

# Access to Genetic Counseling for Children With Autism, Down Syndrome, and Intellectual Disabilities

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## KEY WORDS

children with special health care needs, genetic counseling, medical home, health policy

## ABBREVIATIONS

GCS—genetic counseling services

DS—Down syndrome

MR—mental retardation

ASD—autism spectrum disorder

CSHCN—children with special health care needs

NS-CSHCN—National Survey of Children With Special Health Care Needs

HBM—health belief model

FPL—federal poverty level

CI—confidence interval

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## abstract

**OBJECTIVE:** We examined the need for genetic counseling services (GCS) for families of children with autism spectrum disorder (ASD), Down syndrome (DS), and/or mental retardation (MR) and factors that influence the receipt of needed GCS for those children relative to other children with special health care needs (CSHCN).

**METHODS:** Analysis was conducted on the 2005–2006 National Survey of Children With Special Health Care Needs, a nationally representative sample. Bivariate analyses were conducted by examining need for and receipt of GCS for children with ASD, DS, and/or MR and other CSHCN as well as differences by contextual variables using the health belief model (HBM). Logistic regression analyses were conducted to assess the relative impact of receipt of needed GCS by HBM constructs.

**RESULTS:** Families of children with diagnoses of ASD, DS, and/or MR perceive significantly higher need for GCS than other CSHCN. The presence of a medical home is the single most important factor in facilitating access to GCS, together with the presence of insurance, particularly private or a combination of private and public insurance. As income and education attainment decrease, barriers to GCS rise.

**CONCLUSIONS:** This analysis supports strategies for improving linkages between specialty providers and the medical home at which primary care is delivered. Increased effort should be made to attend to those who experience barriers that result from lack of insurance, poverty, low education, or racial or ethnic differences. Health professionals need to collaborate in developing solutions to underinsurance or lack of insurance for CSHCN. *Pediatrics* 2009;124:S443–S449

The recent expansion of newborn screening programs across the country and the ongoing increase in capacity for genetic diagnostic testing is expected to increase the demand for clinical genetic services, including genetic counseling services (GCS). There have been few studies that addressed barriers to genetic health care services including GCS. Genetic counseling has been defined as “helping people understand and adapt to the medical, psychological, and familial implications of genetic contribution to disease.”<sup>1</sup> It is recommended that families of children with Down syndrome (DS), intellectual disability (a term used to refer to those with mental retardation [MR]), or autism spectrum disorder (ASD) be offered a comprehensive medical genetics evaluation that includes genetic counseling<sup>2–5</sup> and genetic testing.<sup>6–8</sup> Despite this, many children who should be receiving genetic counseling and testing often do not receive all of the services they require.<sup>9</sup> Factors that contribute to the inability to access these services include the lack of a medical home,<sup>10,11</sup> lack of insurance,<sup>9</sup> and being from a low-income family.<sup>12</sup> Children from families with low income and/or who lack insurance coverage have been found to be less likely to have a usual source of care or a medical home.<sup>13</sup> Insurance coverage alone, however, has not been found to guarantee access to a medical home, especially for children with special health care needs (CSHCN).<sup>14</sup> Studies have shown that access to a medical home is often mitigated by many factors including education, race, and family structure.<sup>15</sup> In a study of the 2001 National Survey of Children With Special Health Care Needs (NS-CSHCN), Wang and Watts<sup>9</sup> found that having continuous insurance coverage and receiving family-centered care were positively associated with receiving needed GCS, whereas cost, health plan problems,

availability, and transportation issues were barriers to the receipt of GCS.

For the purposes of this article the conditions we have chosen to examine are considered “genetic,” broadly defined. Many special health conditions of childhood have genetic risks associated with the development of those conditions; asthma, attention-deficit/hyperactivity disorder, and diabetes are good examples, with each resulting from a combination of genetic and environmental risk factors. However, they are not “genetic” in the sense that DS, ASD, or MR are. Although these conditions differ with respect to treatment and degree of genetic predisposition, they are conditions for which GCS are traditionally indicated. We hypothesize that by using these conditions we will have a valid assessment of the variables that affect receipt of GCS more generally.

We examined the 2005–2006 NS-CSHCN to address the question of what factors influence the need for and receipt of needed GCS for families of children with ASD, DS, and/or MR compared with other CSHCN. We hypothesized that families of children with 1 of these 3 conditions would have both a higher stated need for GCS and be less likely to receive needed GCS than other CSHCN. We also hypothesized that children with fewer barriers to action, specifically those from families with higher household incomes, those covered by insurance, and those who were identified as having a medical home, would be more likely to have received all needed GCS.

## CONCEPTUAL MODEL

In our analysis we used the health belief model (HBM) to assess how individuals adopt a health behavior<sup>16</sup> (obtaining genetic counseling). This conceptual model was chosen for 2 primary reasons. First, we are attempting to explain a health behavior,

and the HBM is one of the most tested and mature models to do so. Second, several, but not all, of the survey variables mapped well to the HBM constructs. The model posits that an individual’s response to an adverse health event or health condition is influenced by a number of factors: perceived threat; barriers to care-seeking and perceived benefits of care-seeking; cues to action; and self-efficacy and modifying factors. A perceived threat is determined by the individual’s perceived susceptibility to, and perceived severity of, the health problem. The greater the perceived severity and susceptibility, the more likely the individual will take action to address it. Second, the decision to act can be influenced by barriers to care-seeking. These barriers can include referral problems, communication problems with providers, lack of a provider, transportation issues, etc. Barriers must then be weighed relative to any perceived benefits (eg, the belief that services or care will mitigate the threat). Third, the model posits that care-seeking can be influenced by certain cues to action. These cues include the recommendations of health care providers or other information from providers, such as posters in providers’ offices, to seek care. Fourth is the individual’s own self-efficacy. This construct identifies a person’s confidence in his or her specific ability to obtain needed care. Finally, modifying factors such as race, ethnicity, and income can further influence the ability to obtain care.

## METHODS

### Data Source

For this study we used the 2005–2006 NS-CSHCN as the data source.<sup>17,18</sup>

### Indicators and Variables

We relied on 2 questions in the NS-CSHCN to examine the need for and re-

ceipt of GCS: (1) “Since (his/her) birth, was there any time when you or other family members needed genetic counseling for advice about inherited conditions related to medical, behavioral, or other health conditions?” and (2) “Did you or your family members receive all genetic counseling that was needed?”<sup>18</sup>

Survey variables were mapped to HBM constructs when possible. In the model, threat comprises measured susceptibility and severity. Susceptibility was measured here by 3 separate questions that asked if the child has ASD, DS, or MR. We posited that families with children who have been diagnosed with ASD, DS, and/or MR would have a high perceived susceptibility to the consequences of these diseases. To measure severity, parents were asked to “rate the severity of the child’s condition.” Modifying factors were measured by the child’s age and race, household education, household income as a percentage of the federal poverty level (FPL), and the child’s insurance status. For records with missing information for the income variable, the multiple imputation file from the National Center for Health Statistics was used.<sup>19</sup>

Sixteen questions that examined barriers to receiving all needed GCS were asked of families who reported needing GCS but not receiving all services needed. These questions included those related to access to referrals, transportation problems, the availability of information on the condition, communication problems with providers, and others. Perceived benefits were not directly measurable from the survey.

Cues to action were measured by the composite variable of having a medical home. We made the assumption that children reported as having a medical home were also more likely to receive 1 or more cues to action in the form of

referrals, patient-education materials, and discussions with primary care providers promoting the use of GCS. The medical home measure was modified for the 2005–2006 version of the NS-CHSCN to better reflect the updated American Academy of Pediatrics definition of a medical home.<sup>20</sup> An indicator variable for the presence of a medical home environment (yes/no) was created from this outcome. Self-efficacy was not measured by the survey.

All survey questions for which the response was “don’t know” or refused were coded as missing data with the exception of income, for which the National Center for Health Statistics imputed values were used.

### Statistical Analyses

We used SPSS 16 (SPSS Inc, Chicago, IL) with the complex samples module for analysis of the data. This module provides adjustment to standard errors to account for differences in estimates from the use of a complex sampling plan. We also used Stata 10 (Stata Corp, College Station, TX) for computing analysis of multiple imputed values of the poverty variable. Stata was used to produce both bivariate results and logistic regression coefficients.

Descriptive weighted percents are reported for all variables examined. We examined the perceived need for GCS as well as receipt of needed GCS services according to HBM constructs. We also examined the differences in HBM constructs for those with ASD, MR, and/or DS compared with other CSHCN who reported both needing and not needing GCS. Statistical differences for all categorical variables were conducted by using  $\chi^2$  analyses. Mean differences were compared by using *t* tests.

Barriers to receiving all needed GCS were examined by using  $\chi^2$  analysis for those who had at least 1 condition

(ASD, DS, or MR) compared with all other CSHCN. Logistic regressions were run to examine the relationship between perceived threats, cues to action, and mitigating factors to receiving all needed GCS. *P* values are indicated for all significant differences at the .05, .01, and .001 levels.

### RESULTS

Weighted survey results revealed that ~577 000 or 5.7% of parents of children with special health care needs reported needing GCS in 2005–2006. Of these, 76% reported receiving all GCS needed, leaving 24%, or an estimated 137 000 children, with unmet need. When examining need for GCS for those with ASD, DS, and/or MR, we found that those with at least 1 of these conditions had a significantly higher need for GCS than other CSHCN (14.1% vs 4.3%; *P* < .001). Table 1 lists differences between those with at least 1 condition compared with other CSHCN according to HBM constructs both for children overall (columns 1 and 2) and those who expressed a need for GCS (columns 3 and 4). The findings indicate that, overall, parents of children with ASD, DS, and/or MR were significantly more likely to rate their child’s condition(s) as moderate or severe, were more likely to be publicly insured or uninsured, and were more likely to be Hispanic or black. They were also less likely to have a medical home, less likely to live in a household with an income of at least 200% of the FPL, and less likely to have more than a high school education. Among those who needed GCS, children with ASD, DS, and/or MR were also more likely to have conditions that were moderate or severe and more likely to have public insurance or a combination of public and private insurance than other CSHCN who needed GCS. There was no significant difference in the number of reported barriers between the groups

**TABLE 1** Sample Characteristics and Need for GCS According to Condition and HBM Constructs

	Perceived Susceptibility, Weighted %			
	Overall <sup>a</sup>		Those Needing GCS <sup>b</sup>	
	With ASD, DS, or MR	Other CSHCN	With ASD, DS, or MR	Other CSHCN
Needed any GCS <sup>a,c</sup>				
Yes	14.1	4.3	100.0	100.0
No	85.9	95.7	—	—
Received all GCS				
Yes	77.2	75.9	77.2	75.9
No	22.8	24.1	22.8	24.1
HBM construct				
Perceived severity, rated severity <sup>a,c,b,d</sup>				
Minor	17.0	57.7	10.0	29.4
Moderate	54.1	35.9	50.5	46.6
Severe	28.9	6.4	39.5	24.0
Cues to action, medical home <sup>a,c</sup>				
Present	29.6	50.0	24.7	27.6
Not present	70.4	50.0	75.3	72.4
Modifying factors				
Child's age <sup>a,b,c,d</sup>	9.6	10.0	8.8	9.7
Child's gender <sup>a,c</sup>				
Male	66.2	58.2	62.9	56.4
Female	33.8	41.8	37.1	43.6
Child's race <sup>a,c</sup>				
Hispanic	14.5	11.3	15.8	16.1
White, non-Hispanic	60.7	66.1	60.2	53.4
Black, non-Hispanic	18.1	15.9	18.2	22.8
Multiracial, non-Hispanic	3.6	3.7	2.4	5.6
Other, non-Hispanic	3.1	2.9	3.4	2.2
Highest level of education (household) <sup>a,c</sup>				
Less than high school	10.5	6.2	13.8	10.6
High school graduate	26.4	22.5	28.8	27.6
More than high school	63.2	71.2	57.3	61.8
Insurance status <sup>a,b,c,d</sup>				
Private only	39.1	63.8	30.1	44.8
Public only	42.1	26.4	48.5	39.2
Both public and private	14.9	6.3	17.6	10.5
Uninsured	3.9	3.5	3.8	5.5
Household income <sup>a,b,c,d</sup>				
0%–99% FPL	27.4	18.1	34.2	30.8
100%–199% FPL	26.9	21.2	25.3	27.6
200%–399% FPL	26.8	30.4	24.9	24.6
≥400% FPL	18.8	30.2	15.5	16.9

Perceived barriers are not shown, because they were only asked of those who reported that they needed but had not received all necessary GCS. Columns total to 100%.

<sup>a</sup> Overall: those with ASD, DS, or MR versus other CSHCN.

<sup>b</sup> Those needing GCS: those with ASD, DS, or MR versus Other CSHCN.

<sup>c</sup>  $P < .001$ .

<sup>d</sup>  $P < .05$ .

for those who reported a need for GCS ( $P < .466$ ).

When examining the receipt of all needed GCS for those who reported having ASD, DS, and/or MR, we detected no significant differences according to HBM constructs between those who received all needed GCS and those who did not (Table 2). For all

other CSHCN we found significant differences for the receipt of all needed GCS according to all HBM factors except age and gender of the child.

Families with children who have ASD, DS, and/or MR were significantly more likely to realize multiple barriers to receiving services than other CSHCN (see Table 2). The 2005–2006 version of the

NS-CSHCN expanded the number of barrier questions for those who did not receive all needed GCS from 5 in the 2001–2002 survey to 16 in 2005–2006. Families of children who were identified as having at least 1 of the 3 specific conditions were more likely to cite problems getting referrals and having adequate resources available at school and less likely to cite provider dissatisfaction as barriers to receiving all needed GCS than other CSHCN (data not shown).

To examine the effects of HBM constructs on the receipt of all needed GCS, logistic regressions were conducted. Those who reported a need for GCS were identified as the subpopulation for all regressions. Regressions were run on all model variables including a variable indicating the presence of ASD, DS, and/or MR. For analysis we used a forward stepwise function. Final model results are listed in Table 3. Children who were identified as having a medical home were 2.8 times more likely to receive needed GCS (95% confidence interval [CI]: 1.5–5.2). This effect remained consistent through multiple model iterations. We also found that those who were uninsured were 55% (95% CI: 0.2–0.9) less likely to receive all needed GCS than those with any form of insurance. Insurance type (public, private, and both) was collapsed, because earlier models revealed similar significant and near-significant odds ratios for each, suggesting that the presence of insurance was of primary significance. We next found that those children who came from households with income at >400% of the FPL were 1.8 times more likely to receive needed GCS than lower-income families (95% CI: 1.0–3.1). Finally, respondents who reported the severity of their children's condition as minor were 1.8 times more likely to receive all needed GCS

**TABLE 2** Receipt of GCS According to Condition and HBM Model Constructs

HBM construct	Perceived Susceptibility			
	With ASD, DS, or MR, Received All GCS, Weighted % <sup>a</sup>		Other CSHCN, Received All GCS, Weighted % <sup>b</sup>	
	No	Yes	No	Yes
Perceived severity, rated severity <sup>b,c</sup>				
Minor	8.2	10.5	23.3	31.1
Moderate	49.8	50.8	42.9	48.0
>Severe	42.0	38.6	33.7	20.9
Cues to action, medical home <sup>b,d</sup>				
>Present	15.5	27.3	10.1	33.1
>Not present	84.5	72.7	89.9	66.9
Modifying factors				
Child's age	8.8	8.8	9.7	9.7
Child's gender				
Male	69.3	61.1	55.7	56.7
Female	30.7	38.9	44.3	43.3
Child's race <sup>b,c</sup>				
Hispanic	14.8	16.1	23.2	14.0
White, non-Hispanic	66.5	58.5	43.8	56.2
Black, non-Hispanic	11.8	19.9	25.1	22.4
Multiracial, non-Hispanic	3.5	2.1	3.8	6.1
Other, non-Hispanic	3.4	3.4	4.1	1.4
Highest level of education (household) <sup>b,c</sup>				
Less than high school	11.4	14.6	11.9	10.3
High school graduate	32.3	27.9	39.1	24.3
More than high school	56.4	57.5	49.0	65.4
Insurance status <sup>b,c</sup>				
Private only	30.9	29.9	34.8	48.0
Public only	43.2	50.1	47.7	36.5
Both public and private	17.8	17.6	8.8	11.2
Uninsured	8.1	2.3	8.7	4.3
Household income <sup>a,b,c,d</sup>				
0%–99% FPL	43.5	31.6	32.8	30.3
100%–199% FPL	25.3	25.1	36.9	24.6
200%–399% FPL	22.7	25.6	19.4	26.2
≥400% FPL	8.4	17.7	10.9	18.9
Perceived barriers				
Barriers to care				
None	8.1	—	6.0	—
1 barrier	70.2	—	79.1	—
>1 barrier	21.7	—	14.9	—

Columns total to 100%.

<sup>a</sup> With ASD, DS, or MR: received all GCS (yes versus no).

<sup>b</sup> Other CSHCN: received all GCS (yes versus no).

<sup>c</sup> *P* < .05.

<sup>d</sup> *P* < .001.

**TABLE 3** Logistic Regression Final Model for All CSHCN: Likelihood of Receiving All Needed GCS

HBM Construct	Predictor Variable and Referent <sup>a</sup>	Odds Ratio	95% CI
Cues to action, medical home	Present vs not present	2.8 <sup>b</sup>	1.5–5.2
Perceived severity, rated severity	Minor vs severe	1.8 <sup>c</sup>	1.0–3.1
Modifying factors			
Household income	≥400% vs <400% FPL	1.8 <sup>c</sup>	1.0–3.1
Insurance status	Uninsured vs insured (any type)	0.5 <sup>c</sup>	0.2–0.9

<sup>a</sup> Controlling for nonsignificant variables: presence of a genetic condition (ASD, DS, or MR versus other CSHCN), child's gender, child's age, child's race (white Non-Hispanic versus nonwhite), highest level of education of anyone in household, perceived severity (moderate versus severe).

<sup>b</sup> *P* < .01.

<sup>c</sup> *P* < .05.

than those who reported them as severe (95% CI: 1.0–3.1).

**DISCUSSION**

Of the entire sample of CSHCN, nearly 6% of the parents reported needing GCS. Of these, 24% reported not receiving all GCS needed. Parents of children with ASD, DS, and/or MR reported a higher demand for GCS but were not less likely to receive all needed GCS than other CSHCN. Regression models point out that having a medical home was of primary importance to receiving GCS overall. This, however, becomes especially important to children with ASD, DS, and/or MR, because the presence of a medical home was reported by only 30% of parents of these children compared with 50% of parents of other CSHCN. This analysis also demonstrated a near twofold increase in the likelihood of receiving all needed GCS for those with conditions rated as minor as opposed to severe. Because children with 1 of the 3 examined conditions were also more likely to rate their condition as severe, these children are even less likely to receive GCS. Insurance was demonstrated to have an impact on the receipt of needed GCS, because the insured were 45% more likely to receive needed GCS. Because there was a significant difference in the number of children with 1 of the 3 examined conditions whose parents reported relying on either public or a combination of public and private insurance, this finding supports the important role that public insurance programs play for children with ASD, DS, and/or MR.<sup>21</sup> In addition, having health insurance has been shown to increase the likelihood of having a medical home by providing a regular source of care, which in turn affects receiving GCS services when needed.<sup>14</sup> Those children who came from homes with incomes of at least 400% of the FPL were also found to be

1.8 times more likely to have received all needed GCS than lower-income children, yet need for GCS was significantly greater for those from lower-income households. Relative to the HBM, using the model allowed us to show that having cues to action (ie, cues provided by having a medical home) were of primary importance in receiving needed GCS. These findings suggest that cues to action could provide the most important impetus to care-seeking. It also supports that those with 1 of the 3 conditions studied perceive a greater threat than other CSHCN and that the severity of that condition is similarly a driving influence to care-seeking, whereas the presence of insurance and household income levels modify that behavior.

The data present some limitations. Because these data were self-reported by parents, the number of children with a condition was not clinically determined. We assumed that parents reported the condition of their child after a clinical diagnosis; however, this was not explicitly assessed in the survey. A similar assumption exists for the reported need for GCS. When measuring severity, it is unknown for which condition the parental response applied. For children with multiple conditions, it is possible that the parent was rating severity on 1 but not another condition. Here we assume that severity was determined across all conditions equally.

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## CONCLUSIONS

We have examined those factors that affect access to needed GCS. We hypothesized that children with conditions thought to be genetic and considered appropriate for GCS experience barriers to receiving all the GCS they may need. Data have indicated that families of children with diagnoses of ASD, DS, and/or MR perceive significantly higher need for GCS, and that the presence of a medical home is the single most important factor in facilitating access to GCS, together with the presence of insurance, particularly private or a combination of private and public insurance. As income and education attainment decrease, barriers to GCS rise. It is not surprising that lack of insurance is a significant barrier to services. Taken together, these barriers to care not only affect the ability of a family who needs GCS to take action but represent a number of what has elsewhere been termed “voltage drops” in accessing care, or places where children fall out of the system and quality of care is sacrificed.<sup>22</sup> Drops such as access to and enrollment in insurance coverage, having access to consistent primary care, and gaining referrals to providers have cumulative policy implications, especially for CSHCN. Insurance is often the precursor to attainment of a medical home and for CSHCN who are underinsured and uninsured; it has been shown to be a correlate to poor health outcomes.<sup>23</sup> Given the importance of public insurance for this

population of children, the current economic realities and threatening state budget cuts pose potentially serious implications for their care, especially for those who rely on public insurance.<sup>24,25</sup>

In 2004, the US Maternal and Child Health Bureau of the Health Resources and Services Administration established 7 regional newborn screening and clinical genetics collaboratives across the United States with the broad mission of improving access to and quality of genetics health care services. The results of our analysis support such strategies proposed by the Health Resources and Services Administration in this effort, specifically to improve linkages between specialty providers and the medical home in which primary care is delivered; to attend to those who experience barriers to care because of income or insurance; to address racial or ethnic differences, poverty, low education, and geographic disparities; and to collaborate in developing solutions to underinsurance or lack of insurance for CSHCN.

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