2023

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Monica Abdul-Chani
University of Alabama at Birmingham

Recommended Citation

Abdul-Chani, Monica, "Rates, Presentation, & Effects Of Public Autism Stigma" (2023). *All ETDs from UAB*. 3469.
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RATES, PRESENTATION, & EFFECTS OF PUBLIC AUTISM STIGMA

by

MONICA MARIA ABDUL-CHANI

SARAH E. O'KELLEY, COMMITTEE CHAIR
ANNE E. BRISENDINE
EDWIN W. COOK, III
MICHAEL G. CROWE
KATHARINE E. ZUCKERMN

A DISSERTATION

Submitted to the graduate faculty of The University of Alabama at Birmingham,
in partial fulfillment of the requirements for the degree of
Doctor of Philosophy

BIRMINGHAM, ALABAMA

2023

RATES, PRESENTATION, & EFFECTS OF PUBLIC AUTISM STIGMA

MONICA MARIA ABDUL-CHANI

MEDICAL/CLINICAL PSYCHOLOGY

ABSTRACT

Limited availability of resources regarding developmental issues, health literacy, linguistic-sensitivity (i.e., use of linguistically appropriate resources and measures), structural barriers (i.e., appointment length, transportation), and cultural values and beliefs are commonly-cited barriers in identifying Latine autistic children. Stigma may also play a role, as it is negatively related to both knowledge/awareness within ASD and to acculturation in other disorders (i.e., HIV). Stigma can have detrimental, pervasive effects on daily living for those stigmatized and their families. Limited research examined the rate, presentation, and effect of ASD stigma within the Latine community, and all available studies explored stigma as reported by Latine parents of autistic children using explicit measures. The present studies elucidate how explicit ASD stigma presents in Latine populations. The first paper examines rates of implicit attitudes towards disability across sociodemographic variables. The second paper addresses explicit attitudes and beliefs towards ASD within the Latine community, as well as the effect on social support and inclusion. The present studies provide information to guide interventions on public awareness and knowledge of ASD in a linguistically and culturally sensitive manner to reduce stigma, assist families of autistic individuals, and utilize strengths of collectivistic culture to increase knowledge of ASD and inclusivity.

Keywords: autism, stigma, disability, implicit attitudes, Latine

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NOTE ON LANGUAGE

Person-First v. Identity-First

Person-first language is characterized by placing a personification term before a diagnosis (i.e., person with autism, child with autism, etc.). Identity-first language is characterized by a facet of an individual's identity being listed before a personification term (i.e., autistic person, autistic child). There is ongoing discussion about the use of these terms when speaking about the autism community. Studies have shown a majority of autistic individuals prefer identity-first language (Taboas, Doepke, & Zimmerman, 2023). Therefore, the current studies will utilize identity-first language.

Latino/a v. Latinx v. Latine v. Hispanic

There is ongoing discussion about the use of these terms and their cultural- and linguistic-sensitivity. For the purpose of being as inclusive as possible and easily accessible across languages, the term "Latine" is used throughout the current studies. Use of any other terms is reflective of participant responses or terminology used in cited articles.

"Abled" & "Disabled"

Paper 1 utilizes data from the Disability Attitudes – Implicit Association Test (DA-IAT). Terms used to describe individuals with a disability versus those without disabilities in the current study follow the terminology used in the methodology for the DA-IAT. Therefore, there will be frequent descriptions of the aforementioned populations as "abled" and "disabled," as these are the terms used in the DA-IAT.

INTRODUCTION

Autism Spectrum Disorder

The most recent definition of Autism Spectrum Disorder (ASD) describes the diagnosis as a neurodevelopmental disorder characterized by impairments in social communication and the presence of stereotyped behaviors, interests, and activities (American Psychiatric Association [APA], 2013). In order to be diagnosed, symptoms must have been present in early life and cause significant impairment across areas of daily functioning, and the symptoms may range in severity (5th ed.; *DSM–5*; APA, 2013). Recent studies estimate 1 in 36 children in the United States (U.S.) meet criteria for a diagnosis of ASD, with an average age of diagnosis of approximately 4 years old (Maenner, Warren, Baio, Robinson Williams, et al., 2023). Despite the finding that many parents of autistic children first report their concerns around age 2 years (Kozlowski, Matson, Horovitz, Worley & Neal, 2011), children often receive official diagnoses at later ages.

Moreover, disparities exist among autistic individuals and their families (World Health Organization [WHO], 2017), especially among those from traditionally underrepresented and underserved groups (i.e., Black/African American, Asian, Latine; Durkin, Maenner, Baio, Christensen, Daniels et al., 2017; Magaña & Smith, 2013). This is especially true among Latine populations, as research has shown that Latine children are diagnosed with ASD at significantly later ages than African American and White children (Mandell, Listerud, Levy, & Pinto-Martin, 2002). Additionally, Latine children aged 8 years old were also significantly less likely to receive an ASD diagnosis (10.1 per

1,000) when compared to non-Latine White (15.5 per 1,000) and non-Latine black children (13.2 per 1,000; Christensen et al., 2016). Furthermore, Latine autistic children have high rates of misdiagnosis (Magaña, Lopez, Aguinaga, & Morton, 2013; Mandell, Listerud, Levy, & Pinto-Martin 2002; Overton, Fielding, & Garcia de Alba, 2007; Wiggins, Baio, & Rice, 2006) and are more likely to be under-identified (Mandell, Wiggins, Arnstein Carpenter, Daniels et al., 2009; Pedersen, Pettygrove, Meaney, Mancilla et al., 2012). These disparities highlight pervasive, systemic difficulty in identifying Latine autistic children and affect diagnosis-specific early intervention. However, recent surveillance data found, for the first time, that non-Hispanic White children and children of two or more races have lower prevalence rates compared to other racioethnic groups (Maenner et al., 2023). Etiologies and implications of these findings are part of an ongoing discussion within the field.

Barriers to Care in Autistic Latine Populations

Historically, estimates suggested that 1 in every 98 Latine children aged 8 years old met diagnostic criteria for ASD (Christensen et al., 2016) and Latine children, foreign-born children, and children born to foreign mothers tend to receive an ASD diagnosis at significantly later ages than other racioethnic groups (Valicenti-McDermott, Hottinger, Seijo, & Shulman, 2012). This suggests increased difficulty receiving a diagnosis for immigrant families and those with limited English proficiency. Moreover, Latine and/or Spanish-speaking children are less likely to be screened appropriately for ASD, identified as needing evaluation, and/or evaluated for the diagnosis (Windham, Smith, Rosen, Anderson et al., 2014). Once referred for evaluation, Latine families continue to face disparities in receiving a diagnosis, as Latine children with more severe symptom presentations are more likely to receive an ASD diagnosis than those who present mildly. Further, providers have reported greater difficulty in identifying ASD presentation within Latine children due to language barriers (Zuckerman, Mattox, Donelan, Batbayar et al., 2013). This disparity persists post-diagnosis as families experience difficulty in accessing intervention, with Latine children receiving less intervention compared to White children with similar severity (Magaña, Parish, & Son, 2016). Therefore, research assessing barriers to ASD care for Latine families demonstrates a variety of factors that influence recognition, evaluation, diagnosis, and treatment across stakeholders.

Frequently cited barriers to seeking ASD-specific evaluation and intervention among Latine groups include limited access to resources regarding developmental issues, general health literacy, linguistic-sensitivity (i.e., use of linguistically appropriate resources, screening and diagnostic measures), structural barriers (i.e., length of appointment, transportation), and cultural values and beliefs (Troxel, Linas, Jacobstein, Biel et al., 2018). Acculturation may also play a role, as Latine individuals who were highly acculturated to U.S. mainstream culture and reported English proficiency indicated ease in accessing care, understanding ASD, and receiving intervention (Voelkel, LeCroy, Williams, & Holschuh, 2013) in comparison to those who had low acculturation levels. Studies have shown a lack of awareness and knowledge about ASD in Latine populations (Zuckerman, Sinche, Mejia, Cobian et al., 2014a), potentially due to cultural differences or a lack of resources available in Spanish. However, while language, acculturation, and knowledge/awareness about ASD are some of the most commonly cited factors influencing ASD screening, diagnosis, and intervention among Latine populations (Troxel et al., 2018; Voelkel et al., 2013; Zuckerman et al., 2014a), there are also schema in the form of explicit and implicit attitudes – such as stigma – that may play a key role. Specifically, stigma has been shown to be negatively related to knowledge/awareness on an ASD-specific knowledge and stigma measure (Abdul-Chani, 2020), and may have detrimental, pervasive effects on daily living for stigmatized individuals and their families (Alonso, Buron, Rojas-Farreras, de Graaf et al., 2009; Brown, O'Conner, Copeland, Grote, Beach et al., 2010; Corrigan, 2004; Fox, Smith, & Vogt, 2018; Jennings, Cheung, Britt, Goguen et al., 2015; Link, 1982).

Schema & Stigma

Cognitive and social psychology theorists have extensively explored the concept of schema, which is the idea that an individual's conceptualization and experience of the world is formed by a series of abstract mental structures which encode and retrieve information for future use (Bartlett, 1932). As more information is received, new schemas are created and old schemas may be adapted, and this process may occur internally and unknown to the individual (Bartlett, 1932). For example, person schemas are those which focus on other individuals (Baldwin, 1992) and where the person who holds the schema develops their perspective on an individual's appearance, behavior, and personality (Baldwin, 1992). Therefore, schemas affect what one may pay attention to, their conceptualization of the world and others, and the interpretation of new information (Aosved, Long, & Voller, 2009). While schemas may be helpful in thinking about and interpreting new information quickly, theories postulate that an individual's explicit and implicit attitudes, behavior, and beliefs may be influenced by their schema. Thus, negative attitudes, such as prejudice, stereotyping, and discrimination may develop as a result of schemas, and these negative attitudes may also impact or foster stigma.

Stigma is the set of explicit or implicit negative attitudes towards individuals with a characteristic deemed “shameful” by society (Corrigan, 2000; Corrigan, Roe, & Tsang, 2011; Mukolo, Heflinger, & Wallston, 2010). The term “stigma” is a general term regarding different sets of negative attitudes. The term public stigma describes the set of negative attitudes held towards stigmatized individuals by the general public or community (Corrigan & Rao, 2012; Vogel, Bitman, Hammer, & Wade, 2013). Public stigma is associated with poor employment rates (Link, 1982), limited access to mental health services (Corrigan, 2004; Brown et al., 2010; Fox, Smith, & Vogt, 2018; Jennings et al., 2015), and poorer quality of life (Alonso et al., 2009) among those who are stigmatized. While public stigma has been studied in depth with regards to its effects on mental illness and treatment seeking behaviors (Alonso et al., 2009; Brown et al., 2010; Fox, Smith, & Vogt, 2018; Jennings et al., 2015; Kowalski & Peipert, 2019; Pedersen & Paves, 2014), a paucity of research has explored the aspects of stigma regarding disability as a whole (VanPuymbrouck, Friedman, & Feldner, 2020; Wilson & Scior, 2015). Further, limited research has explored stigma within developmental disabilities such as ASD (Ali, Hassiotis, Strydom, & King, 2012; Ali, Kock, Molteno, Mfiki, King, & Strydom, 2015; Ali, King, Strydom, & Hassiotis, 2016; Mitter, Ali, & Scior, 2019; Werner & Shulman, 2015).

ASD Stigma Across Cultures

Studies have suggested relatively adequate levels of ASD knowledge and low levels of ASD stigma among university students and the public (Stronach, Wiegand, & Mentz, 2019). However, research has also shown higher levels of perceived stigmatization among caregivers of autistic children compared to those with intellectual disability or physical disabilities (Werner & Shulman, 2013). Additionally, parents of autistic children report that severity of symptom presentation has been associated with stigma (Zuckerman, Lindly, Reyes, Chavez et al., 2018), supporting the notion that children with higher rates of expressed autism-related behaviors are more stigmatized (Kinnear, Link, Ballan, & Fischbach, 2016). Stigmatization of the entire family, including the autistic individual, has been commonly reported (Gray, 1993; Gray, 2002), potentially resulting in social withdrawal, greater isolation, and discomfort seeking assistance as families begin to fear the negative reactions they may face in general public and community (Mitter, Ali, & Scior, 2019). In fact, families of autistic children who reported higher rates of stigmatization also endorsed greater levels of unmet needs for ASD-specific care (Zuckerman et al., 2018). Consequently, ASD stigma affects not only the individual with the diagnosis, but also their family, their relationship with the general community, and their access to services.

It has been noted that stigma may differ across cultures (Dietrich, Beck, Bujantugs, Kenzine, Matschinger, &Angermeyer, 2004; Griffiths, Nakane, Christensen, Yoskoioka et al., 2006; Scior, Potts, & Furnham, 2013). This may be especially true in traditionally collectivistic cultures (e.g., Hispanic/Latine, Asian), which highly value community perception and inclusion (Fung & Tsang, 2010; Kramer, Kwong, Lee, & Chung, 2002; Ng, 1997). Little research has examined the rate, presentation, and effect of various forms of ASD stigma within the Latine community (Blanche, Diaz, Barretto, & Cermak, 2015; Cohen & Miguel, 2018; Gordillo, Chu, & Long, 2020; Zuckerman et al., 2018). Latine parents of autistic children consistently report experiencing high levels of stigma from family and general community members (Blanche et al., 2015; Cohen &

Miguel, 2018). Latine limited English proficiency (LEP) parents of autistic children have reported higher rates of stigma compared to their English-proficient counterparts (Zuckerman et al., 2018). Moreover, Latine parents report negative experiences such as others questioning their parenting skills and criticizing their child’s behavior (Cohen & Miguel, 2018). In response, many parents reported attempting to educate their family members and general community about the ASD diagnosis because of their belief that stigmatization was a result of a lack of awareness about the disorder. Parents also reported a negative impact of culturally-rooted values such as being “bien educado” or “well educated” in social interaction and proper social behavior (Cohen & Miguel, 2018), an area in which autistic individuals demonstrate difficulty. Consequently, this cultural expectation coupled with the symptomology of ASD may increase stigmatization for the family. Latine parents who reported personal experience with ASD stigma also endorsed high levels of anger and discomfort as well as using strategies to avoid public shaming such as not telling others about difficulties to avoid gossip and tickling their child when the child began to laugh randomly so that the behavior did not seem odd (Blanche et al., 2015). These approaches to cope with public stigma can result in self- and social isolation. Moreover, Latine mothers of autistic children feared rejection and demonstrated internalized self-blame after their child was diagnosed. Many mothers reported they rejected the diagnosis given to their child in hopes that they and their child would be more likely to be accepted by the general community (Gordillo et al., 2020).

While few studies have focused solely on understanding the presentation and rates of stigma within the Latine ASD community, available studies explored stigma as reported by Latine parents of autistic children. However, studies examining general developmental disability stigma have shown that parents of autistic children or children with a developmental disability report high levels of stigmatization by the general community but the general community reports lower levels of stigmatization (Abdul-Chani, Moreno, Reeder, Zuckerman, & Lindly, 2021). Consequently, a gap between those stigmatized and the public perception of stigmatization exists. Furthermore, to the authors' collective knowledge no literature exists exploring public stigma and its effects on social support as described by members of the Latine community who are not parents of autistic children. Moreover, research examining ASD stigma within the Latine community has used questionnaires or qualitative interviews, which has resulted only in understanding of explicit measures of stigma (Blanche et al., 2015; Cohen & Miguel, 2018; Zuckerman et al., 2018) and has not addressed the impact of implicit attitudes within stigma.

Implicit Attitudes in Disability

Schema may also affect implicit associations or biases – the internal attitudes and beliefs of an individual (Bartlett, 1932; Project Implicit, 2020) – which may not be accurately measured using self-report questionnaires due to social desirability when responding on explicit measures. Current literature on implicit attitudes in disability is limited, but there has been an increased interest in recent years (VanPuymbrouck, Friedman, & Feldner, 2020; Wilson & Scior, 2015). Using the implicit association test (IAT), these studies have addressed implicit attitudes in populations such as health care providers and the general population, with both finding implicit attitudes to be more discrepant compared to explicitly-rated attitudes (VanPuymbrouck, Friedman, & Feldner, 2020; Wilson & Scior, 2015). Specifically, individuals are likely to respond more favorably on explicitly-reported measures that elicit information regarding external attitudes compared to responses on implicit measures assessing internal attitudes.

Utilizing the publicly-available dataset from Project Implicit to explore healthcare provider perspectives regarding disability, results suggested that older age, being nondisabled, identifying as male, having no family members or friends with disabilities, and identifying as more conservative resulted in higher implicit negative associations regarding disability. While White providers had lower explicit bias compared to non-White providers, when compared to indigenous or Latine providers they had higher implicit bias (VanPuymbrouck, Friedman, & Feldner, 2020). Older age, being nondisabled, identifying as male, having no family members or friends with disabilities, and identifying as more conservative remained factors associated with significantly higher negative implicit associations. Interestingly, results also suggested that identifying as White resulted in higher negative implicit bias regarding disability compared to all other groups except East Asian (VanPuymbrouck, Friedman, & Feldner, 2020). However, results from a general population study suggested contradictory results with gender, education, and contact with individuals with disabilities resulting in no group differences in implicit association (Wilson & Scior, 2015).

These mixed findings in an understudied area suggest need for further exploration. Moreover, there are only a few available studies exploring implicit associations towards disability, and these studies utilized different populations and methodologies. Therefore, more research is needed to begin to understand implicit attitudes towards individuals with disability, especially within the general population and across sociodemographic variables.

THE CURRENT STUDIES

The current studies aim to fill several gaps in the literature regarding explicit and implicit attitudes towards disability and ASD. The goals include understanding the presentation of implicit attitudes regarding disability across sociodemographic characteristics, and understanding explicit public stigma towards autistic children and their families and its potential impact on social support within the Latine community.

There have been mixed results on rates of explicit public ASD stigma within the general population, with some studies suggesting relatively adequate levels of ASD knowledge and low levels of ASD stigma (Stronach, Wiegand, & Mentz, 2019). However, this may be due to measures focused on self-reported explicit attitudes rather than implicit attitudes. Explicitly-reported stigma towards developmental disabilities such as ASD has been shown to differ as a function of sociodemographic group (Blanche et al., 2015; Cohen & Miguel, 2018; Zuckerman et al., 2018). Yet, there is a paucity of research exploring explicit public stigma and its effects within the Latine population, a group traditionally considered to be from a collectivistic culture which places high importance on community perception and inclusion (Fung & Tsang, 2010; Kramer et al., 2002; Ng, 1997).

Similarly, most research on negative attitudes in disability has focused solely on self-report of explicit attitudes (VanPuymbrouck, Friedman, & Feldner, 2020; Wilson & Scior, 2015), creating a dearth of literature aimed at understanding implicit attitudes.

Research has noted the discrepancy between explicit and implicit attitudes towards disability amongst health care providers (VanPuymbrouck, Friedman, & Feldner, 2020), but this has not been explored in the general population and across specific sociodemographic groups. Consequently, very little is known about the effects of sociodemographic variables, including race and ethnicity as well as familiarity with disability, on implicit attitudes towards disability.

Therefore, the first paper examines differential rates of implicit associations (i.e., favorable or unfavorable) towards disability across sociodemographic variables. While the study is not ASD-specific, it is a starting point in a much-needed line of research that can inform future studies on implicit attitudes towards ASD. Additionally, it will provide an understanding of how implicit attitudes present across sociodemographic variables, such as self-identified racial/ethnic groups and familiarity with disability – a severely understudied area. The second paper addresses the explicit attitudes and beliefs towards ASD within the Latine community to provide insight into the general understanding of ASD in this population. Additionally, the second paper also details the effect of these beliefs about ASD on social support and community inclusion in the Latine public. Understanding the effects that explicit stigma may have on families of autistic children, as reported by Latine community members, may elucidate areas for intervention to increase knowledge and improve understanding, decrease stigma, and result in improved and targeted strategies for assisting families.

SPECIFIC AIMS

Aim 1

Test whether implicit attitudes towards disability differ across sociodemographic variables and self-reported explicit attitudes, and explore potentially predictive factors for implicit attitudes.

Hypothesis 1.1

Based on previous literature suggesting differential rates of implicit bias across racial/ethnic and cultural groups, it is predicted that Latine participants will demonstrate lower rates of implicit negative associations towards disability, followed by Black/African American participants, and then White participants.

Hypothesis 1.2

Based on previous research suggesting lower levels of implicit negative associations among individuals who know someone with a disability, it is predicted that individuals who have a disability and/or know someone with a disability will have lower rates of implicit negative associations compared to individuals who do not have and/or know a person who has a disability.

Hypothesis 1.3a

Based on previous research suggesting differential rates of reporting explicit attitudes compared to measured implicit associations, it is hypothesized that explicit attitudes will be reported as neutral prior to DA-IAT completion and measured implicit associations will be higher showing preference towards abled individuals.

Hypothesis 1.3b

Based on previous research suggesting differential rates of reporting explicit attitudes compared to measured implicit associations across race/ethnicity, it is hypothesized that the relationship between explicit and implicit attitudes will differ across racioethnic groups. Specifically, it is predicted the discrepancy will be strongest for White participants – indicating that these participants reported neutrality explicitly but demonstrated high implicit preference towards abled individuals – followed by African American/Black and then Latine participants.

Hypothesis 1.4

Based on previous research with mixed results with regard to implicit negative associations across sociodemographic variables, but the strong results from Project Implicit regarding health care provider biases towards disability, it is predicted that older age, White racial identity, non-Latine ethnic identity, male sex, lower education, and stronger conservativism will result in higher implicit negative associations among the general population.

Additionally, exploratory analyses assessed the differences between subsamples of the Latine population and culture. This analysis was conducted to examine whether specific cultural subsets of the Latine population – Caribbean and South/Central American – differ in implicit attitudes towards disability.

Aim 2

Characterize and define the general understanding and beliefs about ASD within the Latine community, as well as the effect of these beliefs on social support and community inclusion utilizing qualitative techniques.

PAPER 1: IMPLICIT ATTITUDES TOWARD DISABILITY ACROSS SOCIODEMOGRAPHIC VARIABLES & FAMILIARITY WITH DISABILITY

Brief Introduction

A paucity of research has explored the presentation of implicit attitudes towards disability, with most studies exploring explicitly-reported attitudes (VanPuymbrouck, Friedman, & Feldner, 2020; Wilson & Scior, 2015). The few studies which have examined this have shown mixed results with one study finding that older age, being nondisabled, identifying as male, having no family members or friends with disabilities, and identifying as more conservative resulted in higher implicit negative associations regarding disability amongst healthcare providers (VanPuymbrouck, Friedman, & Feldner, 2020). The second study found no significant differences across gender, education, and contact with individuals with disabilities in a general population dataset (Wilson & Scior, 2015). Moreover, explicit and implicit attitudes towards disability amongst health care providers was observed to be disparate in that explicit attitudes were reported as more neutral and implicit attitudes showed bias against disability (VanPuymbrouck, Friedman, & Feldner, 2020). However, no study has examined this using general population datasets, especially across sociodemographic groups. The current study aims to explore implicit attitudes and the discrepancy between explicit and implicit attitudes towards disability across sociodemographic variables, including race and ethnicity as well as familiarity with disability using a general population dataset.

Objectives

Schema theory posits that attitudes, including potentially negative attitudes such as stigma, exist in all individuals and function to characterize and understand their world (Bartlett, 1932). Explicitly-measured attitudes may differ from implicit attitudes due to variables such as social desirability in responding. Given the differential rates and presentations of stigma across cultural and racial/ethnic groups (Dietrich et al., 2004; Griffiths et al., 2006; Scior et al., 2013), the first aim was to examine differences between racial/ethnic groups in negative implicit associations towards disability. Additionally, higher levels of negative implicit associations may be more likely among individuals who do not have a disability or who do not know at least one person with a disability. Consequently, the second aim was to understand the presentation of implicit attitudes in relation to familiarity with disability. The third aim examined whether explicit responses of preference align with implicit attitudes towards people with and without disabilities. Lastly, the present study explored the relationship between implicit associations and sociodemographic characteristics.

Publicly-available data from Project Implicit and the Disability Attitude Implicit Association Test (DA-IAT) were utilized for the present study. The DA-IAT measures implicit attitudes towards “disabled” and “abled” individuals using response latencies for “negative” and “positive” words paired with each concept. The IAT and DA-IAT are described in more detail in the Measures.

Methods

Participants

Participants for the current study completed the DA-IAT between 2017 and 2019, which initially included 197,823 completed sessions, (i.e., participants remained engaged in the data collection from consent to debriefing) and were currently living in the U.S. Participants with completed data for all variables of interest for the present study were eligible for inclusion in the current analyses. To obtain the current sample, several steps were taken. Participants were excluded if they had taken the DA-IAT more than once, as indicated by the duplicate variable in the dataset. Participants with potentially erroneous data were also removed; this was determined by calculating approximate age of the participant and removing any participants over the age of 100. Sample sizes for each raciothenic identity were examined and found to be greatly unequal (i.e., one group was at least more than twice the size of another group). To ensure approximately equal racioethnic sample sizes, the smallest racioethnic group sample size ($n = 234$) was used as a reference to match the approximate sample size of the remaining racioethnic groups so that no groups were more than twice the size of the smallest group. Therefore, participant session IDs were randomly selected for each racioethnic identity for inclusion in subsequent analyses. After data cleaning and random selection of participants to form relatively equal groups, the final sample for the current study consisted of 2,060 individuals. Detailed information about the sample characteristics is reported in the results section.

Procedure

Participants accessed the IAT through the Project Implicit website (https://implicit.harvard.edu/implicit/), which is run by researchers at Harvard University. Volunteer participants are first directed to a webpage titled “Preliminary Information” which outlines the test and its purpose, data privacy procedures, and study disclaimers. Participants are then asked to select “I wish to proceed” after reading the webpage and acknowledging its contents. Upon continuing, participants are taken to a page listing several IATs including, “Transgender IAT,” “Race IAT,” and “Religion IAT,” for example. Each IAT has a brief description beside it to aid participants in selecting a task. The Disability IAT states: “Disability (‘Disabled – Abled’ IAT). This IAT requires the ability to recognize symbols representing abled and disabled individuals.” Volunteers then select which IAT they wish to complete. Participants can complete as many IATs as they wish.

Participants who select the DA-IAT are directed to a preliminary webpage detailing the nature of the DA-IAT and the tasks to be completed. After reading the information, participants must click “continue” and are directed to complete a series of questionnaires regarding beliefs, attitudes, and demographics prior to completing the DA-IAT. Participants also complete a measure regarding their familiarity with and proximity to disability (i.e., do they have or know someone who has a disability). Following completion of all pre-test measures, the individual is directed to a webpage detailing the IAT, which includes instructions about the tasks, such as the positive and negative words and the pictures of abled and disabled individuals used in the administration. Participants are informed there are 7 parts to the task and are asked to complete these tasks following the specified instructions. At the conclusion of the 7 tasks, participants press the space bar to continue to their individual results and debriefing. On the final page, participants are given additional information regarding how the DA-IAT works, what to do about implicit preferences that are undesirable, how their score compares to others' scores, and additional debriefing information.

Measures

Pre-Test Measures. In the most recent iteration of the DA-IAT, participants first complete a series of surveys and questionnaires regarding a range of topics (e.g., anxiety). All participants completed an extensive demographics questionnaire. Participants also completed a questionnaire assessing familiarity with and proximity to disability. See Table 1 for items and the responses used in the current study, and for items and responses regarding disability – namely whether they have or know someone who has a disability and explicit preference towards "disabled" and "abled" people.

Table 1. *Pre-Test Items Used in Current Study*

Item	**Response**
Sex Assigned At Birth	Male Female
Current Gender Identity	Male Female Trans male/Trans man Trans female/Trans woman Genderqueer/Gender nonconforming A different identity
Birth Month	List of all 12 months
Birth Year	Write-In
Race	American Indian/Alaska Native East Asian South Asian Native Hawaiian or other Pacific Islander Black or African American White

	Other or unknown Multiracial
Ethnicity	Hispanic or Latino Not Hispanic or Latino Unknown
Political Identity	Strongly conservative Moderately conservative Slightly conservative Neutral Slightly liberal Moderately liberal Strongly liberal
Religious Affiliation	Buddhist/Confucian/Shinto Christian: Catholic or Orthodox Christian: Protestant or Other Hindu Jewish Muslim/Islamic Not religious Other religion
Religiosity	Not at all religious Slightly religious Moderately religious Strongly religious
Country/Region of Primary Citizenship	List of all countries
Country/Region of Residence	List of all countries
U.S. State of Residence	List of all U.S. states
Highest Level of Education	Elementary school Junior high Some high school High school graduate Some college Associate’s degree Bachelor’s degree Some graduate school Master’s degree JD MD PhD Other advanced degree MBA
Occupation	List of occupations
Disability (Self)	Yes No
Disability (Other)	Yes No

Explicit Preference	I strongly prefer disabled people to abled people I moderately prefer disabled people to abled people I slightly prefer disabled people to abled people I like abled people and disable people equally I slightly prefer abled people to disabled people I moderately prefer abled people to disabled people I strongly prefer abled people to disabled people

Implicit Association Test. The Implicit Association Test (IAT) is an online measure used to assess internal attitudes of individuals that may not be assessed through purely explicitly-reported measures. It does this by measuring the strength of automatic associations between two targets through performance speed on two tasks where association strength affects performance speed (Greenwald, Nosek, & Banaji, 2003). The IAT has target concepts and an attribute dimension. For the current study assessing disability, the target concepts were images of “Abled” versus “Disabled” individuals, and the attribute dimension was “Positive” or “Negative” words. The entire test has seven tasks (Greenwald, Nosek, & Banaji, 2003). First, participants engage in the “Initial Target-Concept Discrimination” which prompts the participant to separate out images that represent abled versus disabled individuals by clicking cursors on the left or right side of the screen for each respective target for 20 trials. Following this, participants complete the second task: “Evaluative Attribute Discrimination” in which they separate positive and negative words by clicking cursors on the left or right side of the screen for each respective attribute dimension for 20 trials. The third task is considered a “Practice” of the target-attribute combined task containing 20 trials. In this task, targets and attributes appear on alternating trials and participants were prompted to click the cursor based on the previous instructions as quickly as possible. If a participant makes an error (i.e., clicks the wrong cursor), a red X appears on the screen and the participant must select the correct cursor (Greenwald, Nosek, & Banaji, 2003). Task 4 is considered the "Test" and is identical to task 3 but contains 40 trials. In task 5, the targets reverse sides so the target that was on the left is now on the right and vice versa. The attributes stay where they were originally. Participants complete 20 trials for the new reversed targets. Following this, participants complete task 6, a 20-trial practice with the targets in the new reversed positions. Finally, participants complete task 7, which is the 40-trial test with targets on the new reversed positions (Greenwald, Nosek, & Banaji, 2003). See Table 2 for a schematic of the DA-IAT testing procedure.

Table 2. *Sequence of Trial Tasks in the Disability IAT*

Task	**Number of Trials**	**Purpose**	**Items on left-key response**	**Items on right-key response**
1	20	Practice	Disability images	Non-Disability Images
2	20	Practice	Positive words	Negative words
3	20	Practice	Disability images + Positive words	Non-Disability images + Negative words
4	40	Test	Disability images + Positive words	Non-Disability images + Negative words

5	20	Practice	Non-Disability images	Disability images
6	20	Practice	Non-Disability images + Positive words	Disability images + Negative words
7	40	Test	Non-Disability images + Positive words	Disability images + Negative words

IAT Scores. Data collected from the IAT is measured as response latencies, or the amount of time it takes for the participant to correctly click the designated key for each target and attribute presented. Response latencies are measured in milliseconds (Greenwald, Nosek, & Banaji, 2003). The theory behind the IAT is that if the target concepts are differentially associated with the attribute dimension, then either task 4 or 7 will be easier (i.e., quicker response latencies, lower millisecond count). Consequently, the IAT score is based on how quickly – on average – a person sorts words in the tasks assigned (tasks 3 and 4, tasks 6 and 7; Greenwald, Nosek, & Banaji, 2003). If a person has an implicit preference towards abled individuals compared to disabled, for example, they should react faster when abled and positive attributes are paired compared to disabled and positive.

A new scoring algorithm was developed to address major limitations and difficulties with the conventional scoring algorithm. Namely, the new scoring algorithm included the following: 1) use of both practice and test tasks, 2) inclusion of errors by replacing the error latency with the task mean plus 600 milliseconds, 3) inclusion of the first two trials of all tasks (practice and test), 4) removal of participants who had more than

10% of response latencies faster than 300 milliseconds, and 5) deletion of response latencies greater than 10,000 milliseconds (Greenwald, Nosek, & Banaji, 2003). The new scoring algorithm IAT score – called the D score – is calculated by averaging the values for the 4 tasks (tasks 3, 4, 6, and 7), subtracting tasks 6 and 3 and 7 and 4, dividing the differences by the pooled standard deviation for all tasks, and finally, averaging the quotients. Of note, the IAT score (hereby referred to as the D score), is categorized into small, medium, and strong preferences which correspond with criteria for small, medium, and large effect sizes of Cohen's d (Greenwald, Nosek, & Banaji, 2003). This is described in more detail below. See Table 3 for the steps in calculating the overall D score.

Table 3. *Steps to Calculate Overall D Score*

Steps	Calculation
1	Average values for task 3 Average values for task 4 Average values for task 6 Average values for task 7
2	Subtract the average for task 3 from the average for task 6 6 – 3 Subtract the average for task 4 from the average for task 7 7 – 4
3	Divide the differences by the pooled-trials standard deviations (SD) 6 – 3 / Pooled SD of Trials 3 & 6 7 – 4 / Pooled SD of Trials 4 & 7
4	Average the quotients of the two calculations from the previous step

Studies exploring reliability and validity of the IAT overall D score utilizing the conventional rather than the new scoring algorithm found somewhat mixed results. Namely, a majority of most early studies argued that the IAT demonstrated acceptable test-retest reliability with an average value between from 0.50 and 0.60. Moreover, internal consistency was found to have an alpha as high as 0.80 (Bosson, Swann, & Pennebaker, 2000; Greenwald, Banaji, Rudman, Farnham, Nosek et al., 2002; Greenwald & Nosek, 2001). A meta-analysis of 50 studies found the average Cronbach alpha value for internal consistency was 0.79 (Hofmann, Gawronski, Gschwendner, Le, & Schmitt, 2005). However, it is important to note that previous research has argued that internal consistency of measures that are dependent on response latencies as the primary outcome, as with the IAT, is typically lower than internal consistency of self-report measures (Buchner & Wippich, 2000). Therefore, it was also important to consider the validity of the measure.

Previous studies on the conventional scoring algorithm showed mixed results with regards to convergent validity for the IAT. Specifically, a previous study looked at the correlations of the IAT with other implicit measures and found no significant relationships (Bosson et al., 2000). However, this was also true for 14 other implicit measures in the same study, with only two pairs of measures showing significant correlations (Bosson et al., 2000). Moreover, authors argued that when reliability was held constant, the implicit measures were more likely to be related – potentially due to the aforementioned limitation with response latency measures (Cunningham, Preacher, & Banaji, 2001). Mixed results have also been found for discriminant validity for the IAT. Namely, previous research has demonstrated that IAT data that are expected to converge (conceptually similar) typically do while those that are not expected to converge typically do not (Cunningham et al., 2001). However, other studies have found significant correlations between conceptually distinct IATs as well (McFarland & Crouch, 2002; Mierke & Klauer, 2003).

To remedy all of these concerns, the new scoring algorithm improved scoring procedures and has been shown to increase discriminant validity (Back, Schmukle, & Egloff, 2005; Greenwald et al., 2003), and still is the preferred method for IAT scoring

(Richetin, Costantini, Perugini, & Schönbrodt, 2015). Additionally, overall the IAT has been shown to correlate with explicitly-rated attitudes towards similar but not distinct concepts (i.e., Weight Attitudes IAT and self-report explicit weight attitude measures; Gawronski, 2002). The IAT has also been shown to predict judgements and behaviors (including health behavior, stereotyping, and prejudice) and group membership (Aidman & Carroll, 2003; Ashburn-Nardo, Voils, & Monteith, 2001; Ashburn-Nardo, Knowles, & Monteith, 2003; Gawronski, Geschke, & Banse, 2003; Greenwald et al., 1998; Greenwald & Farnham, 2000; Hugenberg & Bodhausen, 2004; Jellison, McConnell, & Gabriel, 2004; Jost & Hunyady, 2005; Jost & Hunyady, 2002; McConnell & Leibold, 2001; Nosek et al., 2002a; Nosek et al., 2002b; Rudman & Heppen, 2003; Rudman & Lee, 2002; Rudman, Feinberg, & Fairchild, 2002).

Disability Attitudes Implicit Association Test. Previous research has demonstrated that the DA-IAT was reliable and valid in that participants were able to complete the task accurately, social desirability responding did not affect IAT scores (i.e., participants attempting to respond slower/quicker on purpose did not affect scores), moderate effect sizes were found regarding categorization of positive and negative associations toward disability, and the task was able to measure implicit attitudes towards disability (Pruett & Chan, 2006). Additionally, the DA-IAT has programmed safeguards which identify participants that attempt to answer randomly or fake results, allowing for these participants to be removed from analyses (Cvencek, Greenwald, Brown, Gray, & Snowden, 2010). Participants with greater than 10% response latencies faster than 300 milliseconds are excluded, as this is indicative of participants speeding through the tasks rather than providing accurate responses. Additionally, participants with response latencies greater than 10,000 milliseconds are removed as this is indicative of walking away from the task and returning later, which also leads to inaccurate data (Greenwald, Nosek, & Banaji, 2003). Thus, using the criteria for the new scoring algorithm, data that is made publicly-available has already been cleaned for inaccurate IAT data.

Overall DA-IAT score ranges from 2.0 to -2.0 with high positive scores indicating positive bias, or preference towards abled individuals, and vice versa. Scores of -0.14 to 0.14 indicate no preference, 0.15 to 0.34 indicate a slight preference, 0.35 to 0.64 a moderate preference, and 0.65+ a strong preference towards abled people. Negative values of these scores are classified in the same way but indicating a preference toward disabled people. These scores are derived using the updated scoring algorithm created by Greenwald et al. (2003). Scores are representative of the response latency in stereotype-consistent (i.e., abled, positive) and stereotype-inconsistent (i.e., disabled people, positive) tasks.

Data analysis

Demographic variables used in the present analyses are self-reported race, ethnicity, sex, political identity, religiosity, U.S. region of residence, and education. Additional variables include self-reported disability or familiarity with disability (i.e., family member or friend with disability) answered dichotomously, preference score towards abled and disabled individuals from 1 to 7, and overall DA-IAT score. See Table 1 for information on all variables listed except overall DA-IAT score. Analyses were conducted with untransformed and transformed variables and no differences were found in results. Therefore, the untransformed variables were utilized for all analyses.

Hypothesis 1.1 predicted that Latine participants would demonstrate lower rates of implicit negative associations towards disability, followed by Black/African American participants and then White participants. This was analyzed using a one-way ANOVA using Fisher procedure comparing overall implicit score across White, Black/African American, and Latine participants.

Hypothesis 1.2 predicted that individuals who have a disability and/or know someone with a disability would have the lowest scores for implicit negative associations compared to individuals who do not have and/or know a person who has a disability. This was analyzed using a factorial ANOVA comparing overall implicit score across self-proximity (i.e., reported having a disability or not) and other-proximity (i.e., reported knowing someone with a disability or not) groups.

Hypothesis 1.3a hypothesized that explicit attitudes would be rated as more neutral compared to implicit associations. This was analyzed using a linear regression to examine the relationship between self-reported explicit preference and overall implicit score.

Hypothesis 1.3b hypothesized that the relationship between explicit and implicit attitudes would be stronger for White participants, followed by African American/Black and then Latine participants. This was analyzed using moderation analyses through regression to examine the potential influence of racioethnic identity on the relationship between explicit preference score and implicit score.

Hypothesis 1.4 predicted that older age, White racial identity, non-Latine ethnic identity, male sex, lower education, and stronger political conservativism would result in higher implicit negative associations. Pearson’s correlations were used to examine the relationships between overall implicit score and participant age, political identity, and religiosity. An independent samples t-test was conducted examining implicit score across male and female sex. Additionally, two one-way ANOVAs were conducted assessing differences across U.S. regions of residence and education levels for implicit score, respectively.

Lastly, an independent samples t-test assessed the differences in implicit score between subsamples of the Latine population – Caribbean and South/Central American. U.S. state of residence was used as a proxy for Latine ethnic identity. Specifically, states with majority Latine populations of Mexican and Salvadoran origin, respectively, were combined to create the group “South/Central American” with 503 participants. States with majority Latine populations of Puerto Rican, Cuban, and Dominican origin, respectively, were combined to create the group “Caribbean” with 123 participants. Because the South/Central American group had more than twice as many participants as the Caribbean group, 280 South/Central American participants were randomly selected to create approximately equal groups for comparison and address potential issues with the heterogeneity of variance assumption.

Results

Sample Characteristics

The total sample for the current study was comprised of 2,060 individuals. Of the 3 racioethnic groups of interest in analyses, approximately 30.8% identified as non-Hispanic/Latine White, 20.9% as non-Hispanic/Latine Black/African American, and 48.3% as Hispanic/Latine. Birth date was not collected as part of demographic information, so age was estimated based on birth year and year of DA-IAT completion. Average age approximation was 28.66 years (*SD* = 10.55). Approximately 71.6% of the sample reported their sex at birth as female. Regarding gender identity, 28.1% identified as male, 70.5% identified as female, .1% as a trans-man, .2% as a trans-woman, 1.0% as gender nonconforming, and .1% as a different identity. Education level was relatively high with 30.4% having completed some college, 30.9% having completed college, and 26.6% having an advanced degree. Approximately 16.1% of the sample was unemployed at the time of DA-IAT completion. Approximately 29.4% of the sample reported no religious affiliation (i.e., Catholic, Buddhist, etc.), but 27.4% reported not being religious at all when identifying overall religiosity. Approximately 27.9% of the sample reported political neutrality while 54.7% indicated some level of liberal and 17.4% indicated some level of conservative political identity (i.e., slight, moderate, strong).

Mean implicit score was 0.59 (*SD* = 0.45), indicating a moderate preference towards abled people. Approximately 80.9% of the sample reported not having a disability of any kind, and 40.6% reported not having a family member or friend who has a disability. Approximately 35.6% reported they did not have or know anyone who had a disability. A majority of the sample (61.5%) reported equal preference between abled and disabled people. When asked about how warm they feel towards abled people, 24.8% reported neutrality as compared to 18.0% reporting more warmth for disabled people and 57.2% reporting more warmth for abled people.

Table 4. *Sample Characteristics*

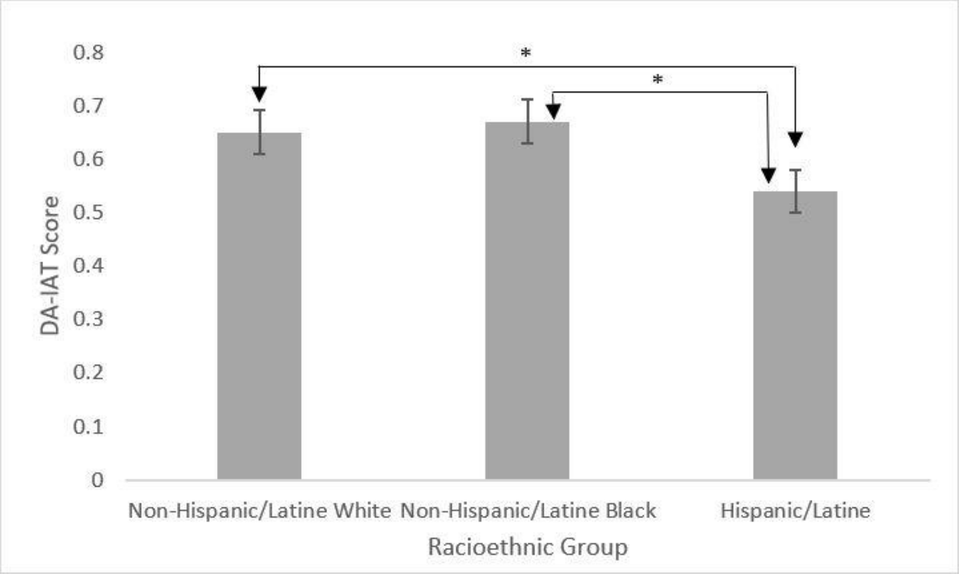
Variable	**Statistic**
Race/Ethnicity	
Non-Hispanic/Latine White	30.8%

Non-Hispanic/Latine Black/African Am.	20.9%
Hispanic/Latine	48.3%
Mean Age Approximation in Years (Standard Deviation)	28.66 (10.55)
Sex at Birth	
Female	71.6%
Male	28.4%
Gender Identity	
Male	28.1%
Female	70.5%
Trans-man	0.1%
Trans-woman	0.2%
Gender nonconforming	1.0%
A different identity	0.1%
Education Level	
Some college	30.4%
Completed college	20.9%
Advanced degree	26.6%
Employment	
Unemployed	16.1%
Political Identity	
Neutral	27.9%
More Liberal	54.7%
More Conservative	17.4%
Religious Affiliation	
None	29.4%
Religiosity	
Not religious at all	27.4%
Average DA-IAT Score (Standard Deviation)	0.59 (0.45)
Familiarity & Proximity to Disability	
Does not have a disability	80.9%

Does not know someone with a disability	40.6%
Does not have or know someone with a disability	35.6%
Neutral Preference Between Disabled & Abled People	61.5%
Warmth Towards Disabled People	
Neutral	24.8%
More Warmth for Disabled People	18.0%
More Warmth for Abled People	57.2%

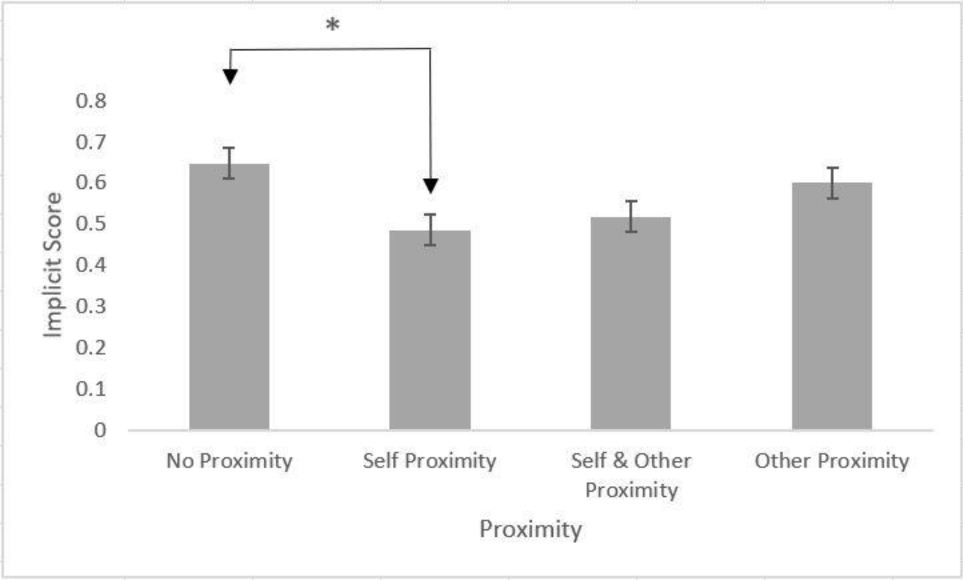
Analyses

Results from a subset of participants identifying as belonging to one of the 3 racioethnic categories of interest included (n = 656) yielded an implicit score that was significantly different across racioethnic groups $F(2, 653) = 5.81$, $p < .01$, partial $\eta^2 = .017$. Non-Hispanic/Latine (NHL) White (M±SE = 0.65±0.03) and Black (M±SE = 0.67±0.04) participants preferred abled persons more so than Hispanic/Latine participants (M±SE = 0.54±0.03; pairwise p's < .03), though there was no significant difference between NHL White and Black participants regarding this preference. See Figure 1. However, it is important to note that the mean implicit scores for NHL White and NHL Black participants indicated a strong preference (i.e., a score at 0.65 or above) towards abled persons, while the score for Hispanic/Latine participants indicated a moderate preference (i.e., a score between 0.35-0.64) towards abled persons overall.



A comparison of the overall implicit score between racioethnic identity groups *$*p < .03$*
Figure 1. *Implicit Score Across Racioethnic Identity (n = 656)*

There was no significant interaction between self proximity (identifies as having a disability) and other proximity (identifies as knowing someone with a disability) for implicit score, $F(1, 2056) = 1.97$, $p = .16$, partial $\eta^2 = .001$. There was no significant effect of other proximity, $F(1, 2056) = 0.07$, $p = .80$, partial $\eta^2 = .000$. As shown in the figure, there was a significant main effect of self proximity, $F(1, 2056) = 18.96$, $p < .001$, partial $\eta^2 = .009$. No proximity (identifies as not having a disability or knowing someone with a disability [$M = 0.62$, $SE = 0.01$]) was associated with a mean implicit score higher than among those endorsing having a disability ($M = 0.51$, $SE = 0.02$), a significant difference, $p < .001$. This indicates that participants without a disability or who did not know someone with a disability preferred abled persons more so than participants with a disability. Additionally, mean implicit score for participants, regardless of proximity to disability, indicated a moderate preference towards abled persons.



A comparison of the overall implicit score between participants with a disability (self proximity) and without a disability/does not know someone with a disability (no proximity) **p* < *.001*
Figure 2. *Implicit Score and Proximity to Disability (N = 2060)*

There was a significant, moderate positive correlation between explicit preference and overall implicit score, $r(2060) = .14$, $p < .001$, indicating that higher explicit preference scores (i.e., more preference towards abled persons) were related to higher implicit scores (i.e., more preference towards abled persons). The relationship between explicit preference score and overall implicit score did not vary with participants' racioethnic identity, $p = .17$.

There was a significant, moderate positive correlation between age and overall implicit score, $r(2060) = .12$, $p < .001$, indicating that higher age was related to higher implicit scores (i.e., more preference towards abled persons). There was a significant, small negative correlation between political identity and overall implicit score, $r(2060) = -.08$, $p < .001$, such that higher political identity scores (i.e., more liberal) were related to lower implicit scores (i.e., more preference towards disabled persons). There was no significant correlation between religiosity and overall implicit score, *r*(2060) = .03, *p* =.15

	Implicit Score	Explicit Preference	Age	Political Identity
Explicit Preference	.142**	-		
Age	.121**	-.014	-	
Political Identity	-.082**	.014	-.046*	-
Religiosity	.032	-.038	.062**	-.359**

**p* < .05   ***p* < .01

Figure 3. *Correlation Matrix of Implicit Score and Self-Report Variables*

Mean overall implicit score was significantly different between males and females, *t*(2058) = 4.45, *p* < .001. Males had a higher mean overall implicit score compared to females, indicating that they preferred abled persons more so than females. However, the median implicit scores fell within the moderately prefer abled individuals range for females and strongly prefer abled individuals range for males, indicating that both groups showed a preference for abled individuals. Additionally the effect size was small, with a Cohen's *d* value of 0.22. Participants were divided into four groups for highest education level completed: high school (*n* = 250), some college (*n* = 627), college (*n* = 636), and advanced education (*n* = 547). The differences between these educational groups for implicit scores was not significant, *F*(3, 2056) = 0.54, *p* = .65, partial η^2 = .001. There were no significant differences in overall implicit score between the different

U.S. regions of residence groups, *F*(3, 2056) = 2.09, *p* = .10 or between South/Central American and Caribbean groups, *p* = .50 See Table 4.

Table 5. *Comparison of Implicit Score Means Across Self-Report Demographic Variables*

	n	M±SE	Significance
Sex			
Female	1474	0.57±0.02	*p* < .001
Male	586	0.67±0.01	
Education			
High School	250	0.59±0.03	
Some College	627	0.58±0.02	n.s
College	636	0.61±0.02	
Advanced Degree	547	0.61±0.02	
U.S. Regions of Residence			
Northwest	320	0.59±0.03	
Midwest	284	0.64±0.03	n.s.
South	604	0.61±0.02	
West	852	0.57±0.02	
Latine Groups			
South/Central American	280	0.46±0.08	n.s.
Caribbean	122	0.46±0.06	

Discussion

The current study aimed to address limitations in the understanding of implicit associations related to disability across racioethnic groups, self-reported explicit preference, familiarity with disability, and sociodemographic variables. Few studies have examined general disability attributes and schemas utilizing quantitative methodologies, and the current study addressed this gap by examining explicit and implicit bias scores in the general public and exploring these variables within specific groups. Results suggest that disability implicit associations may be related to a variety of self-reported identity factors, such as race/ethnicity and proximity to disability. Moreover, the present study provides a better understanding of how disability implicit associations may present across groups.

To better understand these results and their application and generalizability, it is important to take into consideration a few important statistical characteristics. First, participants in this study consistently demonstrated at least a moderate preference towards abled individuals, with this range increasing to strong preference for certain groups. Therefore, even if one group – for example female or Latine participants – was shown to have lower preference towards abled individuals, this did not mean that they were neutral in preference or preferred disabled individuals. Rather, the mean still demonstrated a certain level of preference towards abled individuals, typically at least a moderate preference. Additionally, for many of the analyses the effect sizes were small, which may limit confidence that the significant effects are truly generalizable to the public. This may be due to the very large sample size, as larger sample sizes increase the possibility of finding statistically significant results simply due to the number of participants rather than a true meaningful difference between groups.

Analyses addressing the influence of racioethnic identity suggested that Latine participants had the lowest preference towards abled persons as compared to non-Latine Black and non-Latine White participants, in that order. There was no difference in the relationship between explicit attitudes and implicit bias across racioethnic groups. Results from the current study of a general population are consistent with previous research utilizing DA-IAT data which showed that Latine groups had the lowest preference towards abled individuals among providers (VanPuymbrouck, Friedman, & Feldner, 2020).

These findings are descriptive in nature as they do not expand on the mechanism behind the biases observed. For example, cultural differences among racioethnic groups may impact stigma as measured by both explicit and implicit preference (Dietrich et al., 2004; Griffiths et al., 2006; Scior et al., 2013). The Latine population is considered collectivistic, meaning it places value in community inclusion and perception (Fung & Tsang, 2010; Kramer et al., 2002; Ng, 1997). Utilizing this schema, one may hypothesize that explicit and implicit preferences towards disability would favor abled individuals more so than disabled individuals, especially when compared to more individualistic cultures such as U.S. mainstream culture. However, while there was a moderate preference towards abled individuals across all 3 racioethnic groups, the Latine group showed the lowest preference towards abled individuals. Therefore, other factors may be impacting these scores. For example, the Latine population in the U.S. faces barriers to accessing information and resources about disability that other groups may not – such as language differences (Zuckerman et al, 2014a; Zuckerman et al., 2014b). Anecdotal evidence suggests that simply providing definitions or characteristics of disabilities without in vivo experience with disabled individuals may inadvertently perpetuate negative schemas and attributes as it “otherizes” disabled individuals, potentially increasing ableism. Such conclusions cannot be definitively drawn from the current study as the mechanisms behind the differences in implicit associations across racioethnic groups were not included in data collection. Therefore, future studies should examine the factors behind differences in both explicit and implicit associations regarding disability such as culture, barriers to information, understanding of information provided, and trust/mistrust. Examining the nuance of these biases and their consequential negative impact on disabled individuals and their families will help create a better understanding of this phenomenon and guide next steps on how to increase inclusivity and quality of life for those stigmatized.

When examining the relationship between explicit and implicit preference in the current sample, analyses suggested that higher self-reported explicit preferences were related to higher implicit association scores. In other words, more explicit preference towards abled individuals was related to more implicit preference towards abled individuals. This is in contrast with the hypothesis that individuals would be more likely to report lower explicit preference scores as compared to higher implicit preference scores due to social desirability responding. While the results indicate that this may not be the case, it is important to note that a majority of the sample indicated neutrality (61.5%) when asked about their explicit preference towards disabled versus abled individuals. However, a majority of the sample demonstrated implicit preference towards abled individuals (85.1%), which does not suggest neutrality. Consequently, further exploration of the relationship between explicit and implicit association within disability is warranted. A mixed methods approach may be useful in obtaining more detailed information about explicit attitudes through qualitative interviews, which gather more nuanced information compared to the Likert scale item measuring explicit preference in the DA-IAT. Moreover, qualitative interviews can also address social desirability responding by exploring participant perspectives of the general community’s attitudes regarding disability rather than relying solely on their personal perspectives. Coupling qualitative interviews with quantitative collection of explicit and implicit preferences through the DA-IAT has the potential to combine a wealth of information to understand this phenomenon.

As predicted, results also showed that individuals with a disability had lower implicit preference scores for abled individuals compared to individuals without a disability or those who did not know or have a family member or friend with a disability. This indicated that individuals without a disability or who know someone with a disability preferred abled people more so than individuals with a disability. This is supported by previous research utilizing data from the DA-IAT assessing attitudes in healthcare workers (VanPuymbrouck, Friedman, & Feldner, 2020) and may suggest evidence against the theory of internalized negative attributes or stigmatization in those with a disability. Specifically, internalized stigma is the stigmatization of – or allocation of negative attributes towards – oneself due to frequent and persistent negative judgement and stereotyping by the general community or society in which one lives (Livingston & Boyd, 2010; Muñoz, Sanz, Pérez-Santos, & Quiroga, 2011). Previous research has postulated that the presence of internalized stigma in individuals with a disability may therefore result in similar or higher levels of implicit preference towards abled individuals. While the results of this study suggest this may not be the case, conclusions are limited by the nature of the current dataset and data collection (i.e., reliance on self-report of disability, missing nuance about lived experience). An additional interpretation of the current findings regarding preference among individuals with personal experience with disability could suggest the impact of direct knowledge of disability on implicit attitudes. Future studies could recruit individuals with confirmed disability – for example, individuals with confirmed autism diagnoses – to participate in research addressing internalized stigma and implicit associations, as compared to individuals who do not have a disability but do know someone with a disability, and compare to those whom do not have a disability or know someone with a disability. Conducting participatory research has recently gained momentum and precedence within the field as it is logical that research about a target population should include stakeholders. Additionally, it would be of interest to explore these phenomena across cultural groups and visibility of disability (i.e., “hidden” disability such as autism versus “visible” disability such as cerebral palsy).

Finally, analyses showed that males had higher implicit association scores compared to females suggesting that males preferred abled persons more so than females. Since implicit associations arise with the introduction of schemas for an individual, the difference in male versus female preference towards abled individuals may be related to differences in cultural and societal schemas that are presented to and perpetuated within the different sexes. However, more research is needed to explore this phenomenon which is understudied potentially due to a variety of factors including difficulty recruiting men for research studies (Ryan, Lopian, Le, Edney et al., 2019), for example.

As hypothesized, results also suggested that older age was related to more preference towards abled individuals, as was more conservative political identity. The results comparing implicit preference across sociodemographic variables have been supported by previous research utilizing other DA-IAT datasets (VanPuymbrouck, Friedman, & Feldner, 2020). Age was also negatively correlated with political identity, suggesting that younger participants self-reported their political identity as more liberal. However, a regression analysis assessing age and political identity on implicit score showed that both variables significantly predicted implicit bias and each variable accounted for significant independent variance. More research is needed to understand the relationship between age, political identity, and bias. Future research may address this possibility to understand if novel campaigns such as “Stamp Out Stigma” or “Make It Okay” are impacting universal change in explicit and implicit bias, as these are campaigns which began in recent years targeting younger generations. Moreover, given the relationship between age and political identity, it would be of interest to explore these campaigns across political affiliation as well.

There was no difference across education or U.S. regions of residence on implicit preference, and no relationship between implicit preference and religiosity. Analyses exploring education and U.S. region of residence were exploratory as no predictions were made and suggest that these factors may not impact implicit preference towards disabled versus abled individuals. However, it is important to replicate and extend these results with samples outside of those that utilize the DA-IAT. Future research should aim to recruit weighted samples of educational background, U.S. region of residence, and religiosity to improve representation across groups.

Limitations

The current dataset had inherent limitations in exploring some of the research goals to the fullest extent. First, participants that completed the DA-IAT as well as other IATs presented to the website for a variety of reasons. Within this sample, a majority of the participants noted they completed the DA-IAT as an assignment for school (66.7%), followed by those who completed it for work (16.9%). The remainder of the sample was a combination of people that completed the DA-IAT because of a news story, recommendation, their own internet search, or some other reason. Many participants self-select the specific IAT that they wish to complete, which could bias results as they may have certain demographic characteristics or undocumented or unmeasured reasons for completing the chosen IAT. For example, individuals with a disability or who know someone with a disability may be more inclined to select the DA-IAT compared to other available IATs. This information regarding the number and types of IATs completed by the current sample was not collected and therefore is not known. Consequently, the potential impact for this self-selection on the results cannot be described. Future research could address this by including an open-ended question at the end of the IAT to inquire about any motivations for selecting the particular IAT that the participant chose to complete. Moreover, participants who complete one IAT may be more inclined to complete other modules potentially influencing results due to familiarity with the test and attitudes or beliefs held which may make one more inclined to participate in the IAT and complete several iterations. Future research should utilize the IAT in populations that may not typically access the test – such as prospectively recruited samples (i.e., Spanish-speaking individuals from Central and South America).

Additionally, those who completed the study did so in English only. Therefore, the study sample was required to be English proficient (i.e., understand the English language well enough to read and understand instructions independently) to accurately complete the DA-IAT. Consequently, the present sample is likely not representative of a wider, diverse population, especially those who are predominantly non-English speakers. Future research could remedy this limitation by translating and adapting English instructions and target words into a chosen language – for example, Spanish. Because the DA-IAT relies on images to capture the variable of interest (i.e., images associated with disabled versus abled individuals), translating and adapting instructions and target words would resolve reliance on English proficient samples. Additionally, the sample was limited to individuals living in the U.S. at the time of completion. This impacts generalizability and understanding of IAT results across other countries and cultures. Future research could remedy this by targeting prospective recruitment at populations outside of the U.S.

Relatedly, individuals who seemed to misunderstand directions by consistently obtaining errors on the DA-IAT were not provided scores due to the number of errors. Therefore, individuals who may have misunderstood instructions due to limited English proficiency or other factors (i.e., disability, etc.) may have been removed from the dataset, further limiting the generalizability of the sample. To address this limitation, an exploration of the mechanisms behind consistent errors on the DA-IAT would need to be completed. Given the nature of this approach to data collection, however, this would likely be impossible as individuals self-select and complete the DA-IAT from a location convenient to them. To address this limitation based on the proposed mechanisms behind consistent errors, future studies could utilize the translation and adaptation method above for individuals who speak other languages. Moreover, to address the potential mechanism of disability impacting completion, studies could recruit targeted samples of individuals with disabilities to complete the DA-IAT in person with an assistant who can aid the individual in completing the task. Future studies could also use voice-recognition software for individuals with physical disabilities that limit mobility. These adjustments could better engage persons with lived experience in this type of research.

Conclusion

Results from the current study suggest that sociodemographic variables such as racioethnic identity, sex, age, and political identity as well as proximity to disability may impact implicit preference towards disabled versus abled individuals. Additionally, analyses revealed that explicit preference score was related to implicit preference score, such that higher explicit preference towards abled individuals was related to higher implicit preference towards abled individuals and vice versa. This study adds to the current literature by specifically examining the impact of racioethnic identity on implicit preference toward disabled and abled individuals, as well as replicating previous results in other IAT datasets.

Overall, the obtained results may be considered descriptive in that they do not explore the unique mechanisms behind the differences across groups. Future research should address the aforementioned limitations and expand on current literature by recruiting specific populations of interest. Moreover, all future research would benefit from exploring these questions across culture and “visibility” of disability, as these factors will most likely impact results and conclusions drawn. By laying a groundwork for this research, the current study helps to expand next steps in understanding implicit preference towards/against disability. This is a crucial and understudied aspect within research addressing disability stigmatization and stereotyping. Development of this field of study can inform efforts to promote inclusivity and improve quality of life of those with disability and their families by addressing negative schemas prevalent in the general community.

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PAPER 2: PUBLIC BELIEFS ABOUT ASD & THE EFFECT OF ASD STIGMA ON SOCIAL SUPPORT IN LATINE POPULATIONS

Brief Introduction

Public stigma is the set of negative attitudes held by the general public or community towards individuals categorized as having a shameful characteristic (Corrigan & Rao, 2012; Vogel, Bitman, Hammer, & Wade, 2013) and has been shown to impact access to care and overall quality of life (Alonso et al., 2009; Brown et al., 2010; Corrigan, 2004; Fox, Smith, & Vogt, 2018; Jennings et al., 2015). Few studies have examined the impact of stigma on these factors in ASD (Ali et al., 2012; Ali et al., 2015; Ali et al., 2016; Mitter, Ali, & Scior, 2019; Werner & Shulman, 2015). Existing studies that have explored the presentation and effect of public stigma towards ASD in Latine populations have relied solely on parent report, where the impact of stigma may differ due to distinct cultural beliefs and values (Blanche et al., 2015; Cohen & Miguel, 2018; Dietrich et al., 2004; Gordillo et al., 2020; Griffiths et al., 2006; Scior et al., 2013; Zuckerman et al., 2018). Therefore, the present study aims to address a gap in the literature: understanding the beliefs and attitudes of the Latine public regarding ASD and the influence of these beliefs on social support for caregivers from the perspective of Latine community members.

Objectives

By utilizing qualitative interviews, this investigation aimed to (1) explore the explicitly-reported understanding and beliefs towards ASD held by the general Latine community and (2) understand potentially explicit stigmatizing attitudes held by the Latine community and how these attitudes may affect social support and inclusion for families of autistic children. Of particular interest was potential helping behavior from Latine community members, as Latine community members' desire to help families with autistic children might inform linguistically and culturally appropriate interventions. A better understanding of Latine families' view of ASD and how to help families of autistic children might allow researchers to use collectivistic cultural values to increase and spread knowledge of ASD, provide social support for families, and potentially increase inclusivity. Moreover, a qualitative approach was called for as it is difficult to operationalize and quantify experiences which have not yet been defined. Therefore, this study was a first step in exploring a consistently understudied area in public autism stigma and its effects within Latine populations.

Methods

The study team was comprised of the P.I., a Latina bilingual-bicultural medical/clinical psychology doctoral candidate (MAC), a Latina bilingual-bicultural speech-language pathologist during her Clinical Fellowship Year (AR), a Latina bilingual-bicultural undergraduate research assistant (YMS), and a white non-Latina pediatrician with expertise in autism in the Latine community (KZ); all study team members presented as female. All study team members were either involved in the creation of the study or volunteered to assist with the study out of interest in working with ASD and Spanish-speaking populations. All study team members had previous research experience and were trained on the research protocol as well as use of the qualitative data analysis software used, QSR NVivo 12.

Participants

In accordance with general guidelines for conducting qualitative research, the study proposed recruiting approximately 15 to 20 Spanish-speaking Latine parents of typically-developing children for in-depth interviews. To meet inclusion criteria, a family had to be a patient at the recruitment site, an academic primary care pediatrics clinic with a large low-income population, with a visit within the past year from Oregon Health & Science University (OHSU). Parents had to identify as Latine, be over age 18, speak Spanish or English, and have a child aged 2-5 years. Parents with autistic children or children with another developmental condition were excluded from recruitment and participation. However, language delays were permitted as these may be common in young children that are considered typically-developing.

Procedure

All the subsequently described materials, including the measures used for the study, were first professionally translated and then reviewed by bilingual study team members to ensure the information presented was accurate in both English and Spanish.

A random sample of participants who met inclusion criteria was obtained from the aforementioned clinic’s electronic health record. Eligible parents were mailed a letter that described the project and invited them to participate in a telephone interview, conducted in the preferred language (i.e., English or Spanish). This mailing included an

IRB-approved information sheet and an opt out response card that participants who did not wish to be interviewed or to be called in the future could return. One week later, parents who did not return the opt out card were called by a study team member to assess their interest in the study, complete a screening questionnaire, answer a demographics survey, and schedule an interview; participants were contacted up to five times via phone. For participants who were determined to be eligible based on screening and agreed to participate in the study, an interview date and time was scheduled during the screening call. Because there was no collection of personally identifiable information, verbal informed consent was obtained prior to all interviews in lieu of written consent (i.e., a signature).

All participants first completed a brief sociodemographic questionnaire on the phone with the study team member at the time of screening. This questionnaire assessed race/ethnicity, age, sex, primary language, education, and national heritage and included questions from the National Survey of Children with Special Health Care Needs (Blumberg, Olson, Frankel et al., 2003) to screen for potential developmental disabilities or delays for the purpose of recruiting parents of children that were considered typically developing.

Next, at their scheduled time, participants completed a 30- to 60-minute qualitative interview with either the P.I. or one of the other two bilingual study team members. Interviews were conducted either over HIPAA-compliant Zoom with cameras off or on a secure phone line in a secure room behind a closed door. Method in which the interview was conducted was based on participant preference. Following the interview, participants were sent a $50 gift card as payment.

All interviews were digitally recorded. Audio recordings were sent to GMR Transcription Services to be transcribed in the original language (i.e., English or Spanish). Upon receipt by the study team, the transcripts were uploaded to NVivo and coded by the P.I. (MAC) and a bilingual study team member trained on the coding framework (AR). Coding proceeded iteratively and all transcripts were reviewed for consistency across both coders. Any disagreements in coding were resolved through a conversation with the study team and in the presence of a third team member (KZ).

Measures

The qualitative interview guide contained prompts to ask and guide discussion on attitudes and beliefs about autism within the Latine community, potentially stigmatizing points-of-view, willingness to provide social support for families of autistic children, methods in which the Latine community aids families of autistic children, and the strengths and areas of improvement of the Latine community impacting the perception and support of autistic individuals and their families. The interview guide consisted of 3 broad question areas, each comprised of 3 to 5 sub-questions. The 3 broad question areas included:

a. Information about child & Defining Community

b. Attitudes & Beliefs – Stigma Proxy

c. Willingness to Aid & Methods Utilized/Latine Community Characteristics, Strengths, & Weaknesses

This guide was reviewed with study team members (KZ, YM) for feedback prior to the first interview. Please see appendix A for the full interview guide in English and Spanish.

The goal of the first broad category for questions was to help establish rapport between the participant and the interviewer. Additionally, questions in this category obtained a definition of community as described by the participant. This definition was used in the remainder of the interview as a reference when discussing “the community’s perspective.” The second broad category for questions addressed the first aim of the study: define the Latine community’s perspective on ASD, including attitudes, beliefs, and sources of information. This section also included an explicit discussion regarding stigma. This question was added to the interview guide after several participants were observed to mention stigma and stigmatization in the Latine community without using the specific word. The goal of the discussion regarding stigma was two-fold: (1) gain information on the understanding of and experience with the term “stigma” in the Latine community and (2) provide a definition of stigma to participants and discuss whether this term accurately reflected what they were describing as attitudes and beliefs about ASD in the Latine community. The third broad category for questions addressed the presence of social support and the impact of the attitudes and beliefs held by the Latine community regarding helping behavior towards families of autistic individuals, as well as Latine community strengths and areas of improvement. This category included questions about feasibility of helping, barriers to offering assistance, and perspective-taking on behalf of families who hesitate to ask for help. Additionally, questions assessing values and practices that may strengthen or negatively impact the way the Latine community views ASD and their willingness to provide help were utilized.

The interview guide was created to assess both the participant’s individual perspective as well as their beliefs about the Latine community’s perspective. This was done as an attempt to address response bias. Specifically, participants were provided the opportunity to speak about their beliefs apart from what they feel the Latine community believes. Therefore, for almost every question in the interview guide – aside from those that addressed general Latine community characteristics – the participant was asked to provide their perspective as well as what they felt the Latine community perceived. Participants were also occasionally asked whether they shared the Latine community's beliefs and social support tendencies towards ASD that they had described.

As a separate interview item, participants were asked to think of what they knew about ASD and summarize the diagnosis and their knowledge of it in one word. The specific prompt suggested participants think of ASD or an autistic person and identify a word to describe the diagnosis or the person.

Data Analysis

The present study used a phenomenological approach to analyze the collected qualitative data. Phenomenology focuses on the lived experience of an individual to understand their world (Neubauer, Witkop, & Varpio, 2019). This approach aims to learn from the experience of others to better understand phenomena that exist within a particular group. For example, phenomenology can explore experiences with topics like shame, the meaning given to characteristics or behaviors, communication, and the impact of beliefs or values on certain groups (Ajjawi & Higgs, 2007; Bynum, Artino, Uijtdehaage, Webb, & Varpio, 2018; Patel, Tarrant, Bonas, & Shaw, 2015). This analytic approach aims to capture not only what an individual experienced but also how it was experienced (Teherani, Martimianakis, Stenfors-Hayes, Wadhwa, & Varpio, 2015). Given the nature of the questions for the current study, namely understanding the experience and impact of ASD stigma in the Latine community, a phenomenological approach fit the study goals.

The first step of qualitative data analysis was to develop a coding framework identifying broad themes and subthemes from the data. This was accomplished by having all study team members read transcripts from the first three interviews twice. After reading the transcripts twice, each team member wrote down themes that they identified or initial impressions they had of the participants' responses. Following this, all study team members brought their list of themes and/or initial impressions to lab meeting for review. Each member presented the themes and/or initial impressions they wrote for each transcript, noting aspects of participant responses that captured the idea. During this discussion the P.I. took notes of all themes and/or initial impressions from the study team members to condense into overarching, general themes (called "main" themes) and subthemes within main themes. In step two, the P.I. labeled these overarching themes and subthemes and brought them to the study team for discussion at a subsequent meeting. After two discussions and resolution of any disagreements with main theme names/labels or allocation of subthemes, as well as generation of new themes since the first discussion, the study team finalized the initial coding framework.

To ensure representation for Latine families of typically-developing children and Latine families of autistic children in the study design, stakeholders from both groups participated in developing the initial coding framework. The stakeholder for Latine families of typically-developing children was a 38-year-old bilingual mother of three children. The stakeholder for Latine families of autistic children was a bilingual provider of in-home ASD services for Latine families. Stakeholders read the initial coding framework and separately discussed their impressions and thoughts with the P.I. on a 60-minute phone or Zoom call. These discussions resulted in two edits to the coding framework, including adding “Events” as a facilitator to discussion about ASD and interactions with the Latine community. “Events” included spontaneous mention of the importance or desire of having community events to make connections. The additional edit was noting the use of social media as a form of information gathering.

Review of the coding framework was completed with the study team and the two stakeholders one final time before proceeding with data analysis. The final step of data analysis included iterative coding of transcripts using the coding framework created in the previous steps. Iterative coding was completed in sets of two transcripts. This was done so that main themes and subthemes could be added, condensed, or changed. Changing of themes included editing the name and definition to clarify the intended meaning for the theme. In this process, no themes were removed from the coding framework.

Results

Sample Characteristics

Out of 44 invited participants through OHSU, a total of 12 participants responded to, were screened, and completed the study leading to thematic saturation. Thematic saturation was defined as no qualitative changes or additions to the themes based on participant responses. One participant completed only half of the interview due to losing cell phone connection with the interviewing site. The study team member conducting the interview attempted to reconnect with the participant that day and via follow-up in the subsequent days without success. The remaining 32 potential participants either declined participation or were unreachable via mail and phone. The average time for the interviews was approximately 32 minutes with a range from 21 minutes to an hour. See Table 1 for information on participant demographics.

Table 1. *Participant Demographics*

Demographic	**n**
Sex	
Female	11
Male	1
Age	
18-24	2
25-34	4
35-44	3
45-54	1
Unknown	2
Interview Language	
Spanish	7
English	5
Education	
Less than high school	3
Some high school	2
Certificate	1
Some college	2
Associate degree	2
Unknown	2
National Heritage	
Mexican	7
Venezuelan	1
Costa Rican	1
Guatemalan	1
Colombian	1
Unknown	1

One Word

Only 10 of the 12 participants provided responses to this prompt. Four participants described: “muy/super inteligente (very or super intelligent/smart).” One participant described: “different.” One participant described: “sensitive,” and one participant described: “special.” One participant said: “el chico está aquí pero como que le hablas y no puedes conectar (present but unable to connect).” One participant described: “unique” and, finally, one participant described: “very shy.”

Thematic Analysis – Thematic Connection

Data analysis revealed several broad themes comprised of subthemes spanning the awareness and knowledge of ASD in the Latine community and the presentation and impact of ASD stigma within this population. A connection across the broad themes also emerged, demonstrating the origin of beliefs about ASD and the consequences of these beliefs on the public’s behavior towards autistic individuals and their families. Participants endorsed a lack of resources which led to a lack of awareness and information. This then resulted in misinformation or uncertainty about the disorder which caused stigmatizing attitudes (i.e., “causing damage” or “fear of causing damage”). Causing damage, or the fear of causing damage, led to hesitation from the public to be involved with families of autistic individuals out of a desire not to cause pain. Below, the broad themes are described in the order of this connection to demonstrate the flow and provide examples of each concept. See Figure 1 for a schematic representation of the connection between major themes.

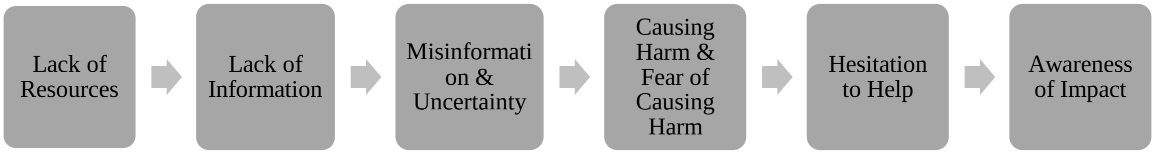

Figure 1. *Thematic Connections*

Thematic Analysis – Major Themes & Subthemes

The remainder of the results section will provide information on the major themes and subthemes that emerged from participant responses. Throughout this section, evidence for the connection described above can be seen through participant responses. See Table 2 for a list of the major themes and respective subthemes.

Table 2. *List of Major Themes & Subthemes*

Major Theme & Subthemes
Information
Lack of Information
Misinformation
Interactions
Barriers & Growth Areas
Facilitators & Strengths
Sources
Comparisons & Conceptualizations
Emotional Reactions
Social Support

Information

The information theme categorized participant responses regarding resources and knowledge about ASD in the Latine community. Participants noted two key aspects of information in the Latine community: a lack of information and misinformation.

Lack of Information. The lack of information subthemes included participant responses detailing the paucity or almost nonexistence of culturally- and linguistically-sensitive information within the Latine community about ASD and the impact of a lack of information on awareness.

> **ASD040:** "Yo creo que cosas que lo desmitifiquen. Que lo normalicen un poco más, información con respecto al tipo de comportamientos y el espectro en sí. Porque yo creo que la mayor parte de la información que yo me he enfocado, o que yo he visto por ejemplo dentro de los pediatras, son busque por estos signos, pero no te informa muy bien, o no hay muchísima educación o recursos que te diga bueno este es el espectro y por eso consideramos esto aquí y este es el espectro y cual es el tipo de comportamiento. De cosas que van desde bueno este es el más extremo a este sería el normal..."
>
>> *"I think things that demystify it [are needed]. That normalize it a bit more, information with respect to the types of behaviors and the actual spectrum. Because I think that a majority of the information that I've focused on, or that I've seen for example at the pediatrician's, it's look for these signs but they don't inform you very well, or there isn't much education or resources that tell you well this is the spectrum and because of that we consider this and this is the spectrum and this is the type of behavior. About things from well this is the most extreme to this would be the norm…"*

Participants also discussed the impact of the lack of information, including causing harm out of ignorance or potentially causing harm by believing something that was incorrect, and that impacting what was said or done.

> **ASD023:** "Yo pienso que a veces la intención de la persona es ayudar, ¿verdad? Pero a veces, lamentablemente si no estamos familiarizados realmente en el tema que nosotros vamos a ayudar, entonces, a veces sin querer podemos tocar puntos

> que son dañinos para las familias…. Que a veces es incómodo para ellos en decir o en platicar porque a veces mucha gente no está familiarizada y a veces sin querer hacer daño, a veces decimos palabras que pueden dañar a la familia cercana o inclusive hasta el niño."
>
>> *"I think sometimes the intention of the person is to help, right? But sometimes, unfortunately if we are not familiar really with the topic that we are going to help with, then, sometimes without trying we can touch on points that that are damaging to the families… That sometimes it is uncomfortable for them to say or chat about because sometimes a lot of people are not familiar with it and sometimes without wanting to they cause damage, sometimes we say words that can hurt the family or even the child."*

Misinformation. The misinformation subtheme detailed commonly held beliefs by participants or the Latine community about ASD that were incorrect or inaccurate. Participants noted beliefs that ASD was due to bad parenting, resulted from vaccinations, a consequence for doing or not doing a certain behavior during pregnancy, or they emphasized religious reasons such as a punishment from God. These beliefs were often used to understand the etiology of the diagnosis.

> **ASD016:** "De hecho, yo pienso o escucho lo que ellos me dicen y por lo que sé, creo o comparto lo mismo, que es posible que alguna vacuna les haya hecho daño por los niños que los conocí de niños chiquitos y fueron creciendo, se miraban niños normales y de repente los diagnosticaron con autismo. Entonces, es por eso, porque se miraban bien los niños."

> *"Really, I think or I've heard what they've [others] said to me and because I know, I think or I believe the same thing, that it is possible that some vaccine has caused damage because the kids that I knew from when they were very little and they were growing up, they looked like normal kids and all of a sudden they diagnosed them with autism. So, because of that, because they looked okay the kids."*

ASD024: "Pues muchos piensan que eso no existe y como que más que nada un descuido de los papás con los niños… Sí, como del comportamiento, los miman mucho, los dejan pasar a correr, pero no lo ven como una enfermedad."

> *"Well many think that it doesn't exist and more than anything it's the parents' carelessness with the kids… Yes, like behavior, they spoil them a lot, they let them run around, but they don't see it like an illness."*

ASD040: "Yo creo que en cierta forma es un poco de… no están haciendo suficiente, los están dejando estar es malcriados, los están dejando… Es un poco más de – aun en el sentido religioso que es una parte que me cuesta mucho entender, pero he oído cosas tan terribles como algo 'tuvieron que hacer para que Dios los esté castigando así.' Y le salieron los chiquitos así. Entonces son opiniones muy atrasadas."

> *"I think in a certain way it is a little… they're not doing enough, they are spoiling them, they are… It is more – although there is a religious piece that is hard for me to understand, but I have heard such terrible things like 'they must have done something so that God is punishing them like*

> *this.' And their kids come out that way [i.e., with ASD]. So those are very backward opinions."*

Interactions

The interactions theme was comprised of responses by participants about conversations or situations that they have experienced with certain groups in the public. Specifically, participants listed groups including: general Latine community, family, friends, autistic individuals and/or their families, and providers. When describing interactions, subthemes of: growth areas, strengths, and sources emerged.

Barriers & Growth Areas. Participants noted the Latine community does not have a lot of information about ASD, so the population tries to make sense of what little information they have, resulting in and often influenced by barriers in communication such as: irrelevance to their lives, lack of awareness, lack of information, stigma, pride or not wanting to be seen as weak, and feeling out of place.

> **ASD012:** "Pues, en realidad – pues la verdad, casi no nos ponemos – nunca me he puesto en pensar, en preguntar en eso ni nunca me han dicho sobre en un niño."
>
> > *"Well, really – well honestly, we almost don't – I have never thought about it, about asking about it, and no one has talked to me about it"*
>
> **ASD040:** "Y si lo tengo que dividir de otra forma, yo creo que el resto de mi comunidad no creo que lo entiendan, o no creo que, si voy y trato de preguntarle a algunos de mis amigos, vecinos que piensan o cual es el espectro, creo que la mayor parte no tenemos la información, o me van a responder así."

> *"And if I had to divide it in another way, I think that the rest of my community I don't think they understand, or I don't think, if I go and try to ask a few of my friends, neighbors what they think or what the spectrum is, I think a majority don't have the information, and they are going to respond that way."*

ASD024: "Pienso que sí, estamos muy cerrados pensar en una enfermedad así porque nuestra crianza siempre es como que nuestros hijos o nosotros somos personas fuertes y siempre estamos como listos para cualquier cosa o como que ese tipo de enfermedades psicológicas o de comportamiento no son para nosotros, como para estar en tratamiento. Es muy difícil entrar dentro de nuestros hábitos como que estar con psicólogos o personas capacitadas de ese ramo. Entonces, sí pensamos como que somos una comunidad muy fuerte y eso no se considera una enfermedad…"

> *"I think that yes, we are very closed off in thinking about an illness like that because of how we were raised, tis more that our kids or we are strong people and always ready for whatever thing, or like those types of psychological or behavioral illnesses are not for us, like being in treatment. It is very difficult to enter into our homes and space and be with psychologists or people qualified in that area. So, we think we are a very strong community, and that is not considered an illness…"*

ASD040: "Orgullo. Yo creo que no sé si es esto algo Latino o qué, pero yo creo que una de las cosas que siempre nos decían… bueno por lo menos cuando yo estaba creciendo era cosas como, deber favores es peor que deber dinero.

> Entonces yo creo que hay un estigma a nivel de eso hay un estigma con respecto a bueno, ‘algo está pasando no soy un buen papa, no soy una buena familia, vea todo lo que estoy haciendo.’ Y yo creo que ahí es cuando viene tal vez el orgullo, tener que abrir las puertas y decir bueno no soy capaz, no puedo.”
>
>> *“Pride. I think I don’t know if this is something Latino or what, but I think that one of the things we were always told… well when I was growing up it was things like, owing favors is worse than owing money. So, I think that there is a stigma about, ‘something is going on so I am not a good parent, I’m not a good family, look at everything I am doing.’ And I think that is when pride comes in, you have to open the doors and say I am not capable, I can’t.”*

Participants reported hesitation in their interactions with others, specifically friends, regarding ASD. Many described a reluctance to say anything because it “was not their place” despite clear concern and a sense of helplessness with how the situation was being managed.

> **ASD021:** “Well, one of my good friends, her two daughters, she was furious, because the school told her that they thought that the girls were both somewhere on the spectrum. She was super offended, angry, and got completely – just said, “No, absolutely not. And don’t ever talk to me about this again, ever.” And I thought, in my head, I thought that’s not gonna help them if they are, but I didn’t wanna push it, and I didn’t – I mean, it’s her kids. I’m not gonna tell her what to do with her kids. I just couldn’t.”

Very few interactions were described with autistic individuals or their families, but the general theme was one of a lack of acceptance and stigmatizing perspectives.

> **ASD040:** "Dentro de la comunidad latina no he oído mucho al respecto. Y voy a ser muy sincera y franca cuando estábamos creciendo. Tengo varios familiares dentro del espectro y la forma en que siempre la familia se refería a ellos era "en retrasados mentales." Entonces talvez se referían como unos tienen retraso, actúa como un chiquito de 5 años o tiene 15 y actúa como 5, tiene cinco años de retraso. Esa era la forma en que se describía este tipo de comportamientos y de dificultades en la escuela."
>
>> *"Within the Latin community I haven't heard much about it. I'm going to be very honest and frank about when we were growing up. I have several family members on the spectrum and the way the family referred to them was that they were 'mentally retarded.' So of course they referred to some of them as retarded, acting like a child of 5, or they are 15 and act like they are 5, they are behind 5 years."*

Responses regarding interactions with providers were variable as some participants reported helpful interactions, though notably these were mostly participants that spoke predominantly English. Many Spanish-speaking participants endorsed feeling out of place, difficulty understanding, and a lack of information when interacting with providers about ASD, resulting in speculations about the disorder. They preferred receiving information from trusted individuals from the same community.

> **ASD028:** “Sí. A veces es muy difícil de comprender las palabras que los doctores hablan, a veces hablan palabras que uno realmente no sabe y en cambio, cuando hay una persona, quizás, de la misma cultura, se identifica un poquito mejor, comprendemos un poco mejor las palabras que dice el doctor, médicamente a veces no entendemos, pero cuando hay una persona de nuestra misma cultura o país, como que se desenvuelve mejor el lenguaje y entendemos mejor y se siente bien uno estar así.”
>
> > *“Yes. Sometimes it is really difficult to understand the words the doctors use, sometimes they use words that one really doesn’t know but when there is a person, maybe from the same culture, you can identify with them a bit better, we understand the words that the doctor says better, medically sometimes we don’t understand, but when there is a person from our same culture or country, the language flows better and we understand better and we feel better being there.”*

Facilitators & Strengths. Participant responses detailed aspects of relationships and interactions, methods of communication, sociodemographic variables, Latine community values, and events that increase opportunity and ease of discussion about ASD. The importance of comfort and confidence in the relationship was frequently cited as something that increases willingness to talk about potentially difficult topics.

> **ASD016:** “Y hay ciertas familias que sí le tienen confianza a uno y son cuando en ocasiones nos pueden contar qué exactamente les pasa con los hijos. Por ejemplo, nos juntamos tres familias y no se tocan esos temas, pero cuando nos juntamos

> dos familias que nos conocemos, es decir, más, es cuando podemos hablar de estos temas, se puede decir, delicados."
>
> > *"And there are certain families that you feel confident [comfortable] with and it's sometimes that they can tell us exactly what is going on with their kids. For example, we get together, 3 families, and we don't touch those topics, but when just two families who really know each other get together, it's to say, more, that's when we can talk about those topics, that are, delicate."*

Education level, age, and language were also frequently mentioned as facilitators to discussion of ASD in the Latine community. Specifically, participants described higher educational attainment leading to more information and resources, which increases discussion due to familiarity and awareness. Participants noted that younger generations tended to be more open to discussion about things like ASD, potentially due to being more highly educated, going to college, and/or being more likely to speak English and thus having more access to information

> **ASD021:** "It depends on who you're talking about, because for example, at my kids' preschool, it's a pretty mixed group. They have little Latino kids and then they have regular white kids. So, the English-speaking parents, and then parents who speak Spanish. So, that's what I mean by that. And the kids that have like 504s and IEPs and have special – they have more resources, more services, are mostly Caucasian, because they have English-speaking mothers who advocate for them, who probably know more about it, who probably have heard more about mental health, and the other kids, not as much, I've noticed, personally."

> **ASD053:** “And I think the younger generation is really trying to make a point that these things can’t be ignored and people have to be educated. And I think the younger generation is really going to help the older generation through that.”

Participants also described a need for events dedicated to learning about and meeting autistic individuals and their families. Participants noted a strong desire to discuss ASD with those that have lived experience to understand the everyday impact and how to support families.

> **ASD021:** “…here in our town… there’s a group called Puentes Entre Culturas (Bridges Between Cultures) and in the summer, so before Covid, they used to have, every other weekend, … a potluck…. And it was just a free community event for everybody to come and meet your neighbor…. So, that would be amazing, something like that would be – because it literally brings people together, and that’s how you build – that’s how you break down walls. That’s how you break down misconceptions, because if you think that that person over there that looks different from you is bad or scary or something, but then you talk to them, and they’re awesome, you’re like, ‘Wow, I could be friends with this person. They’re really nice.’ But I would never know that, because I would never talk to them. It takes an event, like a coordinated event, for that to happen.”

Participants named a variety of community values and characteristics that, if applied to ASD, could make a lasting impact: unity, hard work, generosity, persistence, and positivity.

ASD023: "Yo pienso que la comunidad latina es muy unida y cuando ellos quieren hacer algo, hasta no lograrlo descansan. Tengo esa expectativa de nuestra comunidad y que también somos unidos, que cuando nos proponemos algo como, por ejemplo, si nosotros estamos necesitando ayudar a una persona como por pago de la renta, un ejemplo, ¿verdad? Hacen rifas, hacen comidas, con tal de reunir ese dinero y ayudar. Entonces, son muy decididos y también tengo la expectativa que también es una comunidad que siempre está trabajando."

> *"I think the Latino community is very united and when they want to do something they don't rest until they've accomplished it. I expect that of our community and also that we are united, that when we need something, for example, if we are needing to help someone pay their rent for example, right? They [the community] will do fundraisers, make food, to raise money and help. So, they are very dedicated and I also have the expectation that the community is always working."*

ASD040: "Yo creo que tengo que decir que este nivel de – Yo creo que nosotros somos agradecidos y positivos, siempre vemos la parte positiva. Siempre tratamos de – 'el sol va a salir mañana', ay, 'no hay carga que Dios provee que no podemos cargar', 'vas a ver que las cosas dan, es un día a la vez y gracias a Dios'. Pienso que estas actitudes son muy, muy buenas, esas actitudes de trabajo. Somos trabajadores, somos ayudadores y todas esas actitudes son muy positivas en mi experiencia."

> *"I think that I have to say that this level of – I think that we are very grateful and positive, we always see the positive. We always try to – 'the*

> *sun will come out tomorrow', oh, 'God doesn't give us more than we can handle', 'you'll see what He gives us, one day at a time, thank God'. I think those attitudes are very, very good, those attitudes of work. We are workers, we are helpers, and all those attitudes are very positive in my experience."*

Sources. Participants often named their interactions with others as primary sources of information about ASD. Outside of these interactions, other commonly listed sources of information included schools, TV, church, and social media. There was also an emphasis on the younger generations being a main source of information because of shifting perspectives on mental health and increased education or access to resources. This was noted to be related to language, with English-speaking participants often stated that the younger generation may be more likely to speak English and therefore have greater access to knowledge, information, and concepts such as "stigma." However, participants also detailed how the impetus to learn more fell on them as individuals and seeking out linguistically- and culturally-sensitive information that was easy to access was a big task.

> **ASD021:** "Yeah, there's a lot more information, and even social media, I found a few psychologists in Chile and Mexico and Puerto Rico, and they'll post stuff. They'll post memes, they'll post charts, they'll post quotes, and it's all in Spanish. It's all in Spanish, so it's easy. You share it, just share it. You can put it on your post or whatever, and that's helping because then somebody who's probably never heard of it is like, "Whoa." They read it, they see it, and it exposes them, and who knows?"

> **ASD023:** "Tengo un sobrinito en México que al parecer le habían diagnosticado ese problema. Entonces, quisimos como familiarizarnos para ver qué era realmente, por eso como que prácticamente leímos e investigamos. Entonces, nosotros nos ponemos a investigar o a saber más del tema, nosotros, inclusive como gente de la comunidad podemos ayudar a nuestra propia gente y, sobre todo, a los propios niños de nuestra comunidad para que ellos se adapten y tengan una vida mucho más mejor."
>
>> *"I have a little cousin in Mexico that apparently they have diagnosed with that problem. So, we wanted to familiarize ourselves to see what it really was, because of that we basically read and investigated. So, we investigate or try to know more about the topic, ourselves, including how the community can help our own people and, above all, the actual children in our community so they can adapt and have a much better life."*
>
> **ASD029:** "I feel like now, they can get information through their kids. I've taught my mom about things and my other sisters as well, my brother as well. Through their church, she's learned a lot from church, could be from friends. The word of mouth, that type of thing. Yes, only, again, because we – we do as our parents taught us, or what we learned from them and what – so, I guess, the newer generation now, there is more resources, and then our English obviously helped a lot. So, maybe we know more…"

Differences were noted between older and younger generations in terms of child-rearing practices and beliefs about diagnoses, with younger generations being more open to considering mental health and different parenting methods than what was considered "traditional."

> **ASD024:** "Pues creo que los confunde más porque sinceramente nosotros somos hispanos, siempre estamos, como le digo, preguntando a la mamá. Entonces, a veces los doctores son los que saben de este problema. Dan una información o algún consejo o algo, pero siempre uno piensa como preguntar a otras personas, y no sabes si hacer lo que te dice el doctor o lo que dice la mamá o los abuelos u otras personas que influyen en tus decisiones. Entonces, pienso que eso sí es un poco de – se enlaza con la información, ¿verdad? Y poder abrir un poco más la mente y seguir un poco más las indicaciones de los doctores que los que sí saben, unas recomendaciones de familiares."
>
> > *"Well I think it makes them more confused because sincerely us Hispanics, we are always, like I said, asking our mom. So, sometimes the doctors are the ones who know about a problem. They give information or some advice or something, but you always think to ask other people, and you don't know whether to do what the doctor says or what your mom says, or your grandparents or other people that influence your decisions. So , I think it's a little like– you get tangled in information, right? And to open your mind a little bit and follow the directions or the doctors a bit more because they're the ones that know over recommendations from family."*

Comparisons & Conceptualizations

The comparisons and conceptualizations theme categorized participant responses based on the language used to describe and understand ASD. Participants used other diagnoses, developmental stages, and/or medical or mental health descriptors to explain their understanding or the Latine community's understanding of ASD. Some of the terms were specific to Spanish language and culture. Many of the participants used a variety of descriptors in their responses to help explain the perception of ASD.

> **ASD012:** "…ya tiene como unos seis o siete años que trabajaba con una muchacha y no podía ver los niños que tiene autista o los que tienen síndrome Down."
>
> > *"…it's been 6 or 7 years since I worked with a girl and she couldn't work with autistic kids or kids that had Down Syndrome."*
>
> **ASD040:** "Yo creo que mis papas y mi comunidad de lo que yo llamo Latinos, la mayor parte de mis amigos de aquí yo creo que son estadounidenses o de otra cultura. Y si lo divido entre mi comunidad latina y la comunidad que no es latina, la mayor parte de la comunidad latina yo siento que continua con ese aspecto de identificar el autismo como un retraso mental."
>
> > *"I think that my parents and my community of what I call Latinos, the majority of my friends from here I think are American or from another culture. So if I divide my entire Latino community and the community that isn't Latino, the majority of the Latino community I feel continues with that idea of identifying autism like mental retardation."*

At other times, participants used language such as “special,” “not normal,” “bad,” or “illness” to explain the perception and understanding of ASD in the Latine community.

> **ASD023:** “…como que yo siento que ellos exponen que es un niño especial para ellos, extienden que como que es como que están diciendo que es hasta como un síndrome de Down, pero si nos damos cuenta, hasta el síndrome de Down tiene sus ramas y diferentes, hay niños que van a trabajar de esa manera y son muy independientes como cualquier otra persona.”
>
>> *“…it’s like I feel that they feel the child is special, they extend it to like its like they are deciding that its like Down Syndrome, but if we realize, even Down Syndrome has its branches and differences, that way is going to work for some kids and they’re very independent like any other person.”*
>
> **ASD021:** “Because it makes your children stand out, because it means that your kids aren’t just “normal,” quote unquote, and because I think the Latino community still has a lot of stigma around any kind of mental illness, and so it’s just kinda clumped together with, ‘Okay, these guys are normal, and these guys are not normal.’ So, anything that has to do with mental health in the Latino community, a lot of them still don’t get it. They just know it’s bad, so they think it’s bad.”
>
> **ASD023:** “Yo pienso que ellos piensan que es como una enfermedad.”
>
>> *“I think that they think it is like an illness.”*

Many of the Spanish-speaking participants noted connections with the culture or religious beliefs in understanding ASD, using language such as “malcriado” (i.e., spoiled) and describing ASD as a blessing or burden from God.

> **ASD012:** “Pues hay gente que pues sí lo ven – pues es una bendición, porque los niños – o sea, uno no lo escoge a los niños para – bueno, los hijos no escogen cómo los manda Dios porque ellos son – yo sé que se necesitan un cuidado, mucho cuidado, pues necesita uno tener mucha paciencia con ellos. Pero pues, o sea, Dios te mandó así, no lo escoge uno y hay gente que critican, “oh, ¿por qué tenemos un hijo que es especial?”, o sea, es que cada cabeza es diferente.”
>
>> *“Well there are people that if they see it – well it’s a blessing, because kids – well, you don’t pick your kids – well, you don’t pick the kids it is how God sends them to you because they are – I know they need care, a lot of care, and well you need to have a lot of patience with them. But well, of course, God sent them to you like that, you don’t pick that and people criticize ‘oh, why do we have a child that is special?’ but every mind is different.”*
>
> **ASD024:** “Pues no sé cómo decirlo, pero a lo que yo oigo que como que nomás son niños malcriados”
>
>> *“Well I don’t know how to say it, but from what I have heard its just that they’re spoiled kids.”*

Finally, some participants used the development of other children as a marker in understanding the presentation of ASD and how the diagnosis may impact the individual and their families.

> **ASD040:** "…pero una amiga muy cercana que sabemos que los amigos tienen un hijo de 9 años y un hijo de 5 años y estamos comparando notas todo el tiempo. Yo creo que principalmente por el hijo de ella que tiene 5 años fue diagnosticado hace poco con ADHD y depresión y entonces cada vez que juegan juntos y cada vez que nosotros interactuamos tratamos de… Comparamos mucho. Como están jugando, que tan fácil es disciplinarlos, como están en la escuela."
>
>> *"…but a close friend that we know well the friends have a boy that is 9 and a boy that is 5 and we're comparing notes all the time. I think mostly because her boy that is 5 was diagnosed not that long ago with ADHD and depression and so each time that they play together and each time we interact we try to… we compare a lot. How they are playing, how easy it is to discipline them, how they're doing in school."*

Emotional Reactions

The emotional reactions theme includes participant responses about feelings towards autistic individuals and their families, including "pena," empathy, sympathy, helplessness, judgement, and worry. Most participants endorsed feeling great sympathy for the families, with a handful reporting empathy.

> **ASD029:** "Well, my child doesn't have autism, but it's hard for me to ask for help with anything. I don't know why, and it's something I'm working on. I just feel

> like I’m the mom, so I feel like I should be able to do it all type of thing. I don’t know. I’m really hard on myself, so I feel like they would feel 100 times more of that, just because you’re dealing with such a difficult thing. Or maybe it’s just easier for them to do it themselves than to have to explain to somebody, “Oh, do you have this thing?” or “This is needed.” I don’t know.”
>
> **ASD021:** “I think, definitely, making them feel included would be more important, because that would help them just feel better, like it can make them feel like, “Okay, I’m not alone…” because if you’re all depressed and sad and anxious and scared and frustrated or whatever, then you’re alone and you feel excluded and isolated, just like with your kid, just your child with special needs, and nobody even talks to you? That’s gonna make it worse.”
>
> **ASD040:** “pero yo me pongo en los pies de mi amiga, de la mama y trato de ver que me gustaría que mis amigos hicieran por mi o el sistema de apoyo. Y esa es mi actitud.”
>
> > *“but I put myself in my friend’s shoes, of the mom and I try to see what I would like my friends to do for me or my social support. Yea that’s my attitude.”*

Pena is a Spanish word that does not have a direct translation to English but can take on different meanings depending on the context in which it is used: embarrassment, pity, or sorrow. When participants used it in relation to discussion of ASD, it was used mostly in the context of embarrassment.

> **ASD016:** "De los hijos es muy poco, como que nosotros los Latinos somos como más – como que si nos diera pena contar este tipo de cosas que le pasan a nuestros hijos… Y entonces, yo creo que la respuesta es de que la mayoría de Latinos nos da como pena platicar de esto ante el público."
>
> > *"About the kids its very little, it's like us Latinos are more like – like it embarrasses us to talk about what happens with our kids… And so, I think the response is that a majority of Latinos feel ashamed about talking about that in public."*

Some participants noted that families must be feeling overwhelmed in general and frustrated specifically with the process of seeking care.

> **ASD021:** "Yeah. Yeah, because they're in it, and they're probably so overwhelmed, and even asking for help sounds like, "Do you really want to bring somebody into this, and are they even gonna help me? Are they gonna understand? Are they just gonna judge me? Are they gonna tell me what to do? I'm already having a hard time doing it, much less telling somebody else how to do it."

Participants also attempted to take the perspective of parents of autistic children. When doing this, they endorsed worry and fear related to providing for the child. This was described across contexts: present day, being able to hold a job, taking the child to the doctor, or in the future when the child is an adult and may not be able to care for themselves.

> **ASD016:** "Como le repito, es algo muy difícil, especialmente si los papás estamos grandes y el niño está chiquito, que llegue uno cuando el niño tenga sus 15 años y que todavía sea dependiente de alguien, y ya no vamos a poder ayudarlo, ¿me entiende? Eso es lo más preocupante, que no vamos a poder estar ahí cuando nos necesite más y él ya sea un adulto y siga con sus problemas. No sé, como padre es muy preocupante que no podamos 100 por ciento ayudarlo cuando nosotros ya lleguemos a estar ya grandes, ¿no?"
>
>> *"Like I've said, it's something that is really difficult, especially if the parents are bigger and the child is younger, what happens when the child is 15 years old and still is dependent on someone and we can't help them anymore, you get me? That is the most worrisome, that we are not going to be able to be there when they need us most and they're already an adult and their problems continue. I don't know, as a parent it is very worrisome if we cannot 100% help them when we get to be older, no?"*

Helplessness was discussed frequently as it related to providing, getting support for the child, and a broad sense of "what do I do now?"

> **ASD021:** "So, I don't think that they have the time or the luxury to contemplate, "I need to get help from somebody, and this is how I'm gonna do it. I'm gonna call, I'm gonna talk to them to see if they have some sympathy for me." They are not even gonna – they're not. It's like, it's like, I don't know – I feel so – not comparing my kids. I'm just saying, I am so freaking overwhelmed with my kids without special needs yet that I don't even think about asking for – you don't think about it, because you are drowning. You're literally drowning. You're

> barely capable of brushing your teeth and remembering once in a while to drink water and breathe, because you are so stressed out, so extremely stressed out and drained. So, if I feel that way, and I've been feeling this way, I can't imagine what those parents are feeling. I don't get it. I honestly do not get it. I am – oh, my God, every single day, I'm like, "F**k. I gotta do this again." I'm sorry. That's not a good word, but that's how I feel."

Finally, participants endorsed feelings of judgement towards autistic individuals and their families as well as judgmental beliefs that circulate regarding ASD more broadly.

> **ASD016:** "Como le digo, somos muy – nos da pena, nos preocupa el qué dirá la otra persona. Y hay muchas otras personas que son muy abiertas, entonces no les importa el qué dirán. Y la mayoría de nosotros Latinos, pues al menos yo y el grupo que yo conozco somos así como más como el qué dirá la gente, se van a reír de mí, ¿qué van a decir? No puedo ir para allá porque no sé cómo me van a mirar, ¿no?"
>
>> *"Like I've said, we are very – it's embarrassing, we worry about what the other person will say. And there are many other people that are very open, so what others say doesn't matter to them. But the majority of us Latinos, well at least me and the group that I know are like that like more like what will the other people say, they're going to laugh at me, what will they think? I can't go over there because I don't know how they're going to view me, no?"*

Social Support

The social support theme categorized participant responses that described providing help and assistance to autistic individuals and their families in the Latine community. These responses were organized into forms of social support that were feasible for Latine community members to provide and forms of social support that were more difficult to provide. For feasible support, many participants noted including families in activities, preparing meals, cleaning, taking care of their children, offering emotional support, and overall offering of one's time.

> **ASD016:** "Como le digo, es el tiempo, el tiempo que uno le pueda dedicar a las familias que tienen este problema. La mayoría de gente no quiere dar ese tiempo, no se quiere molestar"
>
> > *"Like I've said, it's time, time that one can dedicate to the families that have that problem. A majority of people don't want to give that time, they don't want to be bothered with it."*
>
> **ASD045:** "Yeah, emotionally. I feel like, especially for Latinos, mental health is nonexistent. You're built to be strong. You're built to overcome anything. And so once you can sit down and tell them you're here for them. "It's not going to be easy, but just know I'm here and I care." I think it's the best you can do. Obviously, financial, cooking, transportation, all of that. But the first initiative should be reaching out and asking."

When discussing social support that was not as feasible or easily offered, participants stated that many of the Latine community would do whatever they could to help without causing harm. The only consistent social support that was not feasible to provide was financial support.

> **ASD012:** "Más o menos, es como económico o se trata de dinero. O sea, que ese sí es muy difícil de – porque no todos estamos dispuestos a ayudar como económicamente."
>
> > *"Kind of, it's economic or having to do with money. So, that is very difficult to – because not all of us are in a position to help financially."*
>
> **ASD029:** "Maybe financial help, maybe, just because I'm not rich or anything. But yeah, that's the only thing I can think of."

Discussion

The current study aimed to gather more information about the attitudes and beliefs about ASD, autistic individuals, and their families within the Latine community. An additional goal was to decipher if stigmatizing perspectives existed within the Latine community and the possible impact these perspectives may have on social support for autistic individuals and their families. Few studies have addressed ASD stigma in the Latine population, and these have focused solely on the report of parents of autistic individuals (Blanche et al., 2015; Cohen & Miguel, 2018; Zuckerman et al., 2018). Consequently, understanding the beliefs and attitudes of those perpetuating stigma, per parent report, is crucial in addressing its presentation and impact.

Overall, participants noted several broad themes describing a lack of resources, lack of information, uncertainty and misinformation about the diagnosis, stigmatizing perspectives and barriers to conversation, strengths and values which can be used as avenues to discussion, hesitance to provide assistance, and emotional reactions. The connection across these themes suggests that the Latine public may have a strong desire to provide assistance to autistic individuals and their families as well as understand ASD. This desire is rooted in collectivistic cultural values of community, work, strength, and support. However, participants also described a myriad of barriers impacting their ability to do so, including lack of resources and information as well as a broad sentiment of uncertainty and misinformation which could result in more difficulty for families to provide support. Consequently, it was reported that the public may feel hesitant to provide assistance out of fear of doing more harm than good and making the lives of autistic individuals and their families more cumbersome.

This thematic connection supports broad findings in the limited literature on ASD stigma within this population and adds missing nuance by increasing knowledge of the process in which the Latine community understands and attempts to provide support for autistic individuals and their families. Specifically, the available research is limited to reports of Latine parents of autistic children who endorse consistently high levels of stigmatization at the hands of a variety of groups especially the general community (Blanche et al., 2015; Cohen & Miguel, 2018; Zuckerman et al., 2018). This high stigmatization causes a myriad of negative effects such as social isolation and withdrawal, poor mental health, and difficulty accessing services (Blanche et al., 2015; Cohen & Miguel, 2018; Gordillo et al., 2020; Zuckerman et al., 2018). Results of the current study show an awareness on behalf of the Latine community that barriers exist to understanding autism and providing subsequent support. Namely, the Latine community is aware of the stigmatization but reports a lack of resources, information, and understanding as the root cause. This results in lack of inclusion of families of autistic individuals, as well as the Latine community's ability to provide support. Collectively, the current results support the limited existing findings that the Latine community and families want the same thing: provision of support. Families of autistic individuals want support from their community, and their community wants support in understanding autism to be better suited to support families.

Many participants described a strong desire to learn as a way to help and provided various ways they could get information, such as social media and the use of podcasts. Interestingly, and potentially also rooted in the cultural value of storytelling, participants emphasized the need to hear directly about the lived experience of autistic individuals and their families living in the Latine community. By doing so, the public could gain crucial perspective in understanding how to be there for their neighbors. Therefore, when detailing social media videos or podcasts as avenues for learning and understanding, many participants requested true stories citing this as much more helpful and impactful than statistics or handouts from a doctor's office. This provides an opportunity to provide information in a way that is meaningful to the Latine community and could make lasting change. Future studies should explore this as a potential option for targeting ASD stigma and its impact on social support in the Latine community, as anecdotally there is an emphasis and movement towards lived experience within the field more broadly.

Notable patterns also emerged related to the primary language spoken by the participant. All participants spoke Spanish in some capacity. However, almost half identified English as their primary language. In those that spoke predominantly English, participants were more likely to use the word stigma, describe access to education and resources leading to increased awareness and knowledge of ASD, and endorse better interactions with providers overall. Future studies could continue to explore the differences between predominantly Spanish-speaking and predominantly English-speaking Latine populations with regard to ASD stigma. It may also be of interest to address differences between the experiences of Latine parents of autistic children and consequences of ASD stigma across language preference (i.e., experiences in predominantly Spanish- versus English-speaking communities). This would also be worth exploring in a larger sample with the general public as well as providers.

Finally, future studies could extend the current research by addressing the provider perspective on ASD in Latine communities and potential impacts of stigmatization on care and support for autistic individuals and their families. Many participants in the current study and Latine parents of autistic children in previous studies (Blanche et al., 2015; Cohen & Miguel, 2018; Gordillo et al., 2020; Zuckerman et al., 2018) have described stigmatization, misunderstanding, and feelings of isolation within the medical community. Similar to the gap addressed by the current study, no research to date has explored the provider's perspective on this phenomenon and how it may influence care, quality of life, and perpetuation and impact of stigma. Such research would benefit from utilizing qualitative methodology at first, as was the case in the current study, to gain a better and fuller understanding of an understudied area and concept. In doing so, groundwork is laid in which interventions rooted in cultural values of the target community can be created and implemented alongside stakeholders within that community.

Limitations

The present study has several limitations. First, while this study is considered the first step in understanding the Latine public's perception of ASD, stigma towards ASD, and potentially deleterious effects (i.e., lack of social support), there was no reference group. It would be of interest to conduct a similar study with Latine parents of autistic children to understand their perception of the Latine community's understanding and inclusivity. Moreover, the current study may be susceptible to response bias as participants may respond positively in the face of an interviewer versus other research designs, such as a completely anonymous survey. This could further skew the difference between public perception of ASD compared to the lived experience of public perception.

Additionally, the present sample was solely comprised of Latine individuals. Consequently, there are no other cultural groups with which to compare results. It would be of interest to include other cultural groups in the future to understand how stigma presents and differs in its effects across populations. Within the Latine sample, and given that a majority of the Latine population in Oregon was comprised of individuals of Mexican origin, the results may not be generalizable to other Latine cultural groups and identities. Future studies should aim to recruit a more representative sample of individuals from diverse Latine backgrounds. Lastly, acculturation was not measured as part of the current study but may play a role in responses as Latine individuals with higher levels of acculturation to U.S. mainstream culture have been shown to have more knowledge about ASD and better access to resources and information (Voelkel et al., 2013), which may influence perspectives and helping behavior. It is of interest to factor in acculturation since it may play a role in responses across individuals and groups.

Conclusion

Schema theory suggests that negative attitudes such as stigma could influence behavior and differ explicitly and implicitly, as studies have shown discrepancy in external and internal attitudes and social isolation by those that are stigmatized (Aosved, Long, & Voller, 2009; Bartlett, 1932). Presentation, rate, and effect of explicitly-reported ASD stigma has only been examined by parent endorsement within Latine populations (Blanche et al., 2015; Cohen & Miguel, 2018; Zuckerman et al., 2018). Moreover, studies have quantified stigma using explicit measures (Blanche et al., 2015; Cohen & Miguel, 2018; Zuckerman et al., 2018), consequently missing implicit attitudes. Investigating implicit associations with disability across sociodemographic variables and familiarity with disability allows for a better and more accurate understanding of general perceptions and attitudes towards disability within the population. Additionally, taking a qualitative approach to understanding the public's explicit beliefs, attitudes, and potentially stigmatizing behavior towards ASD within Latine populations fills a gap in the literature and addresses the overall level of stigma within the Latine community. By also taking into consideration the effect of stigma on social support and helping behavior, the present study was the first step in elucidating how the Latine public approaches families of autistic children. Overall, the present study helped in providing a framework for future studies, potentially developing interventions to increase public awareness and knowledge of ASD in a linguistically- and culturally-sensitive manner to reduce stigma, increase information about ways to assist Latine community and family members of autistic individuals, and understand how to utilize the collectivistic culture to employ Latine community members to increase and spread knowledge of ASD, provide social support for families, and increase inclusivity.

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COMBINED DISCUSSION

Stigma may present as implicit or explicit bias, stereotyping, discrimination, and prejudice based on preconceived schemas (Bartlett, 1932; Corrigan, 2000; Corrigan, Roe, & Tsang, 2011; Mukolo, Heflinger, & Wallston, 2010). When studied across several different diagnoses, stigma has deleterious effects on those that are stigmatized and their families (Alonso et al., 2009; Corrigan, 2004; Brown et al., 2010; Fox, Smith, & Vogt, 2018; Jennings et al., 2015; Link, 1982). Autism and disability stigma are understudied, though there is increasing interest in this area of research (Ali et al., 2012; Ali et al., 2015; Ali et al., 2016; Mitter, Ali, & Scior, 2019; VanPuymbrouck, Friedman, & Feldner, 2020; Werner & Shulman, 2015; Wilson & Scior, 2015). The few studies which have addressed stigmatization in these populations show generally consistent results with the effects of stigma in other diagnoses (Ali et al., 2012; Ali et al., 2015; Ali et al., 2016; Mitter, Ali, & Scior, 2019; VanPuymbrouck, Friedman, & Feldner, 2020; Werner & Shulman, 2015; Wilson & Scior, 2015). There are even fewer studies which have examined the presentation and impact of stigma in autism and broad disability within underrepresented and underserved communities and cultures, namely the Latine community (Blanche et al., 2015; Cohen & Miguel, 2018; Gordillo et al., 2020; Zuckerman et al., 2018).

Given that stigma is defined by the community in which it exists, it may differ in presentation and impact across cultures depending on the values held in distinct communities (Dietrich et al., 2004; Griffiths et al., 2006; Scior et al., 2013). The Latine community is considered collectivistic, meaning it places high value on community inclusion and perception (Fung & Tsang, 2010; Kramer et al., 2002; Ng, 1997).

Community inclusion may be a protective factor against stigma because of the emphasis on being welcoming and supportive to all community members. On the other hand, community perception may be a risk factor for stigma because of the expectation that community members meet and follow community norms and values (Fung & Tsang, 2010; Kramer et al., 2002; Ng, 1997) – a potential area of difficulty for autistic individuals which may reflect poorly on them and their families. Few studies have addressed these concepts in depth, and thus far have been mostly limited to parent report (Blanche et al., 2015; Cohen & Miguel, 2018; Gordillo et al., 2020; Zuckerman et al., 2018).

The limited literature on autism stigma within the Latine community has relied solely on the report of Latine parents of autistic children (Blanche et al., 2015; Cohen & Miguel, 2018; Gordillo et al., 2020; Zuckerman et al., 2018). Across these studies, parents report generally consistent experiences: high levels of stigmatization at the hands of a variety of individuals including immediate and extended family, friends, the general community, and providers (Blanche et al., 2015; Cohen & Miguel, 2018; Gordillo et al., 2020; Zuckerman et al., 2018). This stigmatization contributes to social isolation and withdrawal, difficulty accessing services, and overall low quality of life (Blanche et al., 2015; Cohen & Miguel, 2018; Gordillo et al., 2020; Zuckerman et al., 2018). Interestingly, when assessing stigma in disability within the general community, there are low levels of explicitly reported stigmatization (Abdul-Chani et al., 2021; Stronach, Wiegand, & Mentz, 2019). Consequently, a discrepancy exists between those that are stigmatized and those reportedly perpetuating the stigmatization. Several mechanisms may explain this discrepancy. Firstly, stigma may not be as high as it is perceived to be by parents. While some may argue that this is a possibility, it is an invalidating suggestion to say that what one is experiencing is not true. A second possibility is that the general population is engaging in social desirability responding to paint themselves and their community in a better light. Finally, it is possible that community members are unaware that what is believed and spread in the community is stigmatizing.

The aim of the current studies was to explore this discrepancy. Paper 1 examined the presentation of bias across racioethnic groups and sociodemographic variables and explored the discrepancy between self-reported explicit attitudes and implicit attitudes measured by the Disability Attitudes – Implicit Association Test (DA-IAT). Broadly, results suggested that when explicit preference was higher for abled individuals, so too was implicit preference. Moreover, implicit preference towards abled individuals was highest in non-Hispanic/Latine White, abled, older, more conservative, and/or male participants. However, a discrepancy between explicit report and implicit bias existed such that a majority of the sample reported neutral explicit attitudes while implicit bias indicated preferences for abled individuals in a majority of the sample. These results suggest that social desirability in responding may have impacted the discrepancy. Therefore, it is of interest to explore whether this may have also played a role in the discrepancy between Latine parents of autistic children and the general public when explicitly reporting stigmatization and its impact. While explicit report can capture a wide variety of data in a shorter amount of time, qualitative research is necessary to better understand the nuance behind explicit responses, particularly when examining understudied phenomenon in populations which are historically underrepresented in the field,.

Paper 2 utilized qualitative methodology to gather information and delve deeper into the insights that may be gathered in a quantitative study. Specifically, general Latine community members were interviewed about the understanding and attitudes towards autism in the general Latine public as well as the impact of any potentially stigmatizing attitudes on social support. A clear connection was noted across participant responses. Namely, participants described a general lack of resources leading to a lack of information, a connection which is well established in the literature (Blanche et al., 2015; Cohen & Miguel, 2018; Gordillo et al., 2020; Zuckerman et al., 2018). Beyond this connection, a more nuanced understanding of autism stigma and its impact emerged. Participants endorsed that the aforementioned lack of resources and information lead to either misinformation or uncertainty which resulted in causing harm or a fear of causing harm (i.e., saying or doing the wrong thing). Finally, because of the cultural value of inclusion and unity, participants described difficulty for the general Latine public in providing help to families of autistic individuals because of the potential for causing more harm than good. However, it was also noted that there was a strong desire to learn in order to better serve their fellow Latine community members.

When taken together, results from these two studies support the second and third potential mechanisms for the discrepancy of reporting between stigmatized individuals and those perpetuating the stigmatization. Specifically, it is clear that there is a certain level of social desirability responding when asked explicitly about one’s own opinions. However, general community members also seem aware of the reality that stigmatization exists and carries a negative impact. This awareness resulted in a sort of dissonance in which participants described a strong desire to help those in their community – rooted in cultural values – but they also described a simultaneous strong desire not to cause harm.

Results of studies on autism stigma with Latine parents of autistic individuals demonstrate that they are aware of and are experiencing the presence, consequence, and denial of stigmatization within the Latine community. The current participants also describe an awareness of the presence, consequence, and denial of stigmatization as a method to reconcile the difficulty in being unable to provide the help that is central to the values of the Latine community. Therefore, it appears that both Latine parents of autistic children and general Latine community members desire the same thing: provision of support. Latine parents of autistic children are asking for inclusivity, understanding, empathy, and support (Blanche et al., 2015; Cohen & Miguel, 2018; Gordillo et al., 2020; Zuckerman et al., 2018). The general Latine community is asking for help in being able to fill these needs. When asked how to provide the information necessary to do so, participants emphasized the importance of lived experience, something that can be incorporated easily into strategies to reduce stigma in Latine and other communities.

Provision of culturally- and linguistically-relevant care and support requires that the information and resources provided are based in the values of the communities being served. The cultural value of storytelling within the Latine community is central to passing on messages, lessons, and beliefs. The emphasis in storytelling is also providing the unique perspective of an individual with the lived experience. From this perspective, it is unsurprising to see that many participants in paper 2 requested videos and podcasts of individuals from the Latine community sharing their experiences as a primary source of information. Not only does this respect a strong cultural value within the Latine community, it also provides a safe space for autistic individuals and their families to share their voice. Storytelling in the aforementioned capacity allows for community members to hear from community members, which is already one of the main sources of information for this population. Finally, providing the lived experience of autistic individuals and their families may be more impactful because it allows for much more nuance and authenticity, which is missed when individuals are simply provided with an information sheet or video that lists statistics or symptom descriptions.

Considering this, utilizing storytelling as a potential mechanism to address the limited resources, information, and consequential stigmatization of autism may be beneficial for both autistic individuals and their families as well as the community. Many individuals can provide their lived experiences in a myriad of ways thanks to social media and the internet. While this may be the case, vetting information, its accuracy, and its impact is nearly impossible to do without trained individuals serving as a filter and sounding board to summarize key points, takeaways, and next steps that emerge from these lived experiences. Consequently, creation of videos or podcasts, for example, in which these stories are shared should be collaborative between researchers and the target population in which the target population provides the lived experience and the researchers provide the summary. Moreover, decisions about what is shared and how it is presented should also be collaborative as these resources are meant to represent autistic individuals and their families. Therefore, any production should be reviewed by stakeholders for accuracy and authenticity to the story.

Recent data suggests that, for the first time ever, Latine children have been diagnosed at a higher prevalence rate than other racioethnic groups (Maenner et al., 2023). This new information is important to frame how stigmatization, culture, and awareness may be impacting access to care across stakeholders (i.e., families, community, and providers). However, there is still a gap in the literature understanding the nuanced impact of these concepts on evaluation, diagnosis, and services. Therefore, the current studies provide several directions for future research. First, research within underrepresented and underserved communities is needed. However, the research and its outcomes should always respect and honor the cultural values of the community studied and served. If this does not occur, it is arguably irrelevant to conduct such research because it is not applicable to the target population. Secondly, given the understanding that these populations are underrepresented and underserved, conducting qualitative or mixed methods research is critical to begin to understand the lived experiences of these communities. Quantitative research provides important information and can be bolstered by the understanding of context, nuance, and perspective gained from qualitative research. Working in tandem, quantitative and qualitative research provide ample opportunity to explore a phenomenon from multiple perspectives and record its existence and impact across situations. For example, the qualitative findings from paper 2 may be used to create a quantitative measure for assessing common experiences of stigmatization across cultures. Finally, any work should be collaborative and intentionally incorporate individuals from the target population to best conduct and serve the communities that are being studied. Researchers have the tools to find answers, but the community has the questions, and quite often, the answers as well.

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APPENDIX A

INTERVIEW GUIDE – ENGLISH

Public Autism Stigma in Latines (PAS-L) – Individual Interview for Parents

You have been invited to be in this research study because you have a child between age XXX and XXX years old who is attending {INSERT CLINIC/ORGANIZATION HERE}. We want to know about the perceptions and understanding about autism spectrum disorder in the Latine community. We will be discussing your experience with attitudes towards, beliefs about, and social support for Latine families of children with autism. We know that families have different experiences with disability: it is okay if you don't know very much or even anything about autism, or if you haven't thought much about it. There are no right or wrong answers. We will record this interview and will take notes to make sure we are capturing what you think. All of the things you say will be kept confidential. Your name will not be identified or linked to what you say.

Do you have questions about the interview process?

If it is okay with you, I will start the recorder now.

Warm-Up Qualitative Questions

1. Please tell me:
a. the first name of your child?
b. how old they are?
c. something that you really love or admire about them?
2. Developmental Concerns (Self):
a. Think back from now until the time that [child] was born. In all of that time, have you had a concern about the way [child] plays, learns, speaks, acts and/or moves for his/her age?
b. IF YES i. Pick one time that you remember well. What was the concern? What did you do?
3. Defining Community: Now we are going to switch gears and talk for a little bit about your community. Community can be defined in a lot of ways, for example your family and friends, your neighbors, your job or work, your town, your city, or even the country where you live or were born.
a. Because there are many definitions of community, who is included in each person's community can be different too. In just a few sentences, can you tell me who you think is in your community? **Note:** use the participant's definition of community from here on out.
4. Developmental Concerns (Other):
a. Has a friend, family, or other member of your community ever had concerns about the way their child plays, learns, speaks, acts and/or moves for his/her age?
b. IF YES i. What was the concern? ii. What did the parent do? iii. How did you find out about it? iv. Did you agree?

5. Is this the sort of thing parents talk about in your community? Why or why not?

Attitudes & Beliefs Questions – Stigma Proxy

Now we'd like to change topics and talk more about your understanding and perceptions about autism spectrum disorder. Many people have different amounts of information about autism, and that is okay. We are interested in knowing about what you understand about autism and what you believe your community understands about autism.

1. Autism Attitudes (Self – Perception & Characterization)
   a. Have you heard of autism or autism spectrum disorder?
      i. What do you know about it?
      ii. Where did you hear about it?
      iii. Do you know a little or a lot?

   b. Do you have any friends, family, or community members who have children with autism or autism spectrum disorder?
      i. Who are the people that you know with autism?
      ii. How do you know them?
      iii. If you could describe the child in one word, what would it be?
2. Autism Attitudes (Other – Perception & Characterization)
   a. Have your family, friends, and/or community members talked to you about autism spectrum disorder?
      i. IF YES: Can you remember a specific time? What did they say?
      ii. IF NO: Can you think of any reasons why this has not come up?
3. Autism Beliefs (Other – Feeling & Thinking)
   a. What do your family, friends, or community members think about….
      i. autism in general?
      ii. children with autism?
      iii. families of children with autism?

   b. Do you share your families', friends', or community members' thoughts about autism? Why or why not?

   c. If participant notes negative judgements or beliefs about autism in the community, ask: how might these thoughts or beliefs impact families of children with autism?

   d. If you've expired all the ways to ask about stigma without explicitly saying the term "stigma," ask: Have you heard of the word "stigma?"
   e. IF YES: What does that word mean to you? Does stigma exist in the Latinx community about autism?
   f. IF NO: Stigma is the belief that a person has something they should be ashamed of. Many things are stigmatized. Do you think stigma exists in the Latinx community about autism? Do you feel like this described what you discussed about the thoughts and beliefs about autism in the Latinx community?
4. Autism Information

	a. What kind of information would be helpful to have about autism? b. What would be the best place to get information about autism (I.e., books, fliers, videos, etc.)? c. Who would be the best way to get the information about autism (I.e., doctor, community, family, friends, media, etc.)?

Willingness to Aid & Methods Utilized

Now we'd like to switch topics again and talk more about how you and your community may help or offer support to families of children with autism spectrum disorder. There are many different ways to help families both directly and indirectly. If you or your community have not had the opportunity to help, that is okay. We ask instead that you think about ways you and your community could help, if the opportunity were to arise.

1. Willingness to Aid & Methods Utilized (Other)	
	a. We all help people in our community in different ways. Some examples of ways people help others include, cooking or providing food, giving a ride, talking to families or offering emotional support, giving them financial support, donating items, or including them in gatherings and activities. i. Thinking about all the ways someone could help another person, how do you think people in your community help (or might help) children with autism and their families? ii. Do you think some things are more helpful than others? iii. Have people tried to help but ended up not helping or even hurting families? Why might that happen?
	b. What are some reasons that some people in your community might not want to help children with autism and their families?
	c. Some people may not want help, and that's okay. In your opinion, what are some reasons why families of children with autism may not want help?
	d. What could more information about autism "help" or "solve"?
2. Willingness to Aid & Methods Utilized (Self)	
	a. Have you ever had the chance to help the family of a child with autism? i. IF YES: What happened? How did you feel about it? ii. IF NO: Why haven't you had the chance? If you had the chance in the future, what kind of help might you provide, if any?
	b. Would there ever be a reason or situation where you would not help? i. IF YES: What would that be? ii. Are there some kinds of help that are too hard to provide? Why?
3. General Latinx Views & Willingness to Aid	
	a. Do you think the Latinx community is different from other communities in terms of how they view autism? i. IF YES: How? What makes the Latinx community different from other communities in how they view autism? ii. IF NO: Why not? What makes the Latinx community similar to other communities in terms of how they view autism?
	b. Do you think the Latinx community is different from other communities in terms of their willingness to help children with autism and their families?

i. IF YES: How? What makes the Latinx community different from other communities in how they help children with autism and their families? ii. IF NO: Why not? What makes the Latinx community similar to other communities in terms of how they help children with autism and their families?
c. What are some strengths of the Latinx community that change the way they view autism or help those with autism and their families?
d. What are some areas that could improve in the Latinx community in terms of their perspective on autism or helping those with autism and their families?

APPENDIX B

INTERVIEW GUIDE – SPANISH

Estigma público del autismo en latinos (PAS-L) - Entrevista individual para padres

Se le invitó a participar en este estudio de investigación porque tiene un hijo de entre XXX y XXX años que asiste a {INSERT CLINIC/ORGANIZATION HERE}. Queremos conocer las percepciones y la comprensión sobre el trastorno del espectro autista en la comunidad latina. Discutiremos su experiencia con las actitudes, creencias y apoyo social para las familias latinas de niños con autismo. Sabemos que las familias tienen diferentes experiencias con la discapacidad: está bien si no sabe mucho o nada sobre el autismo, o si no ha pensado mucho en ello. No hay respuestas correctas o incorrectas. Grabaremos esta entrevista y tomaremos notas para asegurarnos de captar lo que piensa. Todo lo que diga se mantendrá confidencial. Su nombre no se identificará ni vinculará a lo que diga.

¿Tiene preguntas sobre el proceso de entrevista?

Si le parece bien, encenderé la grabadora ahora.

Preguntas cualitativas de preparación

1. Por favor, dígame:
a. el nombre de su hijo
b. ¿cuántos años tiene?
c. algo que realmente ame o admire de él o ella
2. Preocupaciones sobre el desarrollo (uno mismo):
a. Piense desde ahora hasta el momento en que nació [el niño]. En todo ese tiempo, ¿le ha preocupado la forma en que [el niño] juega, aprende, habla, actúa o se mueve para su edad?
b. EN CASO AFIRMATIVO i. Elija un momento que recuerde bien. ¿Cuál fue la preocupación? ¿Qué hizo?
3. Definición de comunidad: Ahora vamos a cambiar de marcha y hablar un poco sobre su comunidad. La comunidad se puede definir de muchas maneras, por ejemplo, su familia y amigos, sus vecinos, su empleo o trabajo, su pueblo, su ciudad o incluso el país donde vive o nació.
a. Debido a que existen muchas definiciones de comunidad, quiénes están incluidos en la comunidad de cada persona también puede ser diferente. En unas pocas frases, ¿puede decirme quién cree que está en su comunidad? **Nota:** utilice la definición de comunidad del participante de aquí en adelante.
4. Preocupaciones sobre el desarrollo (otras):
a. ¿Alguna vez un amigo, familiar u otro miembro de su comunidad ha tenido preocupaciones sobre la forma en que su hijo juega, aprende, habla, actúa o se mueve para su edad?
b. EN CASO AFIRMATIVO

i. ¿Cuál fue la preocupación?
ii. ¿Qué hizo el padre o la madre?
iii. ¿Cómo se enteró?
iv. ¿Estuvo de acuerdo?

5. ¿Es este el tipo de cosas de las que hablan los padres en su comunidad? ¿Por qué sí o por qué no?

Preguntas sobre actitudes y creencias - indicador del estigma

Ahora nos gustaría cambiar de tema y hablar más sobre su comprensión y percepciones sobre el trastorno del espectro autista. Muchas personas tienen diferente cantidad de información sobre el autismo, y eso está bien. Nos interesa saber qué entiende usted sobre el autismo y qué cree que entiende su comunidad sobre el autismo.

1. Actitudes del autismo (autopercepción y caracterización)

a. ¿Ha oído hablar del autismo o del trastorno del espectro autista?
i. ¿Qué sabe usted al respecto?
ii. ¿Dónde oyó acerca de eso?
iii. ¿Sabe un poco o mucho?

b. ¿Tiene amigos, familiares o miembros de la comunidad que tengan hijos con autismo o trastorno del espectro autista?
i. ¿Quiénes son las personas que conoce con autismo?
ii. ¿Cómo las conoce?
iii. Si pudiera describir al niño en una palabra, ¿cuál sería?

2. Actitudes del autismo (otro - percepción y caracterización)

a. ¿Su familia, amigos o miembros de la comunidad le han hablado sobre el trastorno del espectro autista?
i. EN CASO AFIRMATIVO: ¿Puede recordar un momento específico? ¿Qué dijeron?
ii. EN CASO NEGATIVO: ¿Puede pensar en alguna razón por la que esto no ha surgido?

3. Creencias sobre el autismo (otros: sentimiento y pensamiento)

a. Qué piensan su familia, amigos o miembros de la comunidad sobre…
i. el autismo en general
ii. los niños con autismo
iii. las familias de niños con autismo

b. ¿Comparte los pensamientos de sus familiares, amigos o miembros de la comunidad sobre el autismo? ¿Por qué sí o por qué no?

c. **Si el participante nota pensamientos negatives sobre el autismo en la comunidad, pregunte:** es posible que estos pensamientos podrían afectar las familias de niños con autismo? ¿En qué manera?

d. **Si ha expirado todas las formas de preguntar sobre el estigma sin decir explícitamente el termino “estigma,” pregunte:** Ha oído hablar de la palabra “estigma”?
e. **EN CASO AFIRMATIVO:** Que significa esa palabra para usted? Existe el estigma en la comunidad latina sobre el autismo?
f. **EN CASO NEGATIVO:** El estigma es la creencia de que una persona tiene algo de lo que debería avergonzarse. Se estigmatizan muchas cosas. ¿Crees que existe el estigma en la comunidad latina sobre el autismo?

¿Sientes que esto describe lo que mencionaste sobre los pensamientos y creencias sobre el autismo en la comunidad latina?
Informacion sobre el autismo
a. ¿Qué tipo de información sobre el autismo sería útil tener o saber? b. Cuál sería el mejor lugar para obtener información sobre el autismo (es decir, libros, videos, etc.)? c. Cuál sería la mejor manera de obtener la información sobre el autismo (es decir, un médico o doctor, la comunidad, familiares, amigos, noticia, etc.)?

Disposición a la ayuda y métodos utilizados

Ahora nos gustaría volver a cambiar de tema y hablar más sobre cómo usted y su comunidad pueden ayudar u ofrecer apoyo a las familias de niños con trastorno del espectro autista. Hay muchas formas diferentes de ayudar a las familias, tanto directa como indirectamente. Si usted o su comunidad no han tenido la oportunidad de ayudar, está bien. En cambio, le pedimos que piense en las formas en que usted y su comunidad podrían ayudar, si surgiera la oportunidad.

1. Disposición a la ayuda y métodos utilizados (otros)
a. Todos ayudamos a las personas de nuestra comunidad de diferentes maneras. Algunos ejemplos de formas en que las personas ayudan a otros incluyen cocinar o proporcionar comida, llevar en el auto, hablar con las familias u ofrecer apoyo emocional, brindarles apoyo financiero, donar artículos o incluirlos en reuniones y actividades. i. Pensando en todas las formas en que alguien podría ayudar a otra persona, ¿cómo cree que las personas de su comunidad ayudan (o podrían ayudar) a los niños con autismo y sus familias? ii. ¿Cree que algunas cosas son más útiles que otras? iii. ¿La gente ha tratado de ayudar pero terminaron no ayudando o incluso dañando a las familias? ¿Por qué podría pasar eso?
b. ¿Cuáles son algunas de las razones por las que algunas personas en su comunidad podrían no querer ayudar a los niños con autismo y sus familias?
c. Es posible que algunas personas no quieran ayuda, y eso está bien. En su opinión, ¿cuáles son algunas de las razones por las que las familias de los niños con autismo podrían no querer ayuda?
d. ¿Que podría “ayudar” o “resolver” más información sobre el autismo?
2. Disposición para ayudar y métodos utilizados (por cuenta propia)
a. ¿Alguna vez ha tenido la oportunidad de ayudar a la familia de un niño con autismo? i. EN CASO AFIRMATIVO: ¿Qué pasó? ¿Cómo se sintió al respecto? ii. EN CASO NEGATIVO: ¿Por qué no ha tenido la oportunidad? Si tuviera la oportunidad en el futuro, ¿qué tipo de ayuda podría brindar?
b. ¿Habrá alguna vez una razón o situación en la que no ayudaría? i. EN CASO AFIRMATIVO: ¿Cuál sería? ii. ¿Existen algunos tipos de ayuda que son demasiado difíciles de brindar? ¿Por qué?
3. Puntos de vista generales de los latinos y disposición para ayudar

	a. ¿Cree que la comunidad latina es diferente de otras comunidades en términos de cómo ven el autismo? i. EN CASO AFIRMATIVO: ¿Cómo? ¿Qué diferencia a la comunidad latina de otras comunidades en cómo ven el autismo? ii. EN CASO NEGATIVO: ¿Por qué no? ¿Qué hace que la comunidad latina sea similar a otras comunidades en términos de cómo ven el autismo?
	b. ¿Cree que la comunidad latina es diferente de otras comunidades en términos de su disposición para ayudar a los niños con autismo y a sus familias? i. EN CASO AFIRMATIVO: ¿Cómo? ¿Qué diferencia a la comunidad latina de otras comunidades en la forma en que ayudan a los niños con autismo y a sus familias? ii. EN CASO NEGATIVO: ¿Por qué no? ¿Qué hace que la comunidad latina sea similar a otras comunidades en términos de la forma en la que ayudan a los niños con autismo y a sus familias?
	c. ¿Cuáles son algunas de las fortalezas de la comunidad latina que cambian la forma en que ven el autismo o ayudan a las personas con autismo y sus familias?
	d. ¿Cuáles son algunas áreas que podrían mejorar en la comunidad latina en términos de su perspectiva sobre el autismo o ayudar a las personas con autismo y sus familias?

OTROS PENSAMIENTOS?