

THAT WHICH WE CALL A ROSE BY ANY OTHER NAME WOULD SMELL AS
SWEET: A FURTHER STUDY OF THE EVOLVING INTERPRETATION
OF INTELLECTUAL DISABILITY TERMINOLOGY

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By
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CERTIFICATION OF APPROVAL

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ABSTRACT

Healthcare providers, including genetic counselors continue to debate which term is most appropriate to describe intellectual disability. A survey was distributed to the National Down Syndrome Congress (NDSC) and Amazon Mechanical Turk (AMT) workers in order to assess their attitudes towards intellectual disability and different terms for intellectual disability. All surveys provided the exact same descriptive narrative of intellectual disability, except the target term used in the narrative was different. The target term used in the narrative was either *intellectual disability*, *mental retardation*, or *developmental delay*, thereby creating 3 different versions of the survey. Participants were asked to evaluate statements that were designed to assess their interpretation of the definitions of the different terms used, the amount of stigma that the participant associated with the specific target term used in the context of the narrative, and the participant attitudes towards each term. Results suggested that the term used did not have a significant effect on how much stigma participants associated with intellectual disability, but other factors did, such as social dominance orientation, knowing someone with intellectual disability and importance of religion. Even though no significant differences in stigma or attitudes towards the term were found between the terms used, results did suggest that participants define *mental retardation* as a more strongly limiting state than the other two terms. This difference in itself may imply that *mental retardation* is stigmatized more than the other two terms. No significant

differences were found between how participants defined *intellectual disability* and *developmental delay*.

INTRODUCTION

Words used to describe intellectual disability have changed numerous times throughout history. In the past, many terms intended for medical use have become colloquial and derogatory over time, creating the need for a new term that describes people with intellectual disability respectfully. Each time this happens, disability rights advocates search for a new term that communicates the same set of characteristics as the old label, but that does not carry with it the same stigma. For example, in 1907, Henry Goddard published literature suggesting that the terms 'imbecile,' 'idiot,' and 'feeble-minded' should be applied to individuals with different severities of intellectual disability (Goddard, 1907). This demonstrates what words providers commonly used at the time.

The first documented use of the term *retardation* was in a study by a school superintendent in Delaware in 1907 to describe students who were not advancing to the next grade (Smith & Smallwood, 2007). The American Association of Intellectual and Developmental Disabilities (AAIDD) adopted and defined the term *mental retardation* in 1959 with some pressure from parents who found the old terms to be offensive (Goode, 2002). Since the widespread acceptance of the term *mental retardation*, it has been used in a derogatory manner frequently enough to evoke the very feelings of discomfort it was originally meant to assuage.

The discussion to discontinue the use of the term *mental retardation* has been going on since at least 1992 when The Arc (formerly Association for Retarded Citizens; no longer an acronym) of the United States changed its name

to eliminate the word *retardation* (Ford, 2013). More recently, Rosa's Law was passed to replace *mental retardation* with *intellectual disability* in all federal legislation. This legislation originated from a mother's concerns about the sensitivity of her daughter's individual educational plan (IEP) and first passed as a state law in Maryland in 2009 and then as a federal law in 2010 (Ford, 2013). AAIDD changed the name of its journal from The American Journal on Mental Retardation to The American Journal on Intellectual and Developmental Disabilities in 2009, again demonstrating the time it has taken for a term for intellectual disability to be stigmatized enough to catalyze a movement to use a new term.

Recent movement towards the widespread use of *intellectual disability* in place of *mental retardation* has not ensued without debate. In an invited comment to The American Journal of Medical Genetics, Chiurazzi (2011) expressed concerns regarding the specificity of the term *intellectual disability*, stating that it would be too broad because it would encompass late onset cognitive impairments (e.g. brain trauma, stroke, etc.). He preferred *mental retardation* to *intellectual disability* because the word *retardation* implies that the issue is in the developmental period while he believes that *intellectual disability* does not insinuate the early onset of intellectual disability. He viewed the word *retardation* to be a more transparent word because it refers to the idea that intellectual disability is a developmental issue. He objected replacing *mental retardation*, but offered terms he thought would be a better substitution if a new term has to be chosen. He suggested using the terms *developmental delay* or

developmental cognitive impairment in order to specify that intellectual disability is apparent in early development or not changing the term at all with the reasoning that social stigma of individuals with intellectual disability would remain unchanged by merely changing the words that are used to describe them. A response to this argument was submitted by Fisch (2011), who stated that the meaning behind the word retardation actually is not appropriate for people with intellectual disability. He cites a study (Crowe, Deitz & Bennett, 1987) that shows that Bayley Scales of Infant Development (BSID) taken at 4 months, 1 year and 2 years of age is not strongly related to preschool-age cognitive motor performance. This shows that Fisch interpreted *retardation* to apply to children that have low BSID scores for their age, but who may end up catching up to their peers. In this case the term *mental retardation* would be too broad to use to describe people who are intellectually disabled. He also goes on to argue that the term *intellectual disability* does not include adult onset conditions because they are not classified under the umbrella of intellectual disability in scientific literature.

The debate about what terms are best to use goes beyond this exchange of ideas. One worry that most professionals in the field of intellectual disabilities tend to share is that any term will be stigmatized over time and that attitudes towards individuals with intellectual disability are not going to be significantly changed by a change in the label used to describe them (Goode, 2002; Russell, Mammen & Russell, 2005; Smith & Smallwood, 2007; Chiurazzi, 2011).

Because the debate on what term should replace *mental retardation* has overtly demonstrated how healthcare professionals in the field of intellectual disabilities interpret the meaning of the terms used to describe intellectual disability differently, it is natural to wonder how potential parents interpret the meaning behind the terms and how much stigma individuals associate the terms used to describe intellectual disability. Few studies have been done to address this issue.

Prior Studies on Intellectual Disability Terminology and Stigma

One such study was done by Panek & Smith (2005). They surveyed psychology students and rural Midwestern residents to evaluate participants' attitudes towards a variety of different terms for intellectual disability and other disabilities. These terms included *Mentally Challenged*, *Intellectual Disability*, *Cognitive Disability*, *Cognitive-Adaptive Disability*, *Developmental Disability*, *Mentally Retarded*, *Visually Disabled*, and *Physically Disabled*. Using the semantic differential technique, an assessment was made on how negatively or positively participants evaluated the terms in the study. The semantic differential technique was a previously developed scale used to assess participant attitudes towards words. This is a technique that is widely accepted by the psychology community to evaluate the attitudes participants associate with a word or concept using a specific series of questions that are organized into a likert scale. Semantic differential technique scales are divided into three categories: the evaluation scale (measures negative or positive attitudes), the potency scale (measures strength of feelings toward the concept or term) and the activity

factor (measures the level of activity associated with a word or concept). The term *mentally challenged* emerged as the most positive term, while *intellectual disability*, *mental retardation* and *developmental disability* showed similarly negative connotations to each other. There are a few limitations of this study. One limitation is the inconsistency of the form of the term used in the study. For example, the noun *intellectual disability* and the adjective *mentally retarded* were used. In order to be more consistent with the prior terms, *mental retardation* should have been used. Because this study was done prior to the implementation of the term *intellectual disability*, it is also possible that attitudes towards that term specifically have changed in the past decade. Another limitation is that the sample population was not geographically diverse (participants were recruited in a rural Ohio community) and was unlikely ethnically diverse according to US census data (US Census, 2010). A broader (i.e. national) sample population may have yielded different results.

Another study conducted by Nash, Hawkins, Kawchuk, and Shea (2012) at the IWK Health Centre in Halifax, Nova Scotia, surveyed patients and healthcare providers by giving them a description of a child with intellectual disability and asking them what terms they preferred to describe the child. The survey for health care providers asked what terms they use with colleagues, other professionals as well as families. They also were asked to choose what term they thought was most positive, what term they were taught to use in their professional training, and if they had ever been criticized for using *mental retardation*. Parents were given a description of a seven-year-old child that had

undergone psychoeducational testing and was found to function much lower than expected, closer to a four-year-old level. The parents were then asked if they understand the meaning of the term *mental retardation*, whether or not they preferred a different term, and how serious *mental retardation* sounds to them compared to *developmental delay* or *mentally challenged*. Participants were approached in different patient waiting rooms throughout the institution.

The professional survey showed that providers chose *developmental delay* as the most positive term and the term that they prefer to use when talking to families when presented with the options *mentally retarded*, *mentally challenged*, *developmentally delayed*, and *intellectually disabled*. The survey for parents revealed that parents generally disapproved of the use of the term *mental retardation* and that parents of intellectually disabled children are significantly more likely to disagree with the use of *mental retardation*. When asked if they would understand the meaning of *mental retardation*, 31% of parents with an affected child, and 27% of parents without an affected child strongly disagreed, disagreed, or were undecided when presented with the statement, 'I would understand meaning of the term mental retardation.' This demonstrates that even parents with a child with intellectual disability are unclear about the meaning of the term. The majority of parents also chose *developmentally delayed* as the most positive term when presented with the same options as the professionals. The authors of this study mentioned they have observed that *intellectual disability* is not a commonly used term in Canada,

so *developmental delay* might be seen as more positive simply because it is considered to be the more accepted term.

One limitation of this study is that the method used to evaluate the attitudes of participants towards the different terms was done via self-reflection, meaning that the participants compared the terms side by side and rated them rather than recording their reaction to each term without the other terms present to help define it. It is also possible that different results would have been found if they used the semantic differential technique used in the previous study.

Another study that helped shape the current study by Bizer, et. al. (2012) analyzed what factors affected how much stigma their participants associated with mental health conditions. 280 participants from Amazon Mechanical Turk were exposed to multiple previously validated psychological scales. This included the 'opinions about mental illness scale' (Cohen & Struening, 1962), which is a common scale used to measure negative attitudes towards people with mental illness (e.g. One statement evaluated by participants included: 'Anyone who is in a hospital for a mental illness should not be allowed to vote.'). The 'social dominance orientation scale' was also included, which is a previously validated scale that measures participants' preference for social equality (e.g. Some groups of people are simply not the equals of others.). A low score on the social dominance orientation scale is indicative of an individual's high preference for social equality. (Pratto, Sidanius, Stallworth, & Malle, 1994). The primary conclusions from this study were that social dominance orientation

scores were a strong predictor of participants' negative attitudes towards mental illness.

Research Question

The above studies have shown that individuals within the same population and overall preferences of different populations often disagree when it comes to what term for intellectual disability is most positive and most commonly used. The goal of the current study was to build on previous research and offer a more in-depth evaluation of how people define and interpret these different terms. One way this was accomplished was by having participants evaluate, define and interpret the terms used in the context of a definition and in the absence of other terms for intellectual disability that may influence their understanding. Another aim was to explore the possibility that the term *intellectually disabled* is already stigmatized even though it is emerging as the most accepted term in the field of intellectual disability in the United States.

MATERIALS AND METHODS

A survey was distributed to members of The National Down Syndrome Congress (NDSC) as well as Amazon Mechanical Turk (AMT) workers. Participants from NDSC were included to make sure that participants who have close relationships with intellectually disabled individuals were included in the study, while participants from AMT were included to represent participants who may not know anyone with intellectual disability. NDSC members include family members of someone with Down syndrome, teachers, therapists and healthcare professionals who work with people with Down syndrome as well as individuals with Down syndrome. NDSC participants were contacted using the NDSC's monthly national newsletter, which included a link to the survey. AMT participants are people who are compensated to take surveys. Anyone can sign up to take surveys through AMT and be compensated with a small fee per finished survey. The fee paid to AMT participants for the current study was \$1.50. Members of the NDSC were encouraged to participate in the survey by being offered the choice to enter into a drawing for one of four \$50 Amazon.com gift cards.

The survey was open from April 15th to May 10th, 2014. Data were analyzed for the 428 participants that met inclusion criteria. Participants were excluded that did not answer any questions and that were beta testers. Partially filled out surveys were included. Participants that did not speak English for at least 3 years were also excluded because they may not yet understand the nuances between the three terms analyzed. Participants that lived outside of the

United States were excluded because they do not accurately represent patients that seek healthcare at hospitals in the United States. A high proportion of participants were recruited through Amazon Mechanical Turk (n = 394; 92.1%) as compared to The National Down Syndrome Congress (n = 32; 7.5%) (not all participants indicated how they heard about the survey). Demographic questions included participants' age (to the nearest year), how much they valued religion (on a likert scale: 1 = extremely important, 2 = very important, 3 = somewhat important, 4 = neither important nor unimportant, 5 = somewhat unimportant, 6 = very unimportant, 7 = not at all important), income level (asked in increments of \$25,000), race (where participants could select all that apply), education level, gender identity, how many children they have (indicated as a single number), and how long they have known English (to the nearest year) (Appendix A).

The survey asked participants to evaluate a narrative of the definition of intellectual disability adapted from the American Association on Intellectual and Developmental Disabilities definition. There were three versions of the survey. All surveys provided a descriptive narrative and were identical, except the target term used in the narrative and subsequent questions was different in each of the 3 surveys. The target terms used in the narrative were either *intellectual disability*, *mental retardation*, or *developmental delay*. One key difference between the current and prior studies is that in the current study, each participant was only exposed to one of the terms; in previous studies, each participant was exposed to all of the terms being evaluated (Nash, et. al., 2012;

Panek & Smith, 2005). Below is the narrative of the definition adapted from the AAIDD definition of intellectual disability that was used:

An individual with **<term>** has significant limitations both in learning, reasoning and problem solving before the age of 18. Other possible areas with limitations include the following:

- Conceptual skills—language and literacy; money, time, and number concepts; and self-direction.
- Social skills—interpersonal skills, social responsibility, self-esteem, gullibility, naïveté (i.e., wariness), social problem solving, and the ability to follow rules/obey laws and to avoid being victimized.
- Practical skills—activities of daily living (personal care), occupational skills, healthcare, travel/transportation, schedules/routines, safety, use of money, use of the telephone.

Individuals with **<term>** generally have IQ scores below 70-75 (a score of 100 is average).

Of the 428 participants, 137 (32.0%) randomly received a version of the survey that used *intellectual disability*, 148 (34.6%) randomly received the version of the survey that used *mental retardation* and 143 (33.4%) randomly received the version of the survey that used *developmental delay*.

Participants were first asked to rate 25 statements that evaluated the amount of stigma they associated with the description (Appendix B). Statements were evaluated using a 7-point likert scale (1 = strongly disagree; 2 = disagree; 3

= somewhat disagree; 4 = neither agree nor disagree; 5 = somewhat agree; 6 = agree; 7 = strongly agree). These statements were adapted from the 'opinions about mental illness scale' that was previously developed by Cohen & Struening (1962) to measure stigma associated with mental health issues and used by Bizer et. al. (2012) to correlate social dominance orientation scores with negative attitudes towards mental illness. Additional statements developed by the author and research mentors of the current study intended to measure negative attitudes towards individuals with intellectual disability were included. Ten of these questions were worded to demonstrate positive attitudes towards individuals with intellectual disability and the remaining 15 were worded to demonstrate negative attitudes towards individuals with intellectual disability. These two types of statements were included in order to make sure that participants paid attention to each question. The positive statements were reverse coded during data analysis. Scores from all questions used to evaluate negative attitudes towards individuals with intellectual disability were averaged together and developed into a new stigma scale.

The same semantic differential technique scale used by Panek & Smith (2005) was also included in order to validate the stigma scale that was created, and to evaluate different aspects of the attitudes associated with the term used. This section of the survey presented the participant with the term only (without the narrative definition) and asked the participant to evaluate their attitudes on 12 separate items on a 7-point likert scale. The semantic differential technique is divided into three different factors (4 items each): the evaluation, potency and

activity factors. The evaluation factor included the following scales: Good::Bad; Worthless::Valuable; Pleasant::Unpleasant; and Unfair::Fair. The evaluation factor score represents how negative or positive a participant's feelings are. The potency factor was measured using the following scales: Weak::Strong; High::Low; Light::Heavy; and Deep::Shallow. The potency factor score represents how strong a participant's feelings are towards the term. The activity factor scales included the following: Fast::Slow; Passive::Active; Relaxed::Tense; and Agitated::Calm. The activity factor score represents how active the participant perceives the presented term to be. The scales from each factor were mixed together in order to make sure the participant did not start to answer all of them in the same way.

The social dominance orientation scale used by Bizer, et. al. (2012) was also included in the current study (Appendix C). The social dominance orientation scale measures the participants' preference for social equality. This scale was included in the survey to determine if the participant's social dominance orientation was correlated with the amount of stigma they associated with intellectual disability. The same described likert scale was used to evaluate these statements: (1 = strongly disagree; 2 = disagree; 3 = somewhat disagree; 4 = neither agree nor disagree; 5 = somewhat agree; 6 = agree; 7 = strongly agree). The statements and scale in this section of the survey were identical to how they were presented in the study that originally developed the scale (Pratto, et. al., 1994).

Statements were also developed to evaluate aspects of the definition of terms used for intellectual disability (e.g. Intelligence will be similar to peers as an adult.) (Appendix D). These questions were developed based on debates in the literature about how patients and providers define the terms (Chiurazzi, 2011; Fisch, 2011; Ford, Acosta, & Sutcliffe, 2013), as well as debates the authors have observed anecdotally. A likert scale was used to evaluate these statements (1 = strongly disagree; 2 = disagree; 3 = somewhat disagree; 4 = neither agree nor disagree; 5 = somewhat agree; 6 = agree; 7 = strongly agree). These questions were mixed in randomly with the questions that evaluated the amount of stigma participants associated with the description of intellectual disability.

The survey was beta tested by 14 people that included research mentors, graduate students, as well as friends and family of the author. Feedback from beta testing was used to develop the final version of the survey. Data from beta testing was excluded from all data analysis.

RESULTS

A total of 428 participants were recruited: 394 participants were recruited from Amazon Mechanical Turk (AMT), 32 participants were recruited from The National Down Syndrome Congress (NDSC) and 2 participants did not indicate how they heard about the survey. The number of AMT participants was predetermined. The survey was sent out to a total of 303 email addresses on the NDSC, however 32 responses were recorded from the NDSC making for a response rate of 10.6%.

Participant Demographics

Participants were shown to be quite diverse across most demographics. This was demonstrated by participant age (Table 1; Figure 1); household income (Table 2; Figure 2); number of children (Table 3; Figure 3); gender identity (Table 4); and education level (Table 5; Figure 4). However participants were not racially diverse. The majority of participants reported European ancestry (Table 6; Figure 5).

Table 1
Age of Participants

Age Group	# of AMT Participants	% of AMT Participants	# of NDSC Participants	% of NDSC Participants	No Response	Total
18-25	76	19%	1	3%	0	77
26-35	173	44%	7	23%	1	181
36-45	73	19%	10	33%	0	83
46-55	39	10%	6	20%	0	45
56-65	29	7%	4	13%	0	33
66-71	3	1%	2	7%	1	6
Total	393	100%	30	100%	2	425

Note: Three participants chose not to disclose their age and two participants did not answer how they heard about the survey.

Table 2
Household Income Level of Participants

Income Level	# of AMT Participants	% of AMT Participants	# of NDSC Participants	% of NDSC Participants	No Response	Total
Under 25k	96	24%	2	7%	2	100
25-50k	137	35%	4	14%	0	141
50-75k	82	21%	4	14%	0	86
75-100k	40	10%	8	29%	0	48
100k+	37	9%	10	36%	0	47
Total	392	99%	28	100%	2	422

Note: Six participants chose not to disclose their income level.

Table 3
Number of Children of Participants

Number of Children	# of AMT Participants	% of AMT Participants	# of NDSC Participants	% of NDSC Participants	No Response	Total
0	242	62%	2	6%	0	244
1	68	17%	6	19%	0	74
2	52	13%	13	41%	1	66
3	23	6%	8	25%	0	31
4	8	2%	3	9%	1	12
Total	393	100%	32	100%	2	427

Note: One participant chose not to disclose how many children they have.

Table 4
Gender Identity of Participants

Reported Gender	# of AMT Participants	% of AMT Participants	# of NDSC Participants	% of NDSC Participants	No Response	Total
Female	196	50%	29	91%	1	226
Male	197	50%	2	6%	1	200
Trans, MTF	1	0%	0	0%	0	1
Trans, FTM	0	0%	0	0%	0	0
No Response	0	0%	1	3%	0	1
Total	394	100%	32	100%	2	428

Note: Two participants did not indicate how they heard about the survey and one participant did not indicate their gender identity.

Table 5
Education Level of Participants

Education Level	# of AMT Participants	% of AMT Participants	# of NDSC Participants	% of NDSC Participants	No Response	Total
Some HS	5	1%	0	0%	0	5
HS Grad	48	12%	1	3%	0	49
Some College	92	23%	3	9%	2	97
AA/TS	56	14%	3	9%	0	59
BA/BS	145	37%	9	28%	0	154
Some GS	11	3%	4	13%	0	15
Grad Degree	37	9%	12	38%	0	49
Total	394	99%	32	100%	2	428

Note: No participant reported having no schooling or leaving school before high school. HS = High School; AA = Associate of Arts; TS = Trade School; BA = Bachelor of Arts; BS = Bachelor of Science; GS = Graduate School

Table 6
Race of Participants

Race	# of AMT Participants	% of AMT Participants	# of NDSC Participants	% of NDSC Participants	No Response	Total
API	34	8%	1	3%	0	35
African/Black	43	10%	1	3%	0	44
Euro/White	307	73%	28	88%	2	337
Hisp/Latino	22	5%	0	0%	0	22
AI/NA	8	2%	1	3%	0	9
Mid Eastern	1	0%	0	0%	0	1
Other	3	1%	1	3%	0	4
Total	418	99%	32	100%	2	452

Note: Numbers add up to more than 428 because 20 participants selected more than one race. API = Asian/Pacific Islander; Hisp = Hispanic; AI/NA = American Indian/Native American; Middle Eastern; Other

Figure 1
Age of Participants

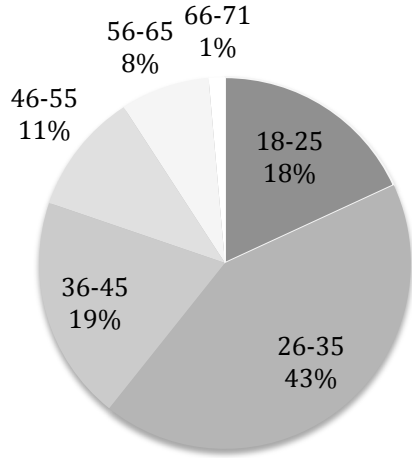


Figure 2
Household Income Level of Participants

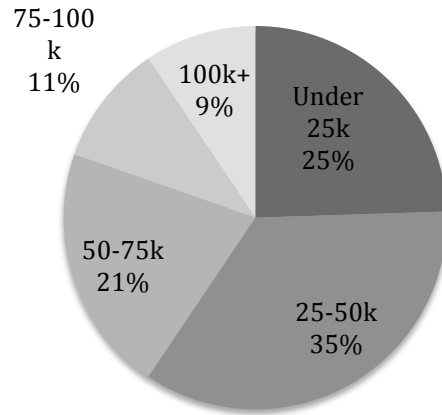


Figure 3
Number of Children of Participants

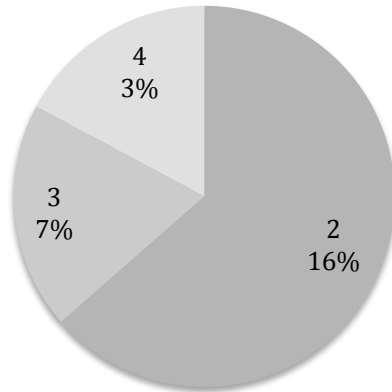
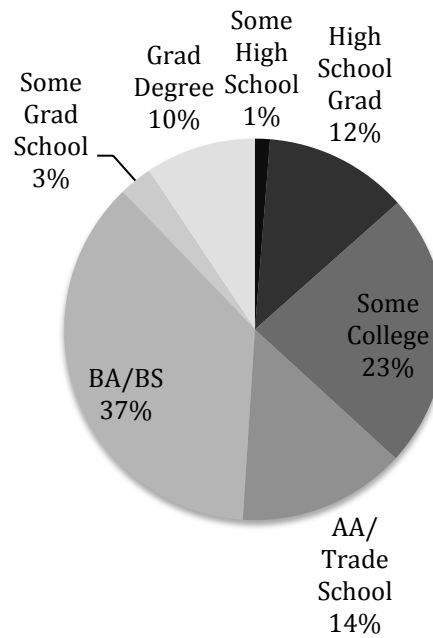
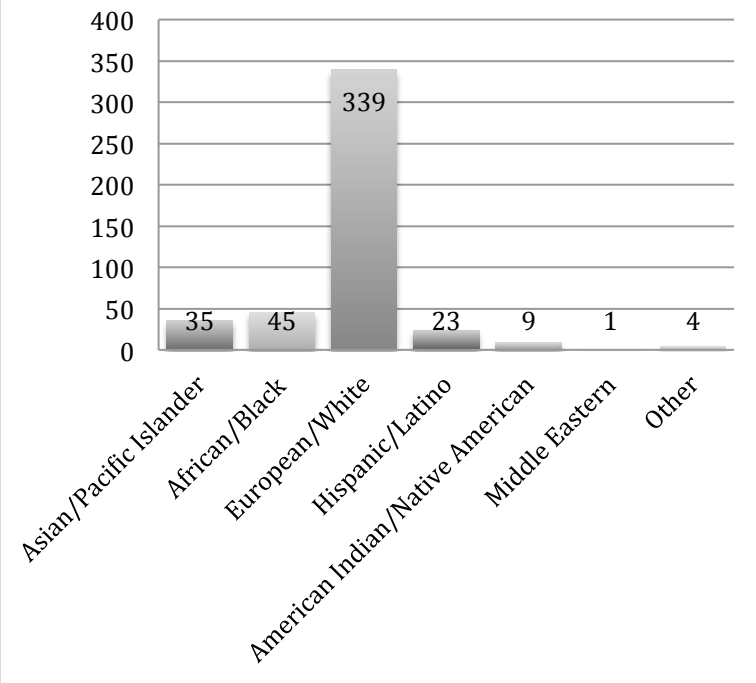


Figure 4
Education Level of Participants



Note: Figures 1-4 show combined data for both AMT and NDSC participants.

Figure 5
Participant Race



Note: Numbers add up to more than 428 because 20 participants selected more than one race. Data shown combines AMT and NDSC participants.

Stigma Analysis

Reliability and Validity

First a reliability test was done with the 25 questions that were developed to measure stigma associated with intellectual disability. All questions were shown to increase the internal consistency upon their inclusion, except question 11: “If our hospitals had enough well trained doctors, nurses, and aides, many individuals with <term> would gain the necessary skills to live independently.” This question was therefore excluded from the scale. The remaining 24 questions had a high internal consistency (Chronbach’s alpha = 0.910, $N = 428$). Scores on this scale can range from 1 to 7 where 1 is the most

accepting of people with intellectual disability and 7 is the most stigmatizing of people with intellectual disability. The average overall stigma score was 2.77 ($SD = 0.78$, $min = 1.17$, $max = 5.71$). In order to evaluate if the scale measures negative attitudes, a correlation test was done between participants' scores on the developed stigma scale and participants' scores on the evaluation factor of the semantic differential technique. It was determined that the developed stigma scale correlated with the evaluation factor of the semantic differential technique ($r = .39$, $p < .001$, $N = 428$). This demonstrated evidence of convergent validity, suggesting that the two scales may both have measured participants' negative attitudes.

A reliability test was also done for each factor of the semantic differential technique. The evaluation factor was determined to have internal consistency (Chronbach's alpha = .771, $N = 428$). The potency factor was not determined to show internal consistency. It's highest internal consistency was seen when the Heavy::Light question was excluded (Chronbach's alpha = .645, $N = 428$); however this is still below the cutoff for a reliable scale. The activity factor did show internal consistency, but was close to the cutoff for a reliable scale (Chronbach's alpha = .695, $N = 428$).

A reliability test was also done on the social dominance orientation scale, which revealed high internal consistency (Chronbach's alpha = .949, $N = 416$). There were 12 participants that did not answer all of the questions for this scale, and were therefore excluded from the analysis.

Factors Influencing Attitudes towards Intellectual Disability

Several statistical tests were done in order to determine what factors influence the participant's stigma score. First, a one-way ANOVA test was done in order to see if the term used in the description and throughout the survey had an impact on the participant's stigma score. The results showed that the term used in the survey did not have a significant effect on participants' scores on the developed stigma scale ($F(2,425) = 0.99, p = .372, \eta^2 = .005$)(Table 7). One-way ANOVAs were also done to compare the term used with the participants' scores on the three factors of the semantic differential technique. No significant differences between what term was used and the score on the evaluation or potency scale of the semantic differential technique were observed [$F(2,425) = 0.51, p = .60, \eta^2 = .002$; $F(2,425) = .036, p = .97, \eta^2 = 1.67 \times 10^{-4}$, respectively](Table 8 and Table 9, respectively). The term used did have a significant impact on the participants' semantic differential technique activity factor scores ($F(2,425) = 3.43, p < .04, \eta^2 = .016$)(Table 10). Homogeneity of variance could be assumed since the Levene's test was not significant, $F(2, 425) = 1.45, p = .24$. Tukey's test was used for post-hoc pair-wise comparisons. It was determined that there is only a significant difference between the average activity factor score between *intellectual disability* and *developmental delay* ($p < .03$) ($M_s(SDs) = 4.67(0.87), 4.81(0.96),$ and $4.96(0.89)$ for *intellectual disability, mental retardation* and *developmental delay*, respectively). No significant difference was seen between *mental retardation* and the other two terms ($p > .3$ for both). On the scale, 1 represented the most active and 7 represented the least

active, so *intellectual disability* was seen as significantly more active than *developmental delay*.

Table 7
AMT, NDSC and Overall Average Stigma Scores

Term Used	AMT Mean Stigma Score	NDSC Mean Stigma Score	Overall Mean Stigma Score	Standard Deviation
Intellectual Disability	2.82	2.15	2.76	0.73
Mental Retardation	2.91	1.85	2.84	0.77
Developmental Delay	2.80	1.73	2.71	0.83
Overall	2.85	1.91	2.77	0.78

Table 8
AMT, NDSC and Overall Average Evaluation Factor Scores

Term Used	AMT Mean Evaluation Score	NDSC Mean Evaluation Score	Overall Mean Evaluation Score	Standard Deviation
Intellectual Disability	4.50	3.64	4.43	1.20
Mental Retardation	4.50	3.87	4.46	1.33
Developmental Delay	4.63	4.24	4.57	1.19
Overall	4.54	3.91	4.48	1.24

Table 9
AMT, NDSC and Overall Average Potency Factor Scores

Term Used	AMT Mean Potency Score	NDSC Mean Potency Score	Overall Mean Potency Score	Standard Deviation
Intellectual Disability	4.70	4.21	4.66	1.05
Mental Retardation	4.68	3.97	4.64	1.09
Developmental Delay	4.69	4.55	4.67	1.02
Overall	4.69	4.25	4.65	1.05

Table 10

AMT, NDSC and Overall Average Activity Factor Scores

Term Used	AMT Mean Activity Score	NDSC Mean Activity Score	Overall Mean Activity Score	Standard Deviation
Intellectual Disability	4.70	4.30	4.67	0.87
Mental Retardation	4.86	4.30	4.81	0.96
Developmental Delay	5.02	4.48	4.96	0.89
Overall	4.86	4.36	4.82	0.92

An Independent sample t-test was done comparing stigma scores between participants that reported knowing someone with intellectual disability and those that did not. This test revealed that on average, people who know someone with intellectual disability ($n = 236$; $M = 2.55$, $SD = 0.74$) stigmatize intellectual disability less than participants that do not ($n = 192$, $M = 3.05$, $SD = 0.73$), $t(428) = -7.02$, $p < .001$, $d = 0.68$ (Table 11).

Table 11

Knowing Someone with Intellectual Disability

Term Used	Number of Participants	Mean Stigma Score	Standard Deviation
Know Someone with ID	236	2.55	0.74
Do Not Know Someone with ID	192	3.05	0.73
Overall	428	2.77	0.78

A correlation test was done between participants' social dominance orientation scores and their stigma scores. Social dominance orientation scores were calculated according to the study where the scale was originally developed (Pratto, et. al., 1994). A score of 1 on the scale indicated the highest preference for social equality, while a score of 7 indicated the lowest possible preference for

social equality. The results of this test showed that the amount of stigma a participant associated with the description is significantly positively correlated to their social dominance orientation score. ($r = 0.43, p < 0.001, N = 416$)(Figure 6). This means that the more participants disapproved of social equality, the more likely they were to stigmatize the description of intellectual disability.

A correlation test was done between participants' age (as a continuous scale) and their stigma scores. The results of this test showed that the amount of stigma a participant associated with the description is significantly negatively correlated to their age ($r = -.15, p = .002, N = 425$)(Figure 7).

Another correlation test was done comparing the importance of religion reported by participants to the amount of stigma they associated with the description of intellectual disability. This revealed that in general, the more important religion is to a participant, the less stigma they associate with someone with intellectual disability ($r = -.25, p < .001, N = 428$) (Figure 8).

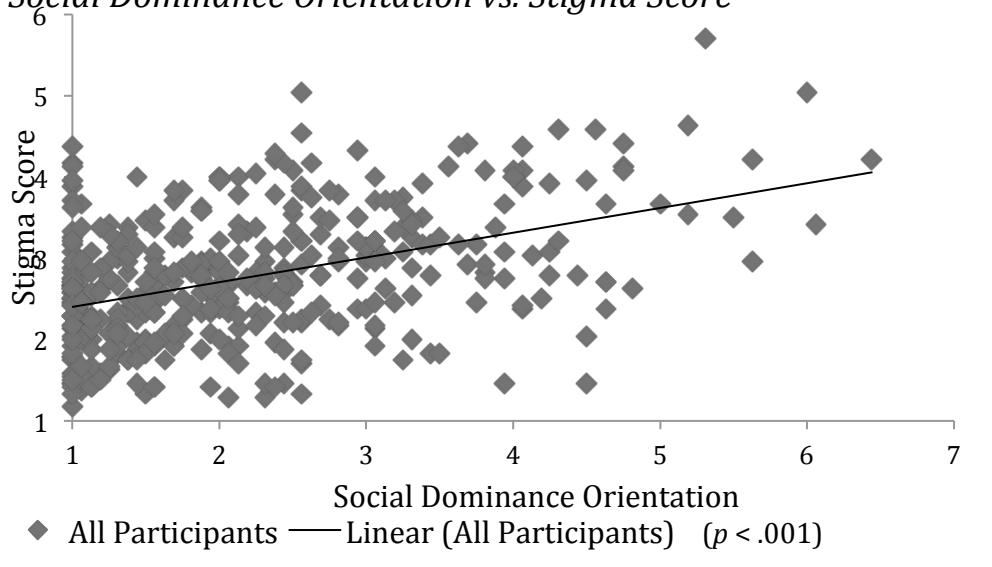
The number of children that a participant had did not significantly correlate with the amount of stigma they associated with the description of someone with intellectual disability ($r = .01, p = .82, N = 428$).

On average, a participant's income level was not determined to significantly correlate with the amount of stigma they associated with intellectual disability ($r = -.09, p = .069, N = 422$). Not all participants responded to this question.

It was also determined that on average, the education level of participants did not correlate with how much stigma they associated with the description of intellectual disability ($r = -.004, p = .93, N = 428$).

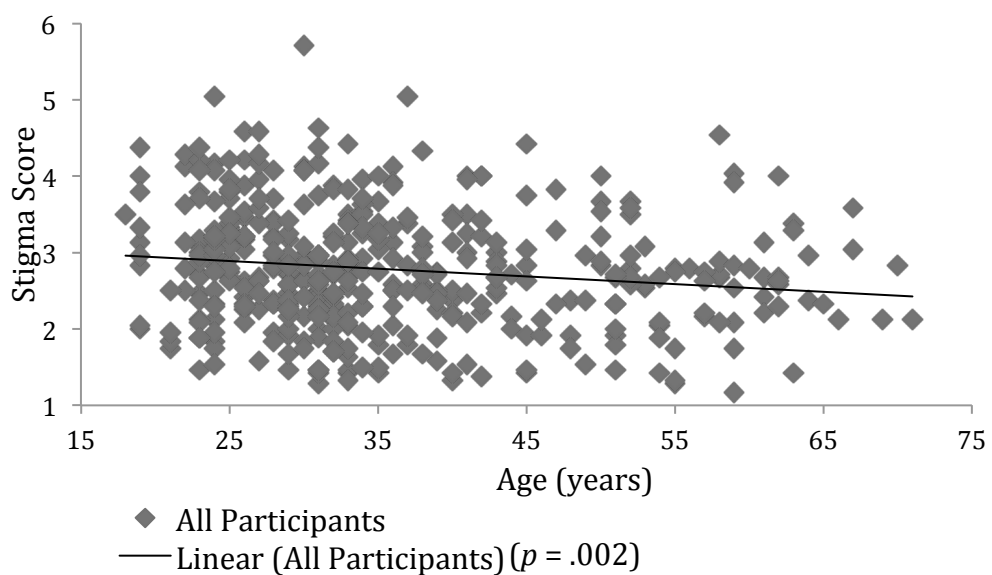
Multiple regression was used to determine how much a participant's social dominance orientation, familiarity with someone with intellectual disability, age and the importance of religion influence a participant's stigma score. Our simultaneous regression model explained a significant portion of the variance in stigma scores, adjusted $R^2 = .33, F(4, 408) = 51.03, p < .001$. The participants' stigma scores were predicted by their social dominance orientation scores ($\beta = .43, p < .001$), whether they knew someone with intellectual disability ($\beta = .25, p < .001$), and how important religion was to them ($\beta = -.21, p < .001$), but not participant age ($\beta = -.070, p = .087$).

Figure 6
Social Dominance Orientation vs. Stigma Score



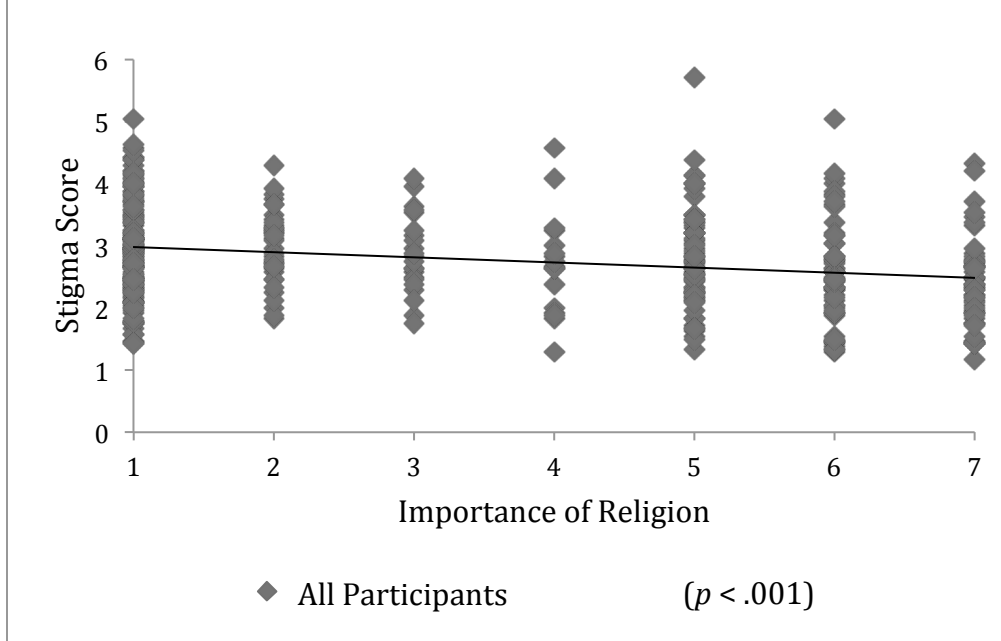
Note: The social dominance orientation scale was from 1-7 where 1 indicated the strongest possible preference for social equality and 7 indicated the strongest disfavor of social equality. The stigma score ranged from 1-7 where a score of 1 indicated the least amount of stigma associated with the narrative and 7 indicated the highest level of stigma towards the narrative.

Figure 7
Age vs. Stigma Score



Note: The stigma score ranged from 1-7 where a score of 1 indicated the least amount of stigma associated with the narrative and 7 indicated the highest level of stigma towards the narrative.

Figure 8
Importance of Religion vs. Stigma Score



Note: Participants indicated the importance of religion on a likert scale where: 1 = extremely important, 2 = very important, 3 = somewhat important, 4 = neither important nor unimportant, 5 = somewhat unimportant, 6 = very unimportant, 7 = not at all important.

Definition Analysis

Statements that were created to analyze how participants define the different terms for intellectual disability were analyzed separately because they each represent different aspects of the definition of intellectual disability. One-way ANOVA's were used to evaluate whether or not there was a significant difference between how participants defined the different terms for intellectual disability.

Intelligence will be similar to peers as an adult.

The results of this statement showed that participants judged this statement to be least true for *mental retardation*, $F(2, 425) = 3.64, p < .05, \eta^2 = .017$. Homogeneity of variance could not be assumed since the Levene's test was

significant, $F(2, 425) = 3.33, p = .037$. Games-Howell test was used for post-hoc pair-wise comparisons. It was determined that whether intelligence will be similar to peers as an adult was deemed as less true for those with *mental retardation* ($M = 2.16, SD = 1.11$) than with a *developmental delay* ($M = 2.52, SD = 1.22; p = .020$). *Intellectual disability* ($M = 2.43, SD = 1.32$) did not differ from either of the other terms $p > .14$. On average participants in each group disagreed with this statement, however participants in the *mental retardation* group disagreed significantly more than those in the *developmental delay* group (Figure 9).

<Term> is a permanent state.

Participants agreed with this statement most when *mental retardation* was used, $F(2, 425) = 20.65, p < .002, \eta^2 = .089$. Homogeneity of variance could not be assumed since the Levene's test was significant, $F(2, 425) = 4.41, p = .011$. Games-Howell test was used for post-hoc pair-wise comparisons. It was determined that on average, intellectual disability was deemed a more permanent state when *mental retardation* was used versus the two other terms ($p < .001$). $M_s(SDs) = 4.96(1.42), 5.74(1.15),$ and $4.80(1.42)$ for *intellectual disability, mental retardation* and *developmental delay* respectively. No significant difference was found between *intellectual disability* and *developmental delay* ($p = .62$). On average participants in each group agreed with this statement, however participants in the *mental retardation* group agreed significantly more strongly (Figure 10).

An individual with <term> would need extra help in school.

Participants judged this statement about the same regardless of the term used, $F(2, 425) = 1.26, p = .29, \eta^2 = .0059$. Homogeneity of variance could be assumed since the Levene's test was not significant, $F(2, 425) = 0.945, p = .39$. $Ms(SDs) = 6.19(0.94), 6.34(0.77),$ and $6.28(0.76)$ for *intellectual disability, mental retardation* and *developmental delay* respectively (Figure 11).

An individual with <term> will likely have learning disabilities.

Participants agreed with this statement most when *mental retardation* was used, $F(2, 425) = 6.10, p = .002, \eta^2 = .028$. Homogeneity of variance could be assumed since the Levene's test was not significant, $F(2, 425) = 0.01, p = .99$. Tukey's test was used for post-hoc pair-wise comparisons. Participants judged intellectual disability to be significantly more linked to learning disabilities when *mental retardation* was used than if *intellectual disability* or *developmental delay* were used ($p = .002; p < .05$ respectively). $Ms(SDs) = 5.91(0.95), 6.28(0.89),$ and $6.02(0.99)$ for *intellectual disability, mental retardation* and *developmental delay* respectively. No significant difference was found between *intellectual disability* and *developmental delay* ($p = .56$). On average, all groups agreed with this statement, but participants in the *mental retardation* group agreed significantly more (Figure 12).

S/he will most likely live with his/her parents through adulthood.

Again, participants agreed with this statement most when *mental retardation* was used, $F(2, 425) = 14.77, p < .001, \eta^2 = .065$. Homogeneity of variance could not be assumed since the Levene's test was significant, $F(2, 425) = 3.19, p = .04$. Games-Howell test was used for post-hoc pair-wise comparisons.

Participants thought it was significantly more likely for someone with intellectual disability to live with their parents through adulthood when *mental retardation* was used instead of *intellectual disability* or *developmental delay* ($p = .001$; $p < .001$ respectively). $Ms(SDs) = 4.45(1.34)$, $5.01(1.26)$, and $4.15(1.50)$ for *intellectual disability*, *mental retardation* and *developmental delay* respectively. No significant difference was found between *intellectual disability* and *developmental delay* ($p = .17$). On average participants in each group agreed with this statement, however participants in the *mental retardation* group agreed significantly more (Figure13).

An individual with <term> will probably be able to live independently.

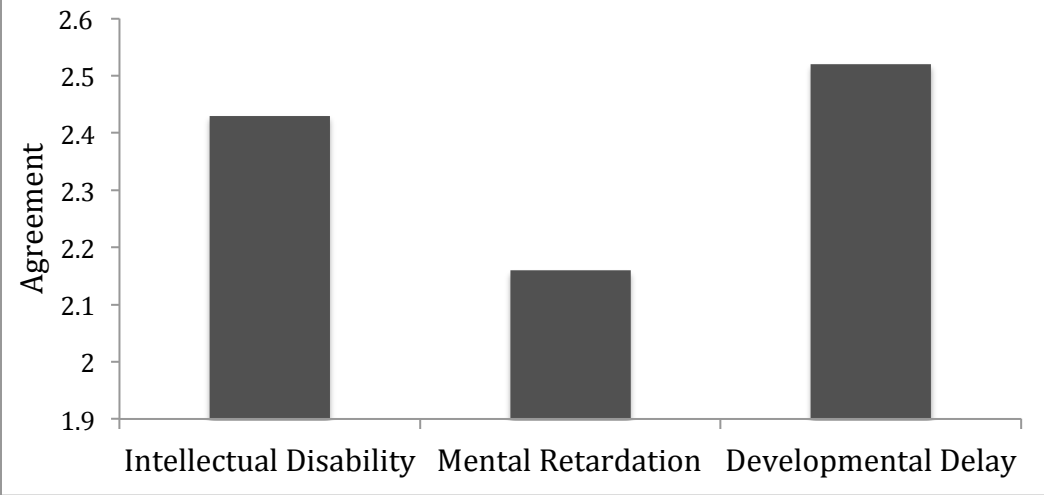
Participants disagreed the strongest with this statement when *mental retardation* was used, $F(2, 425) = 8.37$, $p < .001$, $\eta^2 = .034$. Homogeneity of variance could be assumed since the Levene's test was not significant, $F(2, 425) = 1.14$, $p = .32$. Tukey's test was used for post-hoc pair-wise comparisons. Participants considered it less likely for someone with intellectual disability to live independently when *mental retardation* was used in place of *intellectual disability* or *developmental delay* ($p = .025$; $p < .001$ respectively). $Ms(SDs) = 3.91(1.28)$, $3.50(1.28)$, and $4.13(1.42)$ for *intellectual disability*, *mental retardation* and *developmental delay* respectively. No significant difference was found between *intellectual disability* and *developmental delay* ($p = .37$). On average, participant in all three groups were close to neutral on this statement. However on average, participants in the *intellectual disability* and *developmental*

delay groups disagreed slightly and the participants in the *mental retardation* group agreed slightly (Figure 14).

Autism is a type of <term>.

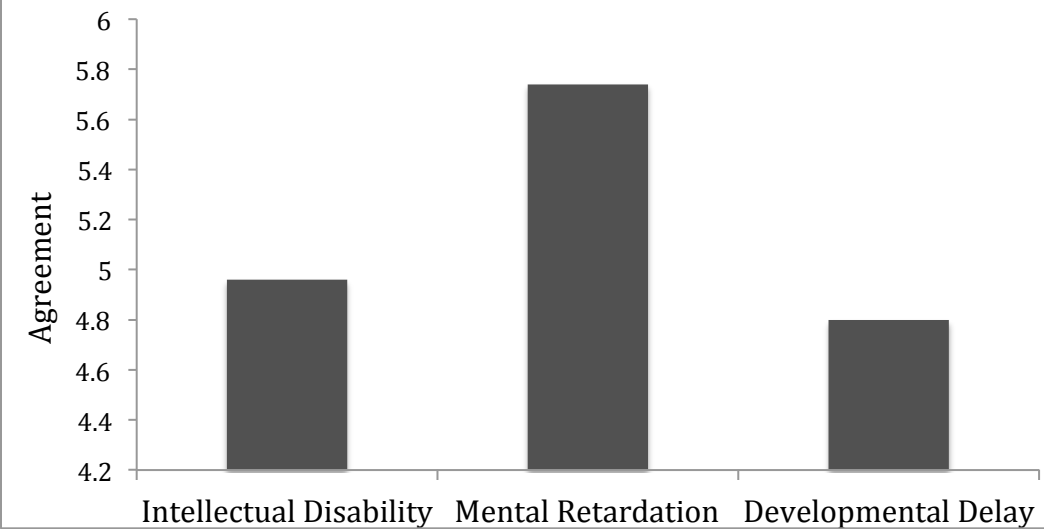
On average participants agreed with this statement when *intellectual disability* or *developmental delay* were used, but not when *mental retardation* was used, $F(2, 425) = 23.36, p < .001, \eta^2 = .10$. Homogeneity of variance could not be assumed since the Levene's test was significant, $F(2, 425) = 7.29, p = .001$. Games-Howell test was used for post-hoc pair-wise comparisons. Participants agreed less strongly that autism is a type of intellectual disability when *mental retardation* was used instead of *intellectual disability* or *developmental delay* ($p < .001$ for both). $Ms(SDs) = 4.81(1.55), 3.70(1.79),$ and $4.80(1.40)$ for *intellectual disability, mental retardation* and *developmental delay* respectively. No significant difference was found between *intellectual disability* and *developmental delay* ($p > .99$). On average, participants in the *intellectual disability* and *developmental delay* groups agreed with this statement, but participants in the *mental retardation* group disagreed with this statement (Figure 15).

Figure 9
Intelligence will be similar to peers as an adult.



Note: A significant difference was only seen between *mental retardation* and *developmental delay* ($p = .020$). No significant difference was found between *intellectual disability* and *mental retardation* or *developmental delay* ($p = .14$ and $p = .81$ respectively).

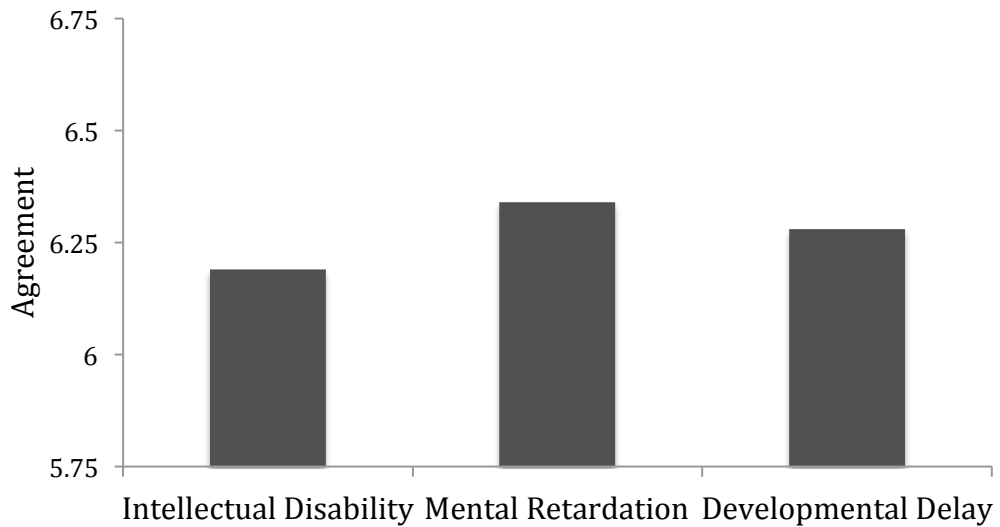
Figure 10
<Term> is a permanent state.



Note: A significant difference was seen between *mental retardation* and the other two terms ($p < .001$). No significant difference was found between *intellectual disability* and *developmental delay* ($p = .62$).

Figure 11

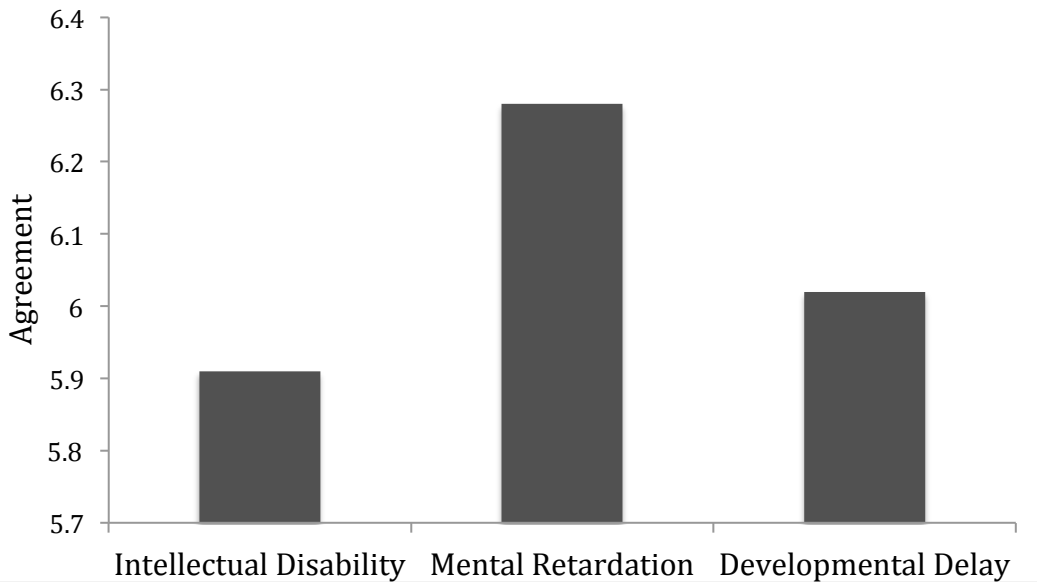
An individual with <term> would need extra help in school.



Note: The term used did not have a significant effect on how much participants agreed with this statement ($p = .29$).

Figure 12

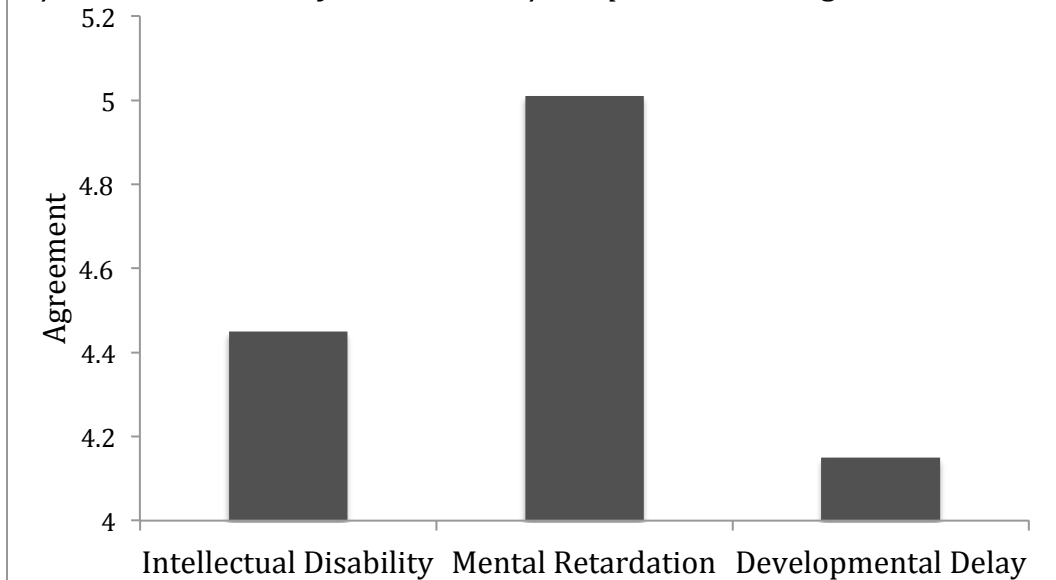
An individual with <term> will likely have learning disabilities.



Note: A significant difference was seen between *mental retardation* and the other two terms ($p = .002$ [*intellectual disability*]; $p < .05$ [*developmental delay*]). No significant difference was found between *intellectual disability* and *developmental delay* ($p = .56$).

Figure 13

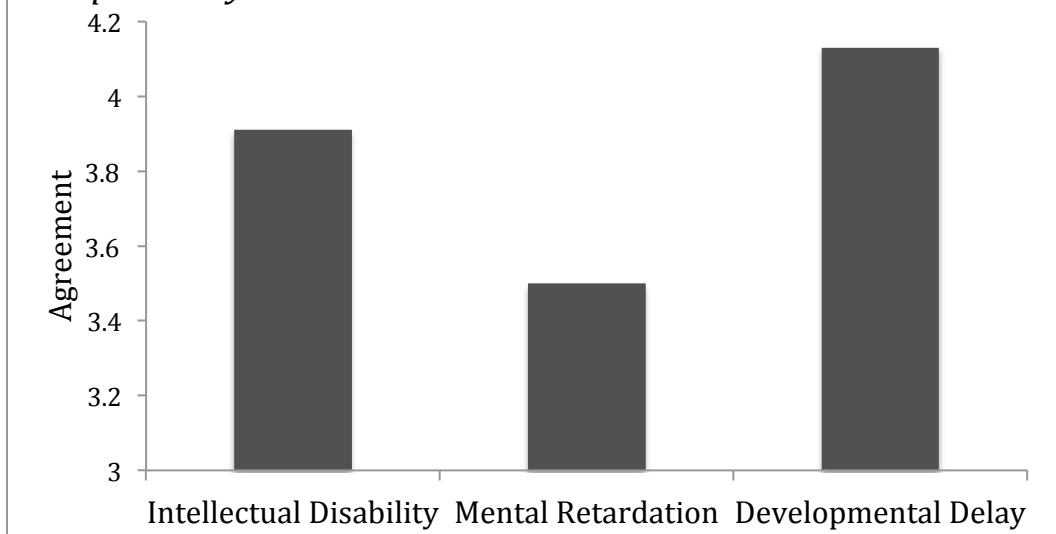
S/he will most likely live with his/her parents through adulthood.



Note: Participants agreed significantly more for *mental retardation* than for *intellectual disability* or *developmental delay* ($p = .001$; $p < .001$ respectively). No significant difference was found between *intellectual disability* and *developmental delay* ($p = .17$).

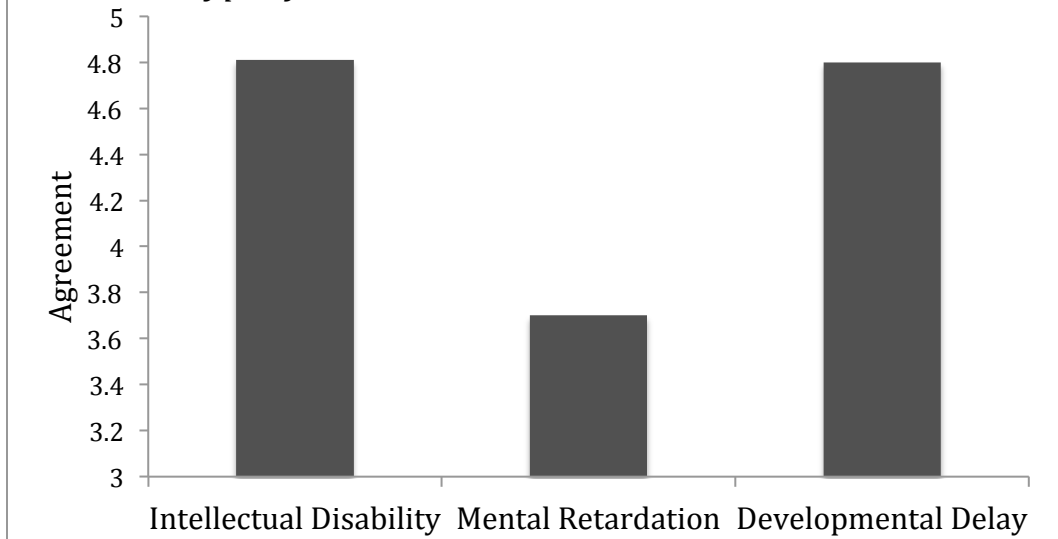
Figure 14:

An individual with <term> will probably be able to live independently.



Note: Participants agreed significantly less for *mental retardation* than for *intellectual disability* or *developmental delay* ($p = .025$; $p < .001$ respectively). No significant difference was found between *intellectual disability* and *developmental delay* ($p = .37$).

Figure 15
Autism is a type of <term>.



Note: Participants agreed significantly less for *mental retardation* than for *intellectual disability* or *developmental delay* ($p < .001$ for both). No significant difference was found between *intellectual disability* and *developmental delay* ($p > .99$).

DISCUSSION

The purpose of the current study was to obtain more information about how terms for intellectual disability were interpreted and stigmatized by participants. Two different scales were used to shed light on how participants interpret terms for intellectual disability. The developed stigma scale was used to evaluate how much stigma participants associated with the concept of intellectual disability, and the semantic differential technique was used to evaluate how much stigma participants associated with the terms themselves. The term used did not significantly change scores on the developed stigma scale, or the evaluation or potency scores of the semantic differential technique. This suggests that the term used (in the context of a generic definition of intellectual disability) did not influence the amount of stigma that participants associated with intellectual disability (according to the developed stigma scale), how negative their feelings were toward the term used (evaluation factor of the semantic differential technique), or how potent their feelings were toward the term used (potency factor of the semantic differential technique). The activity factor was the only scale that showed a significant difference depending on which term was used. On average, all three terms evoked results on the inactive side of the scale, but *developmental delay* was viewed as significantly less active than *intellectual disability*. This may be because the word *delay* inherently implies a slower than usual process. Because the potency factor scale did not have internal reliability and the activity factor was very close to the cutoff for a reliable scale, results from these two scales should be interpreted with caution.

The semantic differential technique findings are consistent with the prior study by Panek & Smith, (2005), which found that there was no significant difference between the evaluation, potency or activity factors of *intellectually disabled, mentally retarded* and *developmental disability*. It was expected that the 9 years that have passed since that study, having a national pool of participants, and consistently using the noun form of the term in the current study may have produced different results. Since this study was performed Rosa's law was passed in the United States, and the movement to use *intellectual disability* in place of *mental retardation* gained momentum. It was expected that this crucial time period in the disability rights movement would have resulted in different results showing a more positive semantic differential technique evaluation factor score in the current study. However, the current study had similar findings for the evaluation and potency factors. The difference in activity factor results in this prior study and the current study can likely be explained by the fact that the current study used *developmental delay* instead of *developmental disability*. The prior study used *developmental disability* and did not find any significant difference in activity factor scores between the *developmental disability* and *intellectual disability*. The present study used *developmental delay* and found that, on average, participants thought of *developmental delay* as less active than *intellectual disability*. This difference may explain why the results of the current study are different. Overall the results from the semantic differential technique and developed stigma scale analyses both demonstrate that the term used to describe intellectual disability has an insignificant impact on

participants' attitudes toward intellectual disability, but they do not interpret the terms synonymously as demonstrated by the definition questions. This suggests that there were other factors that more strongly influenced how much stigma participants associated with intellectual disability.

The current study did find other variables that appear to correlate with participant's stigma scores. A participant's social dominance orientation, familiarity with someone with intellectual disability, the importance of religion and age were all found to influence the amount of stigma a participant associated with the description of intellectual disability. However, when controlling for the other factors that influence a participant's stigma score, age was not a significant predictor. Participants' social dominance orientation, familiarity with someone with intellectual disability and the importance they placed on religion accounted for 32.7% of the variance in participants' stigma scores. This suggests that there are likely many other factors that influence how much stigma people associate with individuals with intellectual disability.

The strongest predictor of a high stigma score in the current study was the participant's score on the social dominance orientation scale. This means that people who do not favor social equality are more likely to stigmatize intellectual disability, which makes intuitive sense because these individuals would be less likely to think that individuals with intellectual disability deserve equal treatment. As expected, these results are similar to the Bizer, et.al., (2012) study that demonstrated the correlation between high social dominance orientation scores and stigamatization of mental illness.

The next strongest predictor of how much stigma the participant associated with the description of intellectual disability was whether or not they knew someone with intellectual disability. This also intuitively makes sense because individuals who have relationships with someone with intellectual disability are more likely to see the value of the relationship. It is also possible that individuals who stigmatize intellectual disability less are simply more likely to be open to have relationships with those with intellectual disability.

The importance of religion was also found to be a significant predictor of the amount of stigma participants associated with the description of intellectual disability. This did not predict their stigma score as strongly as knowing someone with intellectual disability or their social dominance orientation score. On average, the more important religion was to a participant, the lower their stigma score. This may be because many religious teachings encourage compassion toward others.

Age was only found to significantly influence a participant's stigma score when evaluated independently from other factors. This is likely because age correlates with one of the factors that truly predicts stigma (e.g. older individuals may be more likely to have met someone with intellectual disability).

How many children a participant had, their income level and their education level did not have a significant impact on how much they stigmatized intellectual disability. These analyses were not mentioned in prior studies, however, a significant correlation between these demographics and stigma scores was not expected.

Even though the term used did not influence stigma scale scores, it did evoke significant differences in how participants defined different aspects of intellectual disability. The only definition question that did not elicit a significant difference among the different terms for intellectual disability was whether or not individuals with intellectual disability would need extra help in school. It was found that this was communicated equally by all three terms because there was no significant difference in how strongly participants agreed with this, on average. Participants in the three different groups tended to be close to each other on the other definition scales, but tended to agree or disagree significantly more strongly when *mental retardation* was used. In general *mental retardation* communicated more clearly the permanence of intellectual disability, that it is a disability associated with learning, and that these individuals are less likely to live independently. There was no significant difference between how participants defined *intellectual disability* and *developmental delay*, which was unexpected. Debates in the literature suggest that *developmental delay* is interpreted by many as something that children can recover from as they age (Fisch, 2011). The results of the current study suggest that participants did not define these terms differently in the context of a definition.

Even though *mental retardation* did not arouse a significantly different response on the developed stigma scale or on the semantic differential technique, it did evoke significantly different results on the definition-oriented questions that all suggested that *mental retardation* implies a lower level of functioning/ability. This in itself could indicate that *mental retardation* does

illicit more negative feelings from participants. It is possible that participants felt guilty answering questions on the stigma scale truthfully because those questions were more apparently making a value judgment about people with intellectual disabilities.

Overall results of the present study suggest that in some ways, the rose does smell as sweet, and in some ways it does not. That is, the results suggest that the term used to describe intellectual disability does not have a significant effect on how participants answer stigma and overt questions about their attitudes. However, it does have an impact on how the definition is understood, which may suggest that *mental retardation* is a more stigmatized term after all. These data suggest that perhaps the shift to use *intellectual disability* instead of *mental retardation* does not reduce the stigma associated with intellectual disability, but that the various aspects of the definition of intellectual disability are communicated more strongly when using the term *mental retardation*. These nuances may or may not be a reflection of the stigmatization of *mental retardation*. For this reason, some providers may choose to continue to use *mental retardation*. However, this does not take into account the fact that on average responses for *intellectual disability*, *mental retardation*, and *developmental delay* did tend to be on the same side of the likert scale (i.e. for all but one definition statement, the average scores would either be in agreement with the statement for all terms, or be in disagreement with the statement for all terms). Genetic counselors and other healthcare providers can use this information when deciding what term to use. These results should also be

considered in conjunction with previous studies that show that many parents oppose the use of *mental retardation* (Nash, et. al., 2012). In addition, it is natural that as *intellectual disability* becomes more commonly used that the definitions and attitudes associated with it will change. These and many other factors should be considered when deciding what term for intellectual disability to use with patients.

Limitations

Because the survey only mentioned one term for intellectual disability throughout, answers to some of the questions may have been inconsistent. For example, when asked if they knew someone with intellectual disability, participants were asked using the term that was assigned to them at the beginning of the survey (i.e. the participants that were assigned to the *developmental delay* version of the survey would have been asked if they knew anyone with developmental delay instead). This means that participants in the different groups may have been thinking of people with different kinds of conditions when asked this question. Regardless, results from this question show that if participants know someone that they would describe using one of these three terms, they are less likely to stigmatize individuals with intellectual disability.

In general, the demographics of the participants were quite varied. The exception is that the vast majority of participants identified racially as

White/Caucasian. Therefore the results of this study may not be generalizable to reflect the opinions and perceptions of the broader racially diverse population.

Caution should be used when extrapolating results of the current study to the general population. Amazon Mechanical Turk participants tend to be younger, overeducated, underemployed, less religious, and more liberal when compared to the general population. Asians are likely overrepresented and African Americans and Hispanics are likely underrepresented (Paolacci & Chandler, 2014). Because of these differences, it is difficult to speculate how different the attitudes of the general population would be compared to the present study's participants.

Future Studies

The results of the current study were able to ascertain only about a third of the variation in the association of stigma with intellectual disability. Further research in this area is needed to determine what other personality traits and experiences affect a participant's attitudes toward intellectual disability.

Social and political attitudes are constantly changing. Therefore longitudinal research evaluating attitudes toward intellectual disability is recommended.

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APPENDICES

APPENDIX A

DEMOGRAPHIC QUESTIONS

1. What is your age in years?
2. What is your gender?
3. What is your highest level of education?
4. How many children do you have (not including a current pregnancy if you are pregnant)?
5. Do you know anyone with <term>? If you are not sure, please answer yes and indicate why you are unsure in the next question.
6. Is English your first language? If not, please enter your first language.
7. How many years have you been speaking English? If you do not speak English or you have been speaking English for under a year, please enter "0".
8. What is your household's yearly income?
9. Which race(s) best describe you?
10. How important is religion to you?

APPENDIX B

STIGMA SCALE STATEMENTS

1. An individual with <term> will probably have difficulty finding employment and holding down a job.
2. A person with <term> will likely lead a sad life.
3. Someone with <term> could have an active dating life.
4. My children (or future children) would be able to be friends with a person with <term>.
5. If I (or my partner or surrogate) was 10 weeks pregnant and we knew that the child would have <term>, my partner and I would likely terminate the pregnancy.
6. I could have a meaningful friendship with an individual with <term>.
7. I would have difficulty coping if my child had <term>.
8. Even though people with <term> behave in funny ways, it is wrong to laugh about them.
9. It would be foolish for someone to marry a person with <term>.
10. All people with <term> should be prevented from having children by a painless operation.
11. If our hospitals had enough well trained doctors, nurses, and aides, many individuals with <term> would gain the necessary skills to live independently.
12. People with <term> come from homes where the parents took little interest in their children.

13. Children with <term> should never be taught in the same classrooms as typical children.
14. Adults with <term> are in many ways like children.
15. Many people with <term> make wholesome friendships with others who **have** <term>.
16. Many people with <term> make wholesome friendships with others who **do not have** <term>.
17. Many people with <term> are capable of skilled labor.
18. An individual with <term> is going to be a failure in life.
19. Anyone with <term> should not be allowed to vote.
20. Everyone with <term> should be in a facility surrounded by a high fence and guards.
21. Regardless of how you look at it, people with <term> are no longer really human.
22. Individuals with <term> did something to cause it.
23. A person with <term> would be able to take care of his/her own finances.
24. An individual with <term> is inspirational.
25. A person with <term> will be a burden on teachers and health care professionals.

APPENDIX C

SOCIAL DOMINANCE ORIENTATION STATEMENTS

1. Some groups of people are simply inferior to other groups.
2. In getting what you want, it is sometimes necessary to use force against other groups.
3. It's okay if some groups have more of a chance in life than others.
4. To get ahead in life, it is sometimes necessary to step on other groups.
5. If certain groups stayed in their place, we would have fewer problems.
6. It's probably a good thing that certain groups are at the top and other groups are at the bottom.
7. Inferior groups should stay in their place.
8. Sometimes other groups must be kept in their place.
9. It would be good if groups could be equal.
10. Group equality should be our ideal.
11. All groups should be given an equal chance in life.
12. We should do what we can to equalize conditions for different groups.
13. Increased social equality is ideal.
14. We would have fewer problems if we treated people more equally.
15. We should strive to make incomes as equal as possible.
16. No one group should dominate in society.

APPENDIX D

DEFINITION STATEMENTS

1. Intelligence will be similar to peers as an adult.
2. <Term> is a permanent state.
3. An individual with <term> would need extra help in school.
4. An individual with <term> will likely have learning disabilities.
5. S/he will most likely live with his/her parents through adulthood.
6. An individual with intellectual disability will probably be able to live independently.
7. Autism is a type of intellectual disability.

APPENDIX E
CONSENT FORM

“Dear Participant:

You are being asked to participate in a research project conducted by Matt Hall, a graduate student at CSU Stanislaus, in partial fulfillment of the requirements for a Master’s degree in Genetic Counseling. Through this research, we hope to learn more about how the public interprets a commonly used description of a condition. If you decide to volunteer, you will be asked to complete an online survey of 30-35 multiple choice questions and a few open-ended questions. The survey should take 15-20 minutes to complete.

There are no known risks to you for your participation in this study. Precautions will be followed to ensure the privacy of all participants and the confidentiality of gathered information. Data will be coded, de-identified, and stored in a password-protected computer in a secure location. The information collected will be protected from all inappropriate disclosure under the law. There is no cost to you beyond the time and effort required to complete the procedures described above. Your participation is voluntary and refusal to participate in this study will not result in penalty or loss of benefits. You may also withdraw from the study at any time without penalty or loss of benefits.

Although you may not benefit directly by participating in this study, data collected from this study may benefit the larger community by exploring how providers can communicate most effectively with their patients and family

members. The information gathered from this study may provide opportunities to further assist the development of patient educational materials.

If you agree to participate in this research, please indicate this decision by continuing on and completing the following survey. By completing the survey, you have consented to and agreed to participate in the research. If you have any questions about this research project please contact me, Matt Hall, at (630) 291-7133 or mhall3@csustan.edu, or my faculty sponsor, Janey Youngblom, at (209) 667-3487. If you have any questions regarding your rights and participation as a research subject, please contact the Campus Compliance Officer by phone (209) 667-3794 or email IRBAdmin@csustan.edu.

All survey responses are kept anonymous. Please click on the arrow below to begin.

Sincerely,

Matt Hall

Genetic Counseling Student

California State University, Stanislaus”