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Title: Delivering A New Diagnosis of Down Syndrome: Parent Experience

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Abstract

Background: Down syndrome is one of the most common chromosomal abnormalities. In 2014, in conjunction with the passing of House Bill 552, the Ohio Department of Health released a Down syndrome fact sheet to be given to parents at time of diagnosis to answer basic questions regarding the diagnosis. Our survey helps us to understand parental experience in receiving a new Down syndrome diagnosis including information provided.

Methods: An electronic survey was created and distributed to members of established Down syndrome parent groups in Ohio. Questions assessed the parental experience at the time of receiving a Down syndrome. We also looked at parent perceptions after the implementation of a Down syndrome fact sheet. Responses were collected regarding experience at the time of diagnosis and broadly categorized into a trichotomy of positive experience (>5), neutral experience (=5) and negative experience (<5).

Results: Parents report an overall negative experience when receiving a new diagnosis of Down syndrome (mean of 4 on scale of 0 to 10), which did not increase after 2014 ($p > 0.05$). Eighty-five percent of parents with children born in 2014 or after report that they did not receive the Ohio Department of Health Down syndrome fact sheet. Legislation regarding a diagnosis of Down syndrome exists in 20 states with significant variability, readability of those fact sheets.

Conclusion: Legislation requiring accurate information be given to families was not always followed, and printed literature alone did not correlate with improved parent experience; additional efforts are necessary to ensure that the experience receiving a diagnosis of Down syndrome is not a negative one.

Keywords: down syndrome, genetic counseling

Introduction

Pediatricians may be the first medical professional to identify and diagnose a child with Down syndrome. Awareness of policy statements and informational sheets may provide support to pediatricians. Parents reports of their experience shows ongoing concern with the manner of delivery of the diagnosis of Down syndrome dating back to the 1970s.[1,2] A contemporary survey found that parents report feeling anxious and scared after either prenatal or postnatal diagnosis.[3,4] Evidence was collected, synthesized and formed the recommendations for best practices in delivering the diagnosis of Down syndrome.[5,6] The American Academy of Pediatrics provides guidance for care with the suggestions for delivering a diagnosis closely following these recommendations with the overall goal of providing accurate, balanced, up-to-date information.[7] The American College of Medical Genetics and Genomics (ACMGG) states that post-test counseling for aneuploidy should include accurate, up-to-date, and balanced information about Down syndrome, and there are a number of resources available.[8] Similarly, the American Congress of Obstetricians and Gynecologists (ACOG) and the National Society of Genetic Counselors (NSGC) have established opinions on best practice emphasizing timely, respectful disclosure.[9,10]

To improve the quality of information provided to families, various forms of educational materials have been created by the ACMGG, ACOG, NSGC, and others.[8–11] Beginning in 2011, individual states began enacting legislation to require that information be given to parents upon a positive prenatal test result or postnatal diagnosis.[12] Over time additional states have followed suit and in 2014 the Ohio House Bill 552 was signed into law.[13] The Ohio bill requires that physicians, certified nurse-midwives, and genetic counselors provide a fact sheet on Down syndrome from the Ohio Department of Health to patients with a test result indicating Down syndrome, or a prenatal or postnatal diagnosis of Down syndrome.[13] While passing with broad bipartisan report, the role of these fact sheets in the physician-patient relationship remains controversial.[14]

The purpose of this study was to evaluate current practices in delivering a diagnosis of Down syndrome and identify opportunities to improve this practice, including (1) local parent experiences at time of diagnosis of Down syndrome and (2) the use of the Ohio Department of Health Fact Sheet. Lessons learned can guide others who may deliver a diagnosis of Down syndrome. Broadening our efforts, we also aimed to review the current legislation in each state regarding Down syndrome information to inform readers' of existing legislation. This information may be useful to pediatricians who may be meeting with parents of children with Down syndrome.

Methods

Survey

In 2017, building on local experience with genetic counseling for Down syndrome at Nationwide Children's Hospital in Columbus, Ohio, an electronic survey was created in REDCap to study parent perceptions of their experience receiving a Down syndrome test result.[15,16] The survey contained an initial consent statement, collected demographic information, and contained questions surrounding two topics related to the diagnosis of Down syndrome. First, questions assessed the parental experience at the time of receiving a Down syndrome diagnosis (overall experience, professionalism of the person delivering the diagnosis, the language and wording used, the accuracy of information discussed and provided, and if written information was provided) and parent experience with genetics (if they met with a genetics professional, a rating of the experience, and what was gained from that meeting). In addition, parent perceptions of the implementation of a Down syndrome fact sheet as mandated by the 2014 Ohio House Bill 552 were ascertained: an image of the Down syndrome fact sheet from the Ohio Department of Health was included in the survey followed by a question asking if the parent had received the fact sheet. Responses regarding experience were collected using a scale of: 0=extremely negative, 5=neutral, 10=extremely positive. The survey was not validated, and is available in the Supplemental Material.

Participants

To study Ohio parent experiences at the time of diagnosis of Down syndrome, the survey was distributed to members of seven established Down syndrome parent resource groups located in the large Ohio cities of Cleveland, Columbus and Cincinnati..

Survey Administration

A hyperlink to this electronic survey was shared with seven parent resource groups in Ohio. Each parent resource group distributed the electronic survey to their members through email, through posting on their website, or through an affiliated Facebook group.

Legislation Review

Current legislation is public record and was reviewed through 1) each state's online record of rulings using the keyword 'Down syndrome', and 2) review of existing websites tracking legislative information related to Down syndrome.[17,18] For those states found to have

Down syndrome information legislation in place and currently approved, fact sheets were identified by searching 1) each state's department of health website using the keyword 'Down syndrome', and 2) reviewing existing websites. [17,18] The reading level of each fact sheet was scored using the Flesch-Kincaid Grade Level and Flesch Reading Ease readability scores which are calculated through Microsoft Word®. To study the impact of the specific written information required by Ohio House Bill 552, the Down Syndrome Fact Sheet, we focused analysis on infants born after 2014 and impacted by this legislation.

Analysis

Statistical analysis included descriptive statistics for survey responses: frequencies, means, and standard deviations, for the total sample, for the subset of patients born after 2014, and by birth year to evaluate for trends over time.

Using quality improvement methodology and statistics, we plotted yearly overall experience scores as a percentage (score / maximum total score) in p-charts to test the impact of House Bill 552 on parent experience. We tracked the impact of the ODH Fact Sheet. Centerline shifts were determined using standard statistical process control (SPC) chart rules.[19,20] At our institution, we have standardized use of the group of rules that have been published by the American Society for Quality (ASQ) for detecting special cause variation on control charts as in quality improvement research.[21,22]

This study was approved by the Institutional Review Board at Nationwide Children's Hospital. The data that support the findings of this study are available from the corresponding author upon reasonable request, apart from survey data which is not available for sharing.

Results

We received 79 completed parental surveys. Parents reported that their children with Down syndrome were born between 1976 through 2017. Demographic responses showed slight female predominance and a majority of White or Caucasian race (Table 1). Most parents (67%, n=53) identified as members of the Down Syndrome Association of Central Ohio serving the Columbus area. Additionally, more than half of parents held a bachelor's degree or higher.

Of the 79 completed surveys from parents of children with Down syndrome in Ohio, 53 were from parents (70%) who had received a post-natal diagnosis while 26 were from parents who had received a prenatal diagnosis. The person delivering the diagnosis of Down syndrome varied. Most commonly, parents reported that they found out about the diagnosis from the mother's OB/Gyn or the on-call pediatrician (Table 2). Of all families receiving a new diagnosis, 54 parents (68%) met with a genetics professional (either a medical geneticist or genetic counselor). Meeting with a genetics professional increased to 79% from 2014 to 2017. Parents reported gains from meeting with a genetic professional including education, genetic information, and a chromosome report. The experience of meeting with a genetic professional was rated positively at 6.32 for the total sample and 7.07 for the subset born from 2014 to 2017, on a 0-10 scale (Table 2).

Parents report an overall experience at the time of receiving a diagnosis that was slightly negative with a total average overall experience score of 4.16 ranging from 1.85 to 5.62 on a 0-10 scale (Table 2). Trends over time showed stability in this score with the highest overall experience score in 2011-2013 with an average score from nine parents of 5.6% satisfaction (Figure 1). Ratings of written information, professionalism, language, and accuracy of information were neutral to slightly negative; the written information provided showed the lowest score at 4.09 for the total sample and remained negative at 4.22 for the subset born from 2014 to 2017.

Parents who reported receiving ANY written information about Down Syndrome peaked in patients born between 2011-2013 with sixty percent of families reporting written information given at time of diagnosis. The parental view of the written information provided at time of diagnosis was variable with scores of the written information ranging from 0.6 to 6.23, using a scale of: 0=extremely negative, 5=neutral, 10=extremely positive. This score range is for all parent responders, not only those who received the ODH Fact Sheet. It is a limitation that we did not specifically ask which form of written information was provided. Parent evaluation of the written information after 2013 did not differ from total group ($p>0.05$). Of the 34 infants born after, and thus impacted by, Ohio House Bill 552, five parents (15%) reported receiving the required specific written information, the Down Syndrome Fact Sheet (Figure 2).

In evaluating the impact of House Bill 552 and the ODH Fact Sheet, we saw that overall diagnosis experience score did not significantly change over time as shown by a single process stage mean (Figure 1); overall experience score after passing of House Bill 552 in 2014 to 2017 remained negative at a mean of 3.95. Legislation related to delivering the diagnosis of Down syndrome was identified in 20 states (Table 3). Most legal code required 1) the affiliated state department to create / provide information and 2) that parents be given information at the time of a test result for Down syndrome. Individual states differed on the information to be given. Analyzing the readability of these fact sheets identified scores on the Flesch-Kincaid equivalent to a mean grade level of 13.1 with scores ranging from 10.3 to 16.7, and Flesch Reading Ease scores with mean of 34.3 ranging from 21.7 to 51.2.

Discussion

As many pediatricians are on the front lines in communicating the diagnosis of Down syndrome, we began this study to evaluate the current parent experience, the distribution and impact of legally-mandated written information, and to summarize the current legislation on this topic to inform pediatricians' practice. Surveying 79 parents of children with Down syndrome in Ohio identified an overall negative experience when receiving a new diagnosis of Down syndrome, with wide variability between families but no significant change in mean scores over time. Many parents reported not meeting with a genetic professional, not receiving written information, and not receiving the state-mandated Down syndrome Fact Sheet. In this cohort, House Bill 552 in 2014 did not result in demonstrable improvement to overall diagnosis score, nor increase in receipt of written information. Overall, these results demonstrate that we need to continue to take efforts to improve parent experience at the time of a Down syndrome test result. Obtaining data on a larger scale, both in overall number of responses and in breadth of demographics, is needed to evaluate the impact of the growing number of state-mandated Down syndrome information acts throughout the United State and the best route to help clinicians improve this lasting experience for impacted families.

The experience of an unexpected diagnosis, such as having a child with Down syndrome, can be viewed negatively. Indeed, studies to date have shown that this experience can be anxiety-provoking, worrisome, and upsetting if not done in a manner which includes a specific playbook, including: a team approach, with a support person present, with provision of up-to-date, accurate written information, and which connects families to community resources and provides a plan for next steps. Despite publication of national guidelines, best practice statements, and literature to guide clinicians, our parent survey responses continue to show an overall negative experience receiving this diagnosis.[5–7,9,10] With the advances made in prenatal testing and the increase uptake of it, it is more important now, than ever, to consider the reasons for this parent perception and identify ways that clinicians might improve the outcome.[23]

Surveying families has identified the use of written information as one useful step that could be taken by a physician delivering the diagnosis of Down syndrome.[6] Parents may feel overwhelmed with the information being discussed and wish to have written information to reference later when ready. However, our survey identified that more than half of parents do not recall receiving written information at the time the diagnosis of Down syndrome is delivered.

Legislation does not necessarily result in a change in clinical practice. Our cohort shows that implementing legislation to require specific printed literature be given to parents at time of a test result. Parent overall experience score remained negative before and after passage of Ohio House Bill 552 in 2014. In addition, it appears that after the implementation of the Ohio House Bill 552 in 2014, most families did not receive written information and did not receive the required Down Syndrome Fact Sheet. From our review, we identified 20 states which have similar laws regarding information surrounding a Down syndrome test result. Although providing written information is indeed best practice, our results suggest that these laws are not being followed absolutely; most importantly, the passage of the law did not appear to improve the negative experiences that parents report when receiving a Down syndrome test result.[6,10]

To study parent experience, an electronic survey was used which may limit the generalizability of our results based on small sample size, demographics (most respondents were White / Caucasian, educated, members of the Down Syndrome Association of Central Ohio); the demographic that is typically reached by Down syndrome support groups that received our survey may not represent the U.S. Down syndrome population. The response rate on our survey is suspected to be low given the estimated membership of the seven parent groups in Ohio included. We suspect that this may be due to a number of factors which could include: digital email overload, disinterest in completing surveys, discomfort or anxiety in completing this specific survey which may recall an emotional experience, or lack of participant reimbursement. In the future, it would be ideal to survey parents shortly after they receive a diagnosis, and to have funding to reimburse them for completing the survey. However, regardless of these limitations, our survey identified that only 5 of 34 patients had received the ODH Down syndrome Fact Sheet after House Bill 552 was passed. Put another way, 29 parents surveyed did not recall receiving the ODH fact sheet. Even in this small sample, this identifies a relevant number of instances in which HB552 was not successfully followed. This could be due to a variety of factors, such as: lack of physician awareness of HB552, lack of ability to locate the Down Syndrome Fact Sheet on the ODH website, or parent recall in receiving this information. However, these 29 instances bring to light the importance of evaluating the impact of House Bill 552 and other Down syndrome information acts. Further, our review identified legislation regarding Down syndrome fact sheets exists in twenty states, with significant inter-state variability regarding the requirements of the legislation and the form of information specified (Table 3). If a fact sheet or information source was specified, the readability scores of that written information showed a mean grade level of 13.1, with the recommended grade level is 8th grade. There remains a disconnect between the legislation that requires information be given and the real-world practice from parents' perspectives.

Limitations of our study include recall bias. Although receiving a diagnosis of Down syndrome is one that many parents remember, it is possible that parents may not recall details of the experience accurately. This may be especially true for parents recalling more distant memories. As parent responses on the survey are perceptions of their experiences, biases in the interpretation of their experiences are possible. Recall bias may be exacerbated by the emotional intensity of the experience of receiving an unexpected diagnosis, but this also makes it important to deliver the diagnosis well. In addition, our sample of parents in Ohio may not represent the broader experience of families nationally. The parents in our cohort were members of parent resource groups, and may not generalize to all parents of children with Down syndrome. In using the Flesch-Kincaid scale alone, complex genetic information may impact the score, and complex words can be eliminated if they have been defined in simpler terms earlier in the text; we did not eliminate complex word and this may overestimate the reading level and limit our analysis. In addition, our study is limited by the method of ascertainment; for example, we do not know if individuals had mosaic trisomy 21, which may alter the experience of results, or if the diagnosis was verified. Lastly, we searched for legislation through publicly-available resources which may allow us to miss pending legislation. Health care professionals in the 30 states which we did not identify legislation associated with delivering a Down syndrome test result should review their local practices to determine what applies.

Future studies could include surveys of parents at the time of experience, compared to later recall (e.g. at their child's first birthday) to investigate current practice and how the experience changes over time; could focus on a larger sample; could study the impact of information acts and Down syndrome fact sheets in other states; and, could follow the impact the House Bill 552 over time. It is important to determine if specific patient variables correlate with higher satisfaction score though this was outside the scope of the current study. Future study could consider the proposed motivation for passing this legislation and whether the trend for bills like this to pass across the country will continue. In our opinion, the implementation of these laws could be improved with closer involvement of bedside physicians from creation of legislation, its need, and to improve education of physicians once legislation exists and fact sheets are created.

Conclusion

This study's survey demonstrated a continued need to improve parent experience with delivery of a Down syndrome test result. In our cohort, passage of Ohio House Bill 552 in 2014 was not followed by improvement in parent experience scores, and 85% did not recall receiving the mandated Down Syndrome Fact Sheet. Delivering an unexpected diagnosis continues to be an area of opportunity to improve physician practice and parent experience.

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Figure / Table Legends

Table 1: Demographics of survey respondents – 79 parents of children with Down syndrome in Ohio

Table 2: Experience receiving the diagnosis of Down syndrome of 79 parents in Ohio

Table 3: Summary of current legislation regarding the diagnosis of Down syndrome by state as of February, 2019

Figure 1: Overall parent score over time

Solid lines indicate the process stage mean which refers to the arithmetic mean for all points within that process stage; statistical rules indicate that there are two stable process stages, indicated by the shift in September 2016. Dashed lines indicate two stable process stages; dotted lines annotate the control limits (± 3SDs based on the process mean and 'n' for that month).

Figure 2: Information given

Table 1: Demographics of survey respondents – 79 parents of children with Down syndrome in Ohio

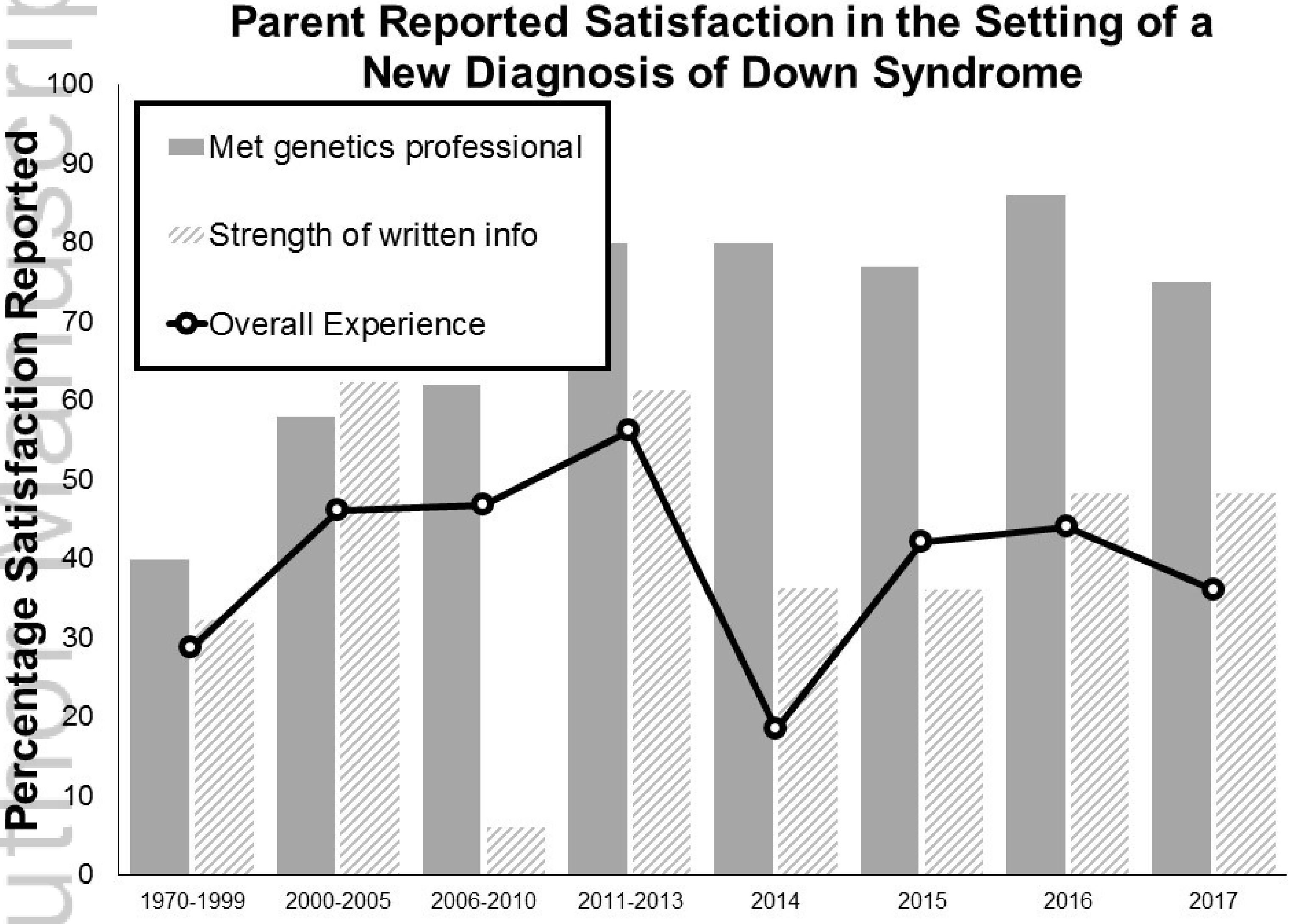
	All (N=79)		Born after HB 522 in 2014 (N=34)		***P* value**
	N	%	N	%	
Race:					
White	76	96	33	97	0.821
Other	3	4	1	3	
Sex:					
Female	43	54	22	65	0.311
Education:					
High school or less	11	16	4	13	0.756
Some college	18	26	10	32	
Bachelor's or higher	40	58	17	55	
Timing of diagnosis:					
Prenatal	23	30	15	45	0.126
Postnatal	53	70	18	55	
Support group affiliation:					
Down Syndrome Association of Central Ohio (Columbus area)	53	65	27	79	0.186
Up Side of Downs (Cleveland area)	9	11	4	12	
Other	12	15	2	6	
None	8	10	1	3	

Table 2: Experience receiving the diagnosis of Down syndrome of 79 parents in Ohio

	All (N=79)		Born after HB 552 in 2014 (N=34)		*p* value
	N	%	N	%	
Which fits best with your history (choose all that apply)?					
My child was suspected to have Down syndrome from ultrasounds before birth.	18	23	10	29	0.454
My child was suspected to have Down syndrome from blood work before birth.	19	24	10	29	0.549
My child was confirmed to have Down syndrome from genetic testing before birth	10	13	6	18	0.485
My child was confirmed to have Down syndrome from an amniocentesis before birth.	4	5	1	3	0.614
My child was suspected to have Down syndrome after birth based on clinical features.	45	57	18	53	0.693
My child was confirmed to have Down syndrome after birth based on genetic testing.	38	48	20	59	0.296
I found out about the diagnosis of Down syndrome from:					
My own OB/Gyn	20	25	7	21	0.643
On-call OB/Gyn	3	4	1	3	0.821
Genetic counselor	10	13	8	24	0.148
Genetic doctor	7	9	4	12	0.633
Nurse	6	8	2	6	0.745
My child's pediatrician	10	13	2	6	0.284
On-call pediatrician	20	25	10	29	0.651
Neonatologist	10	13	4	12	0.895
Social worker	2	3	1	3	0.901
Other	11	14	5	15	0.913
Provided written information about Down syndrome by the healthcare provider who delivered the diagnosis at the time of diagnosis	26	33	14	41	0.399
Received a copy of the Ohio Department of Health Fact Sheet at the time of diagnosis	5	6	5	15	0.031
Met with:					
A genetic counselor	32	41	20	59	0.073
A genetics doctor (geneticist)	22	28	7	21	0.418
Neither, someone else told me the genetic result	13	16	3	9	0.286
Neither, someone else explained recurrence information	3	4	1	3	0.821
From meeting with genetics, gained…					
Education about Down syndrome	30	38	18	53	0.140
Resources	21	27	9	26	0.990
Medical management	12	15	4	12	0.632
Chromosome report	31	39	13	38	0.920
Genetic information	30	38	15	44	0.541
At the time of diagnosis, rating (on the scale: 0=extremely negative, 5=neutral, 10=extremely positive) of…	Mean	(SD)	Mean	(SD)	
The overall experience in how the diagnosis of Down syndrome was delivered	4.16	3.16	3.95	2.93	0.773
The written information provided	4.09	3.24	4.22	2.85	0.868
The professionalism of the person delivering the diagnosis	5.46	3.60	5.60	3.27	0.859
The language and wording used at the time of diagnosis	5.01	3.24	4.85	2.82	0.816
The accuracy of information discussed and provided	5.28	3.08	5.27	2.86	0.980
The experience when you met with a genetic professional	6.32	3.14	7.07	2.45	0.340

Table 3: Summary of current legislation regarding the diagnosis of Down syndrome by state as of February, 2019

	Bill / law	*Year signed*	*Requires the Department to create / provide information?*	*Requires information given at time of diagnosis?*	*Fact Sheet specified:*	*Reading level of Fact Sheet (Flesch-Kincaid Grade Level)*	*Flesch Reading Ease*
Delaware	House Bill 214	2014	Y	Y	None		
Florida	Chapter 383.141	2015			www.lettercase.org www.floridahealth.gov	13.7	23.2
Illinois	House Bill 3158	2015	Y	Y	www.dph.illinois.gov	12.5	33.3
Indiana	Act 1093	2015	Y	Y	Yes	10.3	51.2
Kentucky	KRS 211.192	2015	Y	Y	Yes	13.4	29.3
Louisiana	Act 352	2014			Yes	12.3	38.0
Maine	LD 1134	2015	Y	Y	www.maine.gov/dhhs	12.9	33.7
Maryland	SB 0654 (CH 0323)	2014	Y	N	Yes	10.8	50.1
Massachusetts	Bill H.3825	2011	Y	Y	www.lettercase.org https://www.mass.gov	15.3	22.0
Minnesota	SF 462 (MS 145.471)	2015	N	Y	www.lettercase.org www.health.mn.us	12.0	42.5
Missouri	Chapter 191.923	2011	Y	Y	Yes	16.7	23.7
Nebraska	LB 891	2016	Y	Y	Yes	15.5	21.7
New Jersey	Chapter 173, Title 26	2016	Y	Y	No		
Ohio	House Bill 552	2014	Y	Y	State-specific sheet	14.5	29.6
Pennsylvania	House Bill 2111	2014	Y	Y	Yes	12.3	36.0
South Dakota	House Bill 1155	2015	Y	Y	No		
Tennessee	House Bill 2053	2018	Y	N	No		
Texas	House Bill 3374	2015	Y	Y	State-specific sheet	10.3	48.5
Virginia	Title 54.1-2403.01		N	Y	No		
Washington	House Bill 2403	2016	Y	Y	www.lettercase.org	14.1	31.8



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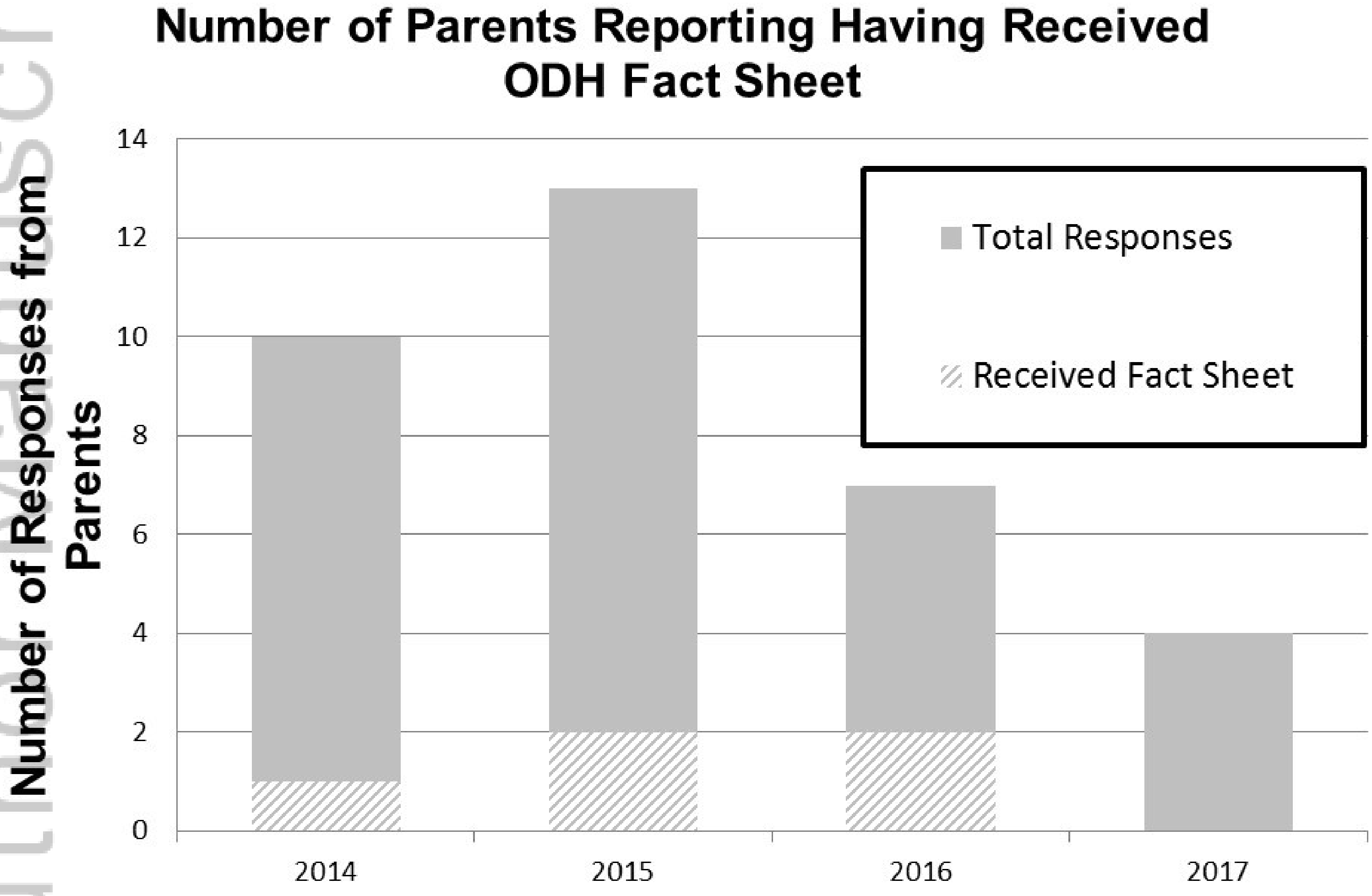

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