent met inclusion criteria (n=107). Demographics are included in Table 1. Compared to the Association of American Medical Colleges Physician Specialty Data Book and the Department of Health and Human Services, the survey respondents were consistent with average national demographics of pediatricians in the United States [21,22]. Pediatricians reported caring for patients with DS of all ages under 21 years old with the highest frequency being 1 to 13 year olds (Figure 1).

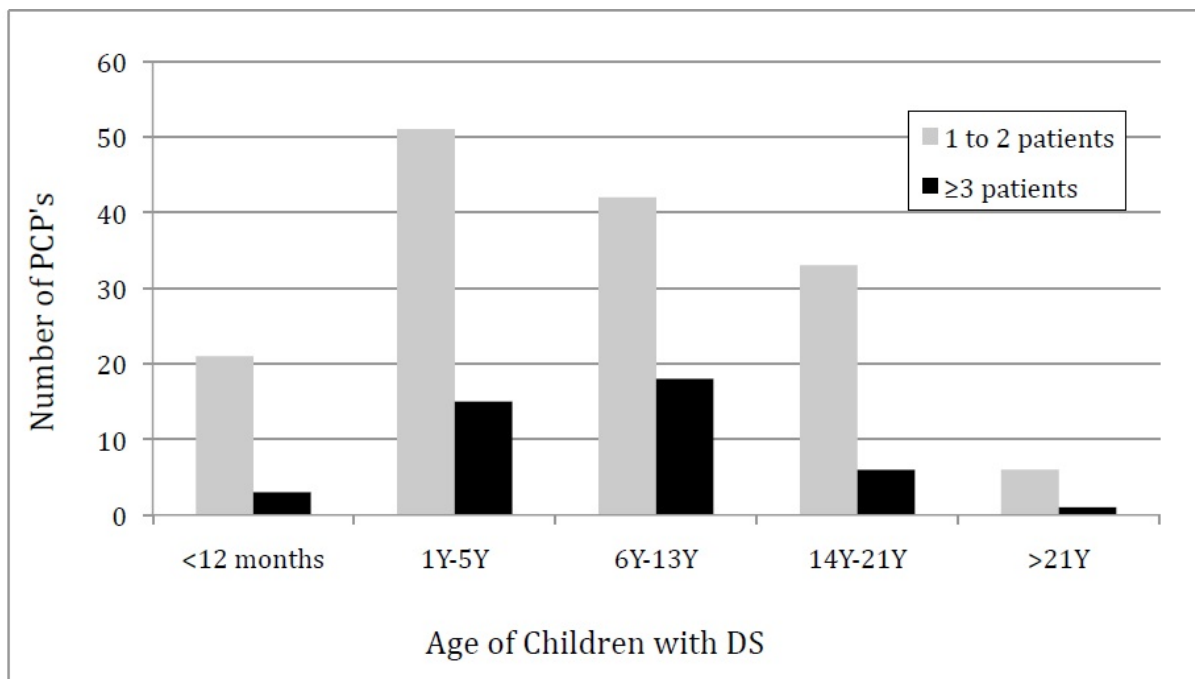


Figure 1: Reported age and frequency of children with DS cared for by PCP's.

Regarding level of comfort with following DS health supervision guidelines in their office, 4% (n=4) of pediatricians reported being “very uncomfortable or uncomfortable” while 17% (n=18) were “neutral” and 79% (n=83) were “comfortable or very comfortable” following the guidelines. When specifically asked about familiarity with the 2011 DS health supervision guidelines, 22% (n=23) of pediatricians reported being “unfamiliar or vaguely familiar” while 6% (n=6) were “familiar” and 73% (n=77) were “more familiar or very familiar” with the updated guidelines. Regarding their frequency of referral to the guidelines, 17% (n=18) of pediatricians reported referring “almost never or rarely,” 21% (n=22) reported “sometimes,” and 62% (n=64) referred to the guidelines “frequently or almost always”. When presented with a multiple-choice question regarding updated guideline content (Question: What test is routinely recommended before the age of 4 in all children with DS? Answer: A sleep study), 72% (n=69) responded incorrectly. Twenty-six percent (n=27) responded that a cervical spine X-ray was recommended, which was consistent with 2001 recommendations but was removed with the 2011 guideline revision. Further, only 47% (n=47) of pediatricians reported routinely giving family members/caregivers resources and reference material such as books, pamphlets, and contact information for parent support groups before age five. Ninety-eight percent of pediatricians (n=100) reported that parents of children with DS “almost never or rarely” brought the AAP guidelines to clinic visits.

Female	70	66
White/Caucasian	87	82
Latino	4	34
East Indian/Asian/Pacific Islander	12	11
African American	3	3
Rural	25	24
Urban	81	76
<b>Usual Practice</b>		
Full time	66	62
Part time	41	38
<b>Care Provider DS Experience</b>		
Current or past DS care provider ONLY	6	6
Anticipate to be future DS care provider ONLY	3	3
Current/past AND future DS care provider	98	92
<b>Number of DS patients/provider EVER</b>		
Zero	15	14
01-May	47	44
Jun-15	33	31
≥16	12	11

	Number of Pediatricians (n=107)	Percentage of Pediatricians
<b>Demographics<sup>a</sup></b>		
Male	36	34

Number of DS patients/provider CURRENTLY <sup>a</sup>		
Zero	23	22
01-May	73	69
≥6	10	9

**Table 1:** Demographics and Provider Characteristics.

There was no significant difference noted between pediatricians practicing in rural versus urban locations on correct responses to the content question, nor on self-reported rates of referral to the guidelines. Comparing pediatricians based on their current patient panels of ≤5 patients versus >5 patients also showed no difference. However, when comparing pediatricians by their total experience of ≤5 patients versus >5 patients, a significant difference emerged in their frequency of referral to guidelines (p=0.001). We found that 37 out of 47 pediatricians (77%) who have had ≤5 total patients with DS refer to the guidelines “frequently” or “always” and only 22 out of 45 pediatricians (49%) who have >5 total patients with DS refer to the guidelines “frequently” or “always”. Pediatricians who reported total experience of ≤5 patients were significantly more likely to refer to the guidelines. Despite that, there was no significant difference in their ability to answer the content question correctly.

Sources used by pediatricians to learn about DS or other genetic conditions/ developmental disorders, in order of highest to lowest frequency were the AAP website, medical journals, textbooks and consultation with specialists. Seventy-three percent (n=88) of respondents listed the AAP as the number one resource they would recommend to pediatricians or other primary healthcare providers caring for children with DS. When asked to rank interventions that would improve their care of patients with DS, respondents listed an electronic health record checklist as the primary preferred method. The second preferred method was a parent-maintained care notebook that could be shared with the pediatrician. A provider-oriented smart phone application was ranked third.

## Discussion

Our results show that 22% of pediatrician respondents in Washington State who indicate past, current or expected future patient care of individuals with DS are not familiar with the 2011 DS guidelines and 17% do not refer to them. In addition to the 17% that do not refer to the guidelines, another 21% of pediatricians refer to the guidelines only “sometimes”. These pediatricians represent a target population who could benefit from strategies and interventions to improve knowledge of and adherence to the DS guidelines. We also discovered that pediatricians who report fewer total numbers of patients were significantly more likely to refer to the DS guidelines but did not have an apparent difference in knowledge from their more experienced colleagues, dispelling the idea that the need to refer to the guidelines is no longer necessary after a certain amount of experience. The need for additional education in this area is re-affirmed by the 72% incorrect response rate to the content specific guideline question. In addition, fewer than half of pediatricians report providing reference materials and support group information to families as recommended in the guidelines. Pediatrician-reported barriers include: lack of familiarity with appropriate resources and lack of awareness about that particular recommendation.

Unfortunately, in busy general pediatric practices often struggling under productivity and related demands, there is a disincentive to interrupting workflow to locate and review guideline recommendations for special patient populations. From the results of our study, it is apparent that the current strategy of disseminating guidelines to busy practitioners with the expectation they will use them as intended is not being executed. Although one would certainly not expect pediatricians to memorize the DS guidelines, it is clear that easier access and greater provider willingness to refer to them would be beneficial.

Incomplete adherence to evidence-based health screening guidelines puts patients with DS at increased risk of delayed treatment for known medical vulnerabilities and health-related impacts on daily functioning and long-term outcomes. For example, Rozien et al. described long delays between symptom onset and treatment of conditions seen occasionally in DS such as celiac disease and juvenile rheumatoid arthritis/other arthritic conditions of 3.8 and 3.3 years respectively in children with DS. However, in neurotypical children, the mean delay for a diagnosis of juvenile rheumatoid arthritis/other arthritic conditions was only 0.7 years [23]. The significant health impact of DS is well described throughout the literature and the development of a secondary condition could risk further impairment, not only of physical health and well-being but also of cognitive and/or functional outcome for individuals with DS [24-26]. It is the responsibility of the primary care provider caring for the patients with DS to monitor for commonly associated conditions and to provide early diagnosis, intervention and initiation of treatment [27].

Unfortunately, poor provider adherence to guidelines in general is well documented [8,28,29]. This is once again proven in our study which is specific to pediatric DS care within Washington State. With this information, we can begin to identify barriers for pediatricians caring for children with DS and how to overcome them.

A systematic review by Cabana et al. examining barriers to physician adherence to a broad range of policies and consensus statements showed that barriers ranged from lack of awareness, familiarity, and/or agreement with recommendations to lack of staff, time, motivation to change and/or support for implementation. Barriers and potential interventions are often unique to specific clinical settings and patient populations [30]. Other studies specifically designed to measure pediatrician administration of a standardized developmental screening instrument as recommended by the AAP policy statement guideline show low compliance rates of less than half [28,29]. Identified barriers included lack of time, lack of available office staff, inadequate reimbursement and under-reliance on parent-completed questionnaires. O’Laughlen et al. reported that most health care providers are aware of guidelines but are not following recommendations due to incorrect beliefs about guidelines, lack of familiarity/self-efficacy, perceptions of negative outcomes, concern about autonomy, and lack of time and inertia [8]. There was also a difference in physician practices based on year of graduation with those graduating more recently being more likely to follow guidelines. According to their analysis of strategies to change provider behavior, key elements for improving adherence were education (what the guidelines are about and how to use them), motivation (explaining why we should use them) and facilitation (making them easy to use) [8]. Grimshaw et al. reported that most guideline implementation strategies achieved improvements in guideline compliance of approximately 10% with reminders and patient-directed implementations faring slightly better at 14% [31]. Review of the

literature on physician practices related to pediatric asthma guidelines demonstrates that computer-based programs, if user friendly, significantly improved adherence and clinical outcomes; however, simply distributing the asthma guidelines by mail did not change clinical practice or outcomes [32]. Last, Davis et al. and Thomson et al. showed that small-group, interactive, case-based discussions can change physician behavior, increase acceptance and adherence and improve patient outcomes [33,34].

Applying findings from these studies to the analysis of our current study, barriers and potential solutions to overcome them begin to emerge. Our findings reveal that included Washington State pediatricians believe electronic health record reminders would be most helpful in improving their consistent use of health supervision guidelines, which is consistent with our interpretation of other studies showing that user-friendly, computer based reminders are beneficial. However, future research to track barriers and target interventions specific to pediatricians and their care of patients with DS is needed. One strategy primary care providers can implement immediately to improve guideline adherence is regularly distribute the AAP's family-friendly DS health supervision guidelines (Health Care Information for Families of Children with Down Syndrome) published on [healthychildren.org](http://healthychildren.org) so families are aware of recommended screenings and can advocate appropriately [35].

Our results are limited by a social desirability bias often seen in self-administered surveys where respondents may overestimate their knowledge of or compliance to guidelines. The relatively low survey response rate of only 17% and social desirability bias may actively mask much lower use of DS guidelines. In addition, we did not receive any input from family practice physicians or nurse practitioners/physician assistants who also care for many children with DS. Last, our results are limited by the fact that rural pediatricians were not well represented and the Washington State Chapter of the AAP membership may not accurately reflect the profile of pediatricians across the country.

## Conclusion

The use of the guidelines within a medical home is one strategy to provide coordinated, preventive care and has been shown to promote adulthood health and social functioning as well as moderation of detrimental factors identified in special-needs populations [23]. Individuals with DS exhibit well-studied health vulnerabilities outlined in the AAP DS health supervision guidelines. Addressing these vulnerabilities will have significant positive effects on the quality of life and other health outcomes for children with DS. Our study shows that a large number of responding pediatricians are either "unfamiliar" with the AAP Health Supervision Guidelines for Children with DS, "almost never or rarely" refer to them or only refer to them "sometimes". The need to refer to the guidelines is supported by the 72% incorrect response rate to a specific content guideline question. Of several potentially helpful interventions, electronic health record guideline integration is the most preferred option among pediatricians. This is consistent with previous studies in other health conditions that found user-friendly computer programs and reminders to be the most helpful. Although specific barriers and interventions to increase DS guideline use require further investigation, our study implies that the need for provider support and education clearly exists and could be targeted by actively increasing provider awareness about the importance of regular DS guideline use along with the implementation of computer based programs such as electronic health record

checklists. Successful guideline implementation promoted through a collaborative medical home partnership is likely to have several beneficial implications on physical and emotional health, vocation, life achievement, self-esteem and family cohesiveness for those with DS and their families.

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