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## Should Genetic Information be Used to Determine Special Education Eligibility and Other Educational Services?

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Should Genetic Information be Used to Determine Special Education Eligibility and Other  
Educational Services?

A Parent's Perspective

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Parent's Perspectives: Should genetics inform special education eligibility for Autism

**Abstract:** Clinically, genetic testing is recommended for all children who have been diagnosed with autism. However, genetic testing is no longer being used solely as a medical tool and social uses of this are being introduced, such as in educational settings. But using this information to determine who is eligible for educational services introduces a litany of ethical, legal and social issues. We recruited 400 parents to complete an online survey to gauge their opinions on using genetic information to determine special education eligibility and other school services for children with autism. Overall, the 77.3% of parents were in support of special education services for a child with autism symptoms, even before genetic information was revealed. In most cases, neither genetic test results nor family history of autism influenced parents' opinions on this topic. The results suggest that parents overwhelmingly support services for children on the basis of symptoms alone and do not support introducing this type of testing into eligibility decisions.

**Keywords:** autism, special education, parents, genetic testing, family history, ELSI

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## Introduction

Approximately 1.6 % of children in the United States have been diagnosed with autism (Baio et al., 2018). Despite its frequency, the exact etiology is still not known. It is well-established that genetics plays a significant role in the development of autism. Twin studies report the heritability, the proportion of phenotypic variance attributable to genetics, to be between 70-80%, with some studies reporting heritability as high as 91% (Ramaswami & Geschwind, 2018; Sandin et al., 2017). Additionally, *de novo* variants, a measure of inherited risk not captured by heritability studies, are suggested to contribute in between to 15-20% of cases (Ronemus, Iossifov, Levy, & Wigler, 2014). More than 100 genes have been implicated in autism. Changes in chromosome structure (e.g. large and small duplications and deletions of chromosomes) can also play a role. While environmental factors may play some role, many experts argue that it is a predominantly genetic condition (An et al., 2018; Chaste & Leboyer, 2012; Ramaswami & Geschwind, 2018) . Despite this, the majority of people with autism do not have an identifiable genetic change that explains their phenotype (Machado, Estevez, Rodriguez, & Leisman, 2017).

Many children with autism are often placed in special education settings or receive therapies and other services from the school (Newschaffer, 2005). The Individuals with Disabilities Education Act (IDEA) lists specifically includes autism in its definition of “children with disabilities.” However, according to the IDEA, these diagnoses are not sufficient to guarantee services. There must also be evidence that the disability disrupts the child’s educational performance (Siegel, 2017). And while parents who seek special education and other services for their child may request that their child be evaluated by the school, the process by

which students are evaluated and what information is included in this evaluation varies by state or district (Maki, Floyd, & Roberson, 2015).

Previous interview-based studies have indicated that US parents of children with autism see genetic testing as beneficial because it may help their child qualify for special education and other services (L.-S. Chen, Xu, Huang, & Dhar, 2013; Johannessen et al., 2017; Reiff et al., 2015). While the vast majority of parents are unaware that clinical genetic testing is available for autism (L. S. Chen et al., 2015; Hanish, Cohen, & Starr, 2018), the American College of Medical Geneticist advises that all clinicians discuss genetic testing with all families and patients with autism (Schaefer & Mendelsohn, 2013).

Genetic data can inform efforts to overcome educational barriers for children with autism by confirming a child's diagnosis, allowing early identification of children at risk and developing more effective individualized interventions. For example, in some cases, parents report that genetic tests results have informed their autistic child's Individualized Education Program (IEP) (Reiff et al., 2017). On the other hand, it also raises concerns that the information may reinforce disability-based segregation, lead to forced medication, violate individual's genetic privacy or incorrectly label a child who merely possess a predisposition gene (Sabatello, 2018). Currently, the opinions of parents in the United States on the use of genetic information to determine eligibility for special education and other services is unknown. Our objective in this study was to gauge whether genetic information—either family history or genetic test results—may impact parents' views on whether a child should be eligible to receive special education and other services from his or her school.

## Methods

### 1. Participants

The study consisted a national representative sample of 400 English-speaking American respondents over age 18 who have a least one child (0 to 21 years old). Gender distribution was split 50-50, while 58% of respondents identified themselves as white, 33% identified themselves as African American and 2% identified themselves with 2 or more races. African Americans were over-represented in this study because African American children are over represented in special education, despite the fact they are less likely to be diagnosed with autism (Jordan, 2005). Additionally, 12% of respondents identified themselves as Hispanic, and 78% identified themselves as non-Hispanic.

### 2. Study Administration

Study participants were recruited through third-party vendor YouGov, a global public opinion and data company with over 6 million panelists across 38 countries allowing the company to provide participants of various ages, socioeconomic status, and ethnicities and races. YouGov has been reviewed and approved for Federal-wide Assurance (FWA) with the Department of Health and Human Services (FWA00010960, <http://ohrp.cit.nih.gov/search.aspx>). YouGov contacted participants via an email link to the survey. The link took participants first to a consent page and, if consent was acquired, they were directed to the survey. Surveys were piloted by four educator-reviewers personally known to the researchers who provided feedback about the vignettes and questionnaire. Participants did not receive any financial compensation for their time, but were promised “at least 500 points with YouGov” users for completing the survey. The accumulated points are redeemable for small gifts (ranging from YouGov Tote Bag and YouGov T-shirt to 2 movie tickets to iPod Shuffle or \$100).

### 3. Study Instrument

The survey comprised 2 vignettes (one of which is reported here) and reaction statements that were incorporated throughout the vignette. In the vignette, parents were asked to consider the case of Mason, an 8-year-old boy in the third grade whose parent described him as smart, active, independent and who has great curiosity about his environment. However, some of Mason's behaviors began to concern his parents, who requested the school evaluate him for special education services. It was expected that the survey would take participants about 20 minutes to complete.

### 4. Study measures

There were four independent variables included in our study. The first was race, Mason was described as either Black or White. The second was evidence. Participants were either told that Mason carried a genetic predisposition to autism, Mason's younger brother has been diagnosed with autism, or not given any additional information. The third was the level of consistency of his behavioral symptoms throughout the school year. The fourth was educational impact. Mason was described as either staying consistent academic performance or declining. Participants were randomized to receive only one condition within each independent variable. The dependent variables were parent responses about special services and education environment for Mason. Responses were gauged using a 4-point Likert scale of dis/agreement.

### 5. Statistical analysis

We used SAS 9.4. Multivariate Logistic regression to analyze the effect of the four independent variables on the dependent variables using a 4-point Likert scale which was dichotomized during analysis to agree vs. disagree. Variables were collapsed when variable cells were too small and for ease of analysis. Covariates controlled for in analysis included: age, race

(Black, White and other), gender, education level (High School, Some College/2yr College and 4yr College/Postgrad), marital status (Divorced/Separated, Widow/Married, and Never Married), and income (<\$29,000, \$30,000 - \$59,999, \$60,000 - \$99,999, \$100,000 or more). A probability level of <0.05 was used to determine statistical significance.

## Results

### 1. Special services

A total of 400 parents completed study. Offered an initial description of Mason, 77.3% of participants (n= n=400) agreed that the child should receive special education services and 22.7% (n= n=400) did not. This was used to gauge baseline agreement or disagreement that Mason should receive special education and services among all participants.

After respondents received different pieces of evidence regarding Mason's condition (genetic information, family history information, or none). Respondents were then asked if this information should be considered in determining Mason's eligibility for special education services (Figure 1). In the control group, 77% of respondents responded positively to the suggestion that (this information) should be used to determine access to educational resources; this compares to 78% of participants who received family history and 92.6% of participants who received genetic information. Being given information on genetic testing was associated with a significant increase in positive responses over control group ( $p=0.02$ ).

Participants were then asked if Mason should receive special education services to prevent further worsening of his behavior. For those who received family history, 78.7% agreed, for genetic testing group 73% agreed, and for the control group 62.9% (Figure 3). However, only the family history group showed a significant increase in respondent number over control

( $p=0.01$ ). Educational level was also observed to effect responses. Those with a 4-year degree or more were more likely to agree that Mason should receive services ( $p=0.05$ ).

Participants were then asked if they believe Mason has autism and most (69%,  $n=400$ ) agreed he did. There was no significant difference between the three evidence groups in response to this question (Figure 2). Those with a 4-degree or more were significantly more likely to agree than those with a 2-year degree that Mason has autism ( $p=0.04$ ).

## 2. Educational Environment

Participants were then asked questions about how Mason should be treated and the type of educational environment he should be placed in. Overall, 90% of all respondents agreed that Mason should be eligible for special education services, such as behavior therapy, to improve his ability to interact with his classmates (Figure 4). However, neither the family history group nor the genetic testing group were associated with a significant increase in responses compared to the control group. Education level did affect responses, as those with a high-school education or less were more likely to agree with the statement of eligibility for special education services than those with a 4-year college degree or more ( $p=0.02$ ). Additionally, when Mason was described as African-American, respondents were significantly more likely to agree with the statement than when Mason was described as white ( $p=0.02$ ).

Participants were also asked if Mason should be placed in another school with children with similar problems if his symptoms don't improve. Overall, 62.5% of respondents agreed that he should. Again, neither the family history nor the genetic testing group were associated with significantly higher levels of agreement compared to control (Figure 5). However, education level again significantly affected responses. Those with a high-school education or less were more likely to agree with the statement than those with at least a 4-year college degree ( $p=0.01$ ).

Furthermore, participants with a 2-year degree or some college were more likely than those with a 4-year degree to agree with the statement at near-significant levels ( $p=0.06$ ).

#### 4. Other assessments

We also assessed whether the consistency of Mason's behavior throughout the school year, or a reduction in his academic achievement affected parents' perceptions on Mason's eligibility. Neither of the independent variables (race, evidence) nor any of the covariates were associated with significant differences in responses.

### Discussion

As genetic information begins to move from primarily a medical indication to impacting other settings, such as education, the views of various stakeholders are important to explore. We sought to understand how parents felt about the use of genetic information in determining special education access and educational services. The results of our study highlight that parents do believe that both genetic and family history could be considered when reviewing a child's eligibility for special education. However, support among parents for the need to provide special education placement and services for children who may or may not be exhibiting signs of autism is high overall and genetics does not appear to be an important factor determining parental opinion. Therefore, our data suggest that because genetic information does not contribute in a meaningful way to shaping opinion and it, therefore, may not be worth the ethical risks involved in using a child's genetic test results to determine eligibility for special education and other services.

Our work is consistent with others in that it shows that parents believe that this information is useful in helping garner services for their children. Several previous studies have

found that this is a key driver of parents who seek confirmatory genetic testing for their autistic child (L. S. Chen et al., 2015; Hanish et al., 2018; Reiff et al., 2015). Similarly, our study found that parents were open to the use of genetic testing information to determine eligibility for these services. While most parents agree that autism has genetic underpinnings, they also believe there are several other factors that cause autism, such as upbringing, stressful circumstances, and immunizations (L. S. Chen et al., 2015; Li et al., 2016). It is likely that genetics and inheritance did not have a more significance influence on responses for this reason.

These results did not vary meaningfully between those who received family history formation and those who received genetic information or no additional information. Interestingly, though, when parents were asked if Mason should be eligible for special education services to improve his ability to interact with his classmates, agreement was high in all groups, but those who received family history information were significantly more likely to agree than those who received genetic information or no additional information. One possible explanation for this is that participants placed greater trust in Mason's parents' opinion about his situation and needs based on their presumed greater experience as parents of two children with autism.

While neither genetic information nor family history appeared to sway the opinions of respondents, one factor associated with significant differences in responses was education level. It was expected that parents with more education would be more likely to understand the condition and related mental health needs and therefore understand Mason's need for services. The results held true when participants were asked questions about Mason and whether he should have access to services. However, the results reversed in questions about his access to various educational environments. It is possible that those with more education have an increased awareness that autism tends to be over-diagnosed in some children and were more hesitant to

dole out services to someone with limited evidence of morbidity (Fombonne, 2018). While it is possible that income may be a confounding variable, income was assessed in this data and our results suggest that income level overall did not influence responses. More research may be needed to understand why those with lower levels of education were more likely to agree that Mason needed services.

The use of genetic information to determine eligibility of children with autism for special education and other services is a controversial issue, but there have been some successful marriages between genetic testing and school systems. One of the earliest known examples of this occurred in Montreal in 1972 where the city began offering high-school students carrier screening for Tay Sachs disease. Later successful school screening programs for Cystic Fibrosis and hereditary haemochromatosis were piloted around the world (Ross, 2006; Delatycki et al., 2012). Since 2010, the National Collegiate Athletic Association has required all student-athletes be screened for sickle-cell trait before competing (Sabatello, 2018). The success of these programs has lied in helping inform people of their hereditary and medical risks and seek treatment before symptom onset.

While none of these programs have tested for psychiatric genetics, some experts believe that special education services present a niche that will likely benefit greatest from the integration of genetic information. In their book, *G Is for Genes*, psychologist Kathryn Asbury and behavioral geneticist Robert Plomin argue that we are failing our children if we fail to incorporate their individual genetic information into school systems (Panofsky, 2015). Elena L. Grigorenko, a psychologist and neuroscientist at the University of Houston, argued that genetic testing will allow for the “best possible pedagogical interventions for children with special needs and reducing the burden that developmental disorders place on society” (Grigorenko, 2007).

However, there are a litany of instances from recent history that suggest such labeling can be detrimental to a child's education. Children have been discriminated against and even removed from their schools because of their suspected HIV status or even minor conditions, such as head lice, have been used to withhold educational opportunities for students. Children who have a genetic test results that indicates they have a predisposition for autism, regardless of their behaviors or whether a behavior exists, could meet a similar fate (Sabatello, 2018). This scenario may be of particular risk because, as some experts have argued, many people equate a genetic predisposition with diagnostic certainty (Marchant & Robert, 2010).

Another concern is that such testing may violate the student's and family's genetic privacy. Due to the fact that autism has a strong genetic component, testing in a child may reveal private or sensitive information about the parents or other relatives. There is also fears that such testing may be used to marginalize or disenfranchise children and families from lower socio-economic statuses (Sabatello, 2018). Currently, African-Americans are already overrepresented in special education, which could be used to justify extensive or forced genetic testing of these children and families (Jordan, 2005; Sabatello, 2018).

The study was limited by a number of factors. The analysis did not differentiate parents on the basis of their own experiences with autism, for instance whether parents had a child with autism or not. It is likely that having first-hand exposure to a child with autism and knowledge of the needs of these families influenced parent's responses. Further work should compare responses among those with exposure to an autistic child (i.e. having 1 child with autism vs a relative with autism vs. no exposure) to discern how this influences parent's opinions. Respondents were also given a significant amount of information about Mason, including information about his progress during the year and his behavior in the classroom. When

answering each question, parents were instructed to consider all information presented, however, it is possible that participants may have forgotten to consider the genetic testing information or the family history information they had been given earlier in the survey. Instead they may have only considered the most recent piece of information given.

However, parents are not the only stakeholders in decisions about special education eligibility for children displaying autistic characteristics. Teachers, school administrators, pediatricians, hearing officers, school psychologists, and those involved in eligibility decisions also play a part in special education eligibility. Future work should gauge whether the influence of genetic information on their opinions is limited in the same manner as it appears to be in this parent population.

#### Acknowledgements

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Figures

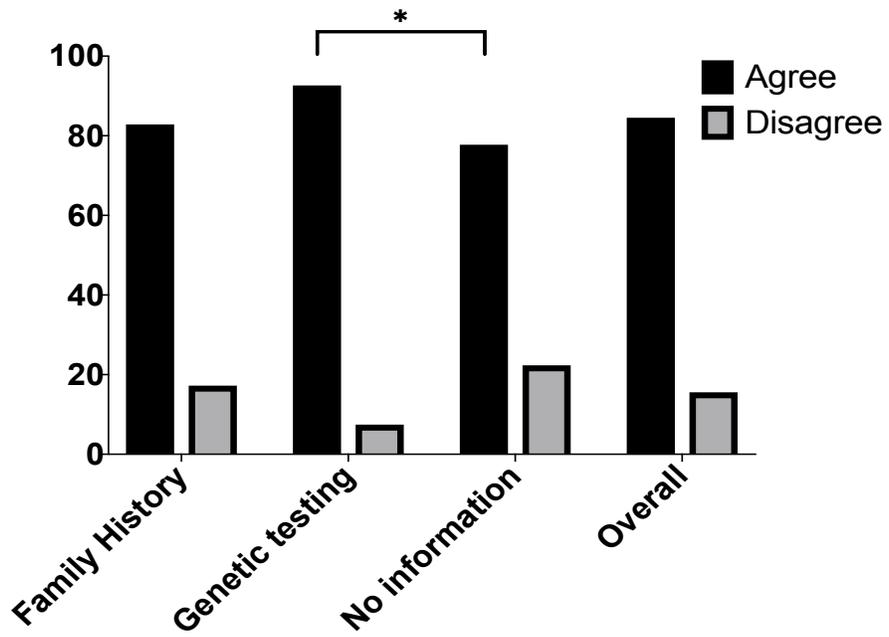


Figure 1: The Hearing Officer should consider this information in reviewing Mason’s eligibility for special education services.

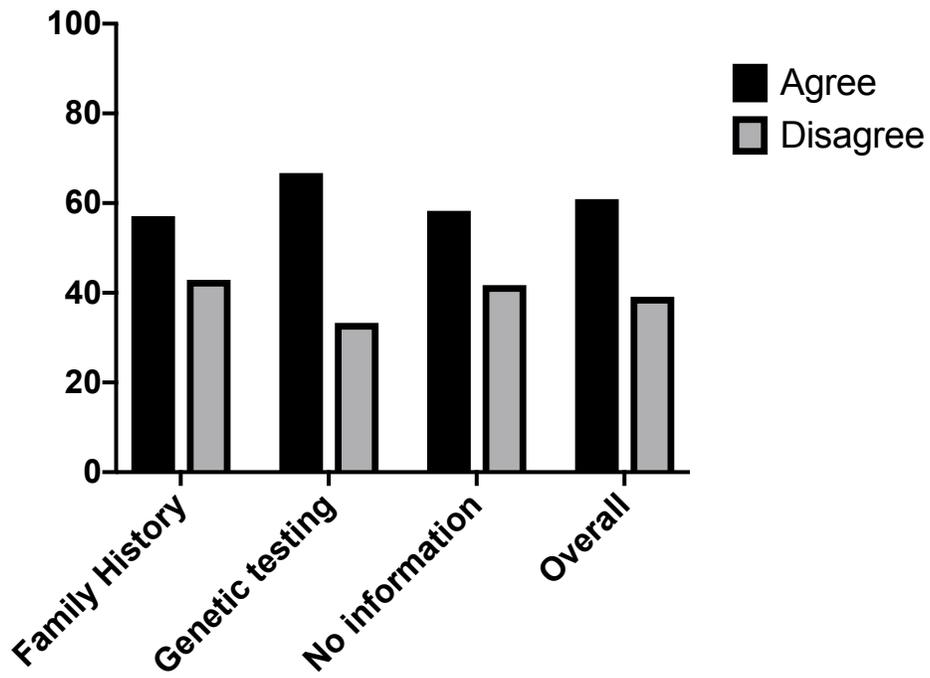


Figure 2: It's likely that Mason has Autism.

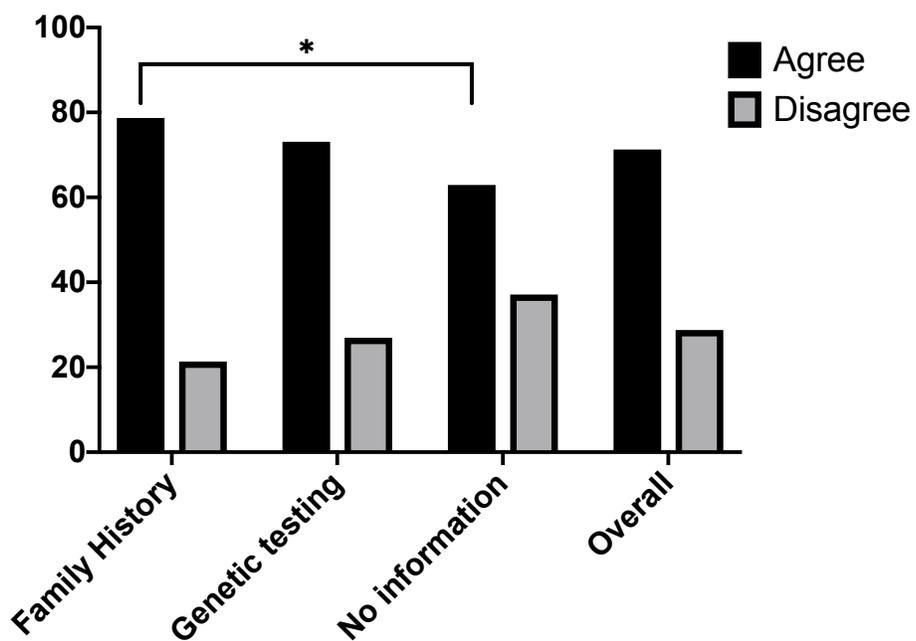


Figure 3: Mason should receive special education services to *prevent* further worsening of his behavior.

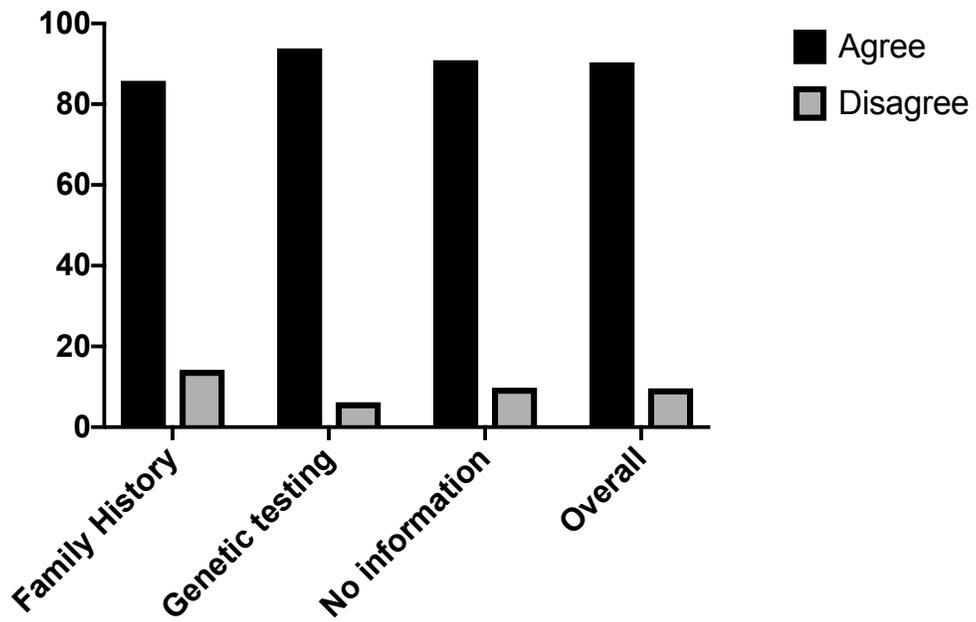


Figure 4: Mason should be eligible for special education services, such as behavior therapy, to improve his ability to interact with his classmates.

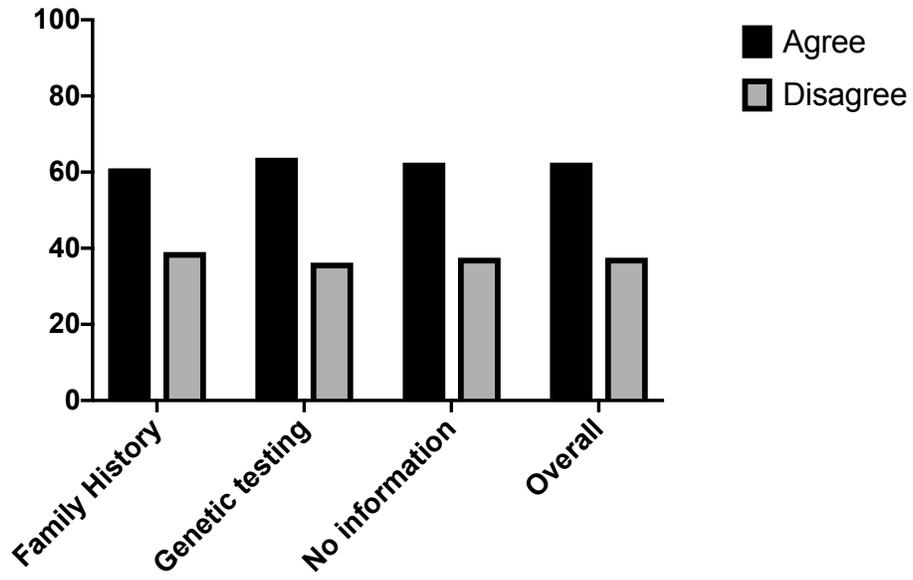


Figure 5: If his behavioral problems do not improve, Mason should be placed in another school for children with similar problems.