

# Understanding the Experience of Stigma for Parents of Children with Autism Spectrum Disorder and the Role Stigma Plays in Families' Lives

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**Abstract** Stigma is widely perceived in the lives of families with autism spectrum disorder (ASD) yet large, systematic studies have not been undertaken. Following Link and Phelan's (Ann Rev Sociol 27:363–385, 2001) model, this study of 502 Simons Simplex Collection families details how different factors contribute to stigma and how each appears to increase the overall difficulty of raising a child with ASD. The model begins with the child's behavioral symptoms and then specifies stigma processes of stereotyping, rejection, and exclusion. Autism behaviors contribute both to the difficulty families experience raising a child with autism and to the stigma processes

associated with those behaviors. Stigma also plays a significant role (.282,  $p < .001$ ) in predicting how difficult life is overall for parents.

**Keywords** Autism spectrum disorder · Stigma · Stereotyping · Rejection · Exclusion · Discrimination · Scales · Regression analysis

## Introduction

While the observation that stigma associated with autism spectrum disorder (ASD) is significant and widespread, a systematic study of a large population of ASD parents is needed that assesses the components and impact of stigma in their lives. To contribute to filling this gap, we considered several questions about stigma and its consequences: To what extent do families experience stigma? What are some of the key features of stigma that families experience? How do these aspects of stigma contribute to how difficult family caregivers feel it is to raise a child with ASD? To address these questions, we developed an instrument to assess the impact of stigma on the lives of 502 parents who are participants in the Simons Foundation Autism Research Initiative's (SFARI) Simons Simplex Collection (SSC). Our empirical work followed the model of Link and Phelan (2001, 2006) that details how different factors may contribute to stigma.

In his seminal essay, Goffman (1963) defined stigma as an "attribute that is deeply discrediting" and reduces the individual "from a whole and usual person to a tainted, discounted one" (p. 3). Following on Goffman, Link and Phelan (2001, 2006) conceptualized stigma in terms of a process that emphasizes the following components: first, people identify and label differences they observe in others.

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In a second component, stereotyping, people make assumptions about the labeled group and apply those assumptions indiscriminately to all the individuals in the designated group. Continuing the process, people distance themselves from the labeled group, positioning the group to some extent as fundamentally different from other people. Often emotions of fear, disgust, or annoyance emerge in the stigmatizing group while emotions of shame, embarrassment, and belittlement are experienced by the stigmatized group. Finally, to complete the stigma process, people use stereotypes and act on emotions to discriminate against individuals in the labeled group excluding them and denying them access to goods and services the society offers to others.

In the autism literature, the concept of stigma has been used to analyze the experiences of shame and social exclusion of parents of children with ASD (Farrugia 2009; Gray 1993, 2002). Farrugia (2009) outlined how the evolution of autism etiology has influenced stereotypes associated with the disorder over time. While the general understanding of ASD etiology may have shifted from psychoanalytic to cognitive or genetic explanations, many of the associated stereotypes linger such as cold and distant parenting, specific types of autistic intelligence, and distancing from siblings because of the perceived heritability of autism.

Parents and siblings of children with disabilities often experience what Goffman (1963) defined as “courtesy stigma,” or, a stigma of association (associative stigma), experienced by people connected to the stigmatized group (Farrugia 2009; Gray 1993, 2002). While Goffman’s courtesy stigma originally referred to voluntary association with the stigmatized group, researchers have extended it to parent–child relationships in the context of disability stigma, noting that parents struggle to both embrace a connection with their child and at the same time wish to detach themselves from a “spoiled social identity” as a result of their child’s diagnosis (Farrugia 2009; Gray 2002).

Studies of associative stigma generally include either a relatively large group of the general public and employ quantitative research methods (Butler and Gillis 2011; Chambres et al. 2008; Huws and Jones 2010; Milacic-Vidojevic et al. 2012) or they sample a small group of parents of children with autism and use qualitative approaches (Farrugia 2009; Gill and Liamputtong 2011; Gray 1993; Neely-Barnes et al. 2011). As an example of a relatively large general population sample ( $N = 181$ ) conducted in Belgrade, Milacic-Vidojevic et al. (2012) found that participants harbored feelings of blame, pity, and the belief that family members are also contaminated.

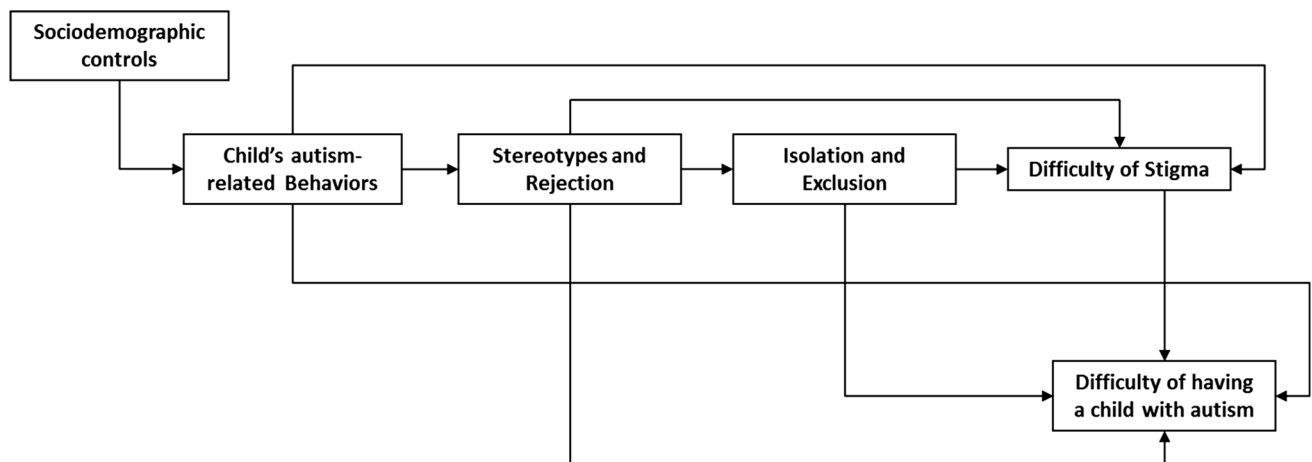
In smaller, qualitative studies, Gray (1993, 2002), one of the early leaders exploring associative stigma as it applies

to parents of people with ASD, commented on the uniquely stigmatizing aspects of autism that provoked stereotypes. In two groundbreaking studies from Australia, one published in 1993 that involved 32 parents and another in 2002 of 53 parents, Gray noted several factors that breed stereotypes: the discrepancy between the normal physical appearance of individuals and the reality of their disability; the distinctive, disruptive, and socially inappropriate behavior; the struggle to receive an accurate diagnosis; and the general lack of knowledge about the disorder. Furthermore, he found that parents of elementary and teen-age children with more severe (and in particular, more aggressive) autism, reported more stigma than did parents of higher functioning, less aggressive, or pre-teen age children.

Other qualitative studies emphasized parents who feel blamed for their child’s behavior (Neely-Barnes et al. 2011), isolated and excluded from family and friends (Farrugia 2009; Gray 1993; Woodgate et al. 2008), and an overall feeling of distress and burden because of stigma (Green 2003).

Drawing on the empirical literature reviewed and on the conceptualization of Link and Phelan (2001, 2006), we developed the following model to guide our measurement and analysis. According to this model, a child’s autism-related behaviors (e.g., symptoms and disruptive behaviors) represent the starting point in the stigma process. The reactions of others are not always informed, rational responses to such behaviors but instead frequently carry assumptions about lack of parental control, about the expression of willfully odd and disturbing behaviors, and assumptions about what someone who displays such behaviors is capable of doing.

The behavior itself, in combination with such stereotypes, generates rejection by others which in turn leads to isolation and exclusion in a broad set of social circumstances. Then, as the conceptual model portrays (see Fig. 1), individuals determine the extent of stigma they internalize and make a judgment of how important stigma is in their lives. Finally the last step in the model captures a parent’s assessment of how difficult it is to raise a child with ASD. The value of the conceptual scheme is that it portrays one path by which the social process of stigma might make the experience of raising a child with ASD more difficult. In our study, this model is under scrutiny and subject to being rejected by the data if we find the data do not support these relationships or if the data support relationships in the direction opposite to what we have proposed. If our results do support this model, it would suggest that addressing the social aspects of stigma could reduce the overall difficulty of raising a child with ASD.



**Fig. 1** Understanding autism stigma—conceptual model

## Methods

### Sample and Procedures

The SFARI, formed to enhance the understanding and treatment of autism, assembled the SSC, a cohort of 2756 families with one child (the proband) on the autism spectrum (Fischbach and Lord 2010). Families were seen by trained clinicians at 1 of 12 SFARI sites including 8 university clinics in the United States and 4 in Canada. The proband was evaluated with the ADOS, ADI-R, and more than 20 other instruments (Lord et al. 1999). Neither biological parent nor any siblings were found to be on the autism spectrum.

The SFARI sites invited these families to join SSC@IAN (the Interactive Autism Network) hired by SFARI to manage the SSC data. A total of 63 % accepted and sent the family's information to IAN, 7 % declined, and 30 % were lost to follow-up. Of the 1736 who agreed to have their information sent to IAN, a total of 1460 (84 %) ultimately completed enrollment and are officially "SSC@IAN families." Parent participants were recruited from this well-defined population (Fischbach et al. 2015).

Our study included two stages of recruitment. In the first, IAN staff mailed a letter to SSC parents describing the survey and asking those interested in participating to reply by email to IAN. A sample of 554 families was randomly selected by IAN from those who agreed to learn more about the survey. Contact information of the self-identified primary caregiver was sent by IAN to the Center for Survey Research (CSR) of the University of Massachusetts Boston (UMASS Boston), a research firm hired to help construct the survey instrument and to conduct the interviews. In the second stage, CSR recruited the parents to participate in the study. Of the 554 parents, 41 were unreachable after numerous attempts, 2 were ineligible,

and 9 refused; 502 completed the interview (91 % response rate). The sample included parents from all 12 SFARI sites who resided in 35 US states and 3 Canadian provinces.

Of the parent sample, 94.8 % were mothers who ranged in age from 28 to 65 years (mean = 43.7 years old, SD = 5.36). Over 70 % had graduated college, 81.5 % were Caucasian, and 84.1 % had at least one additional child.

The children with ASD were mostly male (85.9 %, a ratio of 6:1 boys to girls after over sampling for girls to ensure sufficient numbers for analysis), verbal (88 %), and enrolled in school (97 %). The verbal level and school enrollment provided parents with opportunities to report on their child's interaction with peers and other social experiences. The children ranged in age from 5 to 18 (47.5 % were between 8 and 11 years old; OR mean = 10.95 years, SD = 3.07). Parents reported the diagnoses of their children as autism 52.2 %, PDD-NOS 27.3 %, and Asperger's Syndrome 17.1 % (based on DSM-IV-TR criteria). An additional 3.4 % could not be classified.

We developed a Computer-Assisted Telephone Interview (CATI) in a multi-stage process. We first comprehensively surveyed quantitative and qualitative research on stigma and autism and met repeatedly with experts in the field of both stigma and autism research to both discuss the concepts we might measure and the specific items we proposed. Once we identified initial topical areas of interest, building on the current body of autism literature and conceptual frameworks of stigma, we then assembled three focus groups of young adults on the spectrum (ages 18–21, average 3.7 young adults per group) and three focus groups of parents of children with ASD from the SSC (average of 4.7 parents per group). Focus groups were held at three geographically diverse SFARI university clinic sites: Columbia, Yale, and University of Michigan. The focus groups helped define the concepts and specific areas of

focus for the interview and honed our interest in and understanding of the life experiences of individuals and families and the role stigma played.

After identifying these focus areas, we tested them in qualitative interviews with parents by asking open ended questions that helped assess the specific areas of greatest concern for this population, the language they used when discussing these concepts, and the types of answers they gave. This process helped us refine the interview questions and define the answer categories for the multiple choice questions. After constructing an initial draft of the complete interview, we completed cognitive testing of a small sample of SSC parents by reading each question, asking for answers, and then probing to understand what the participant was thinking when he/she responded to the question. This reduced misunderstanding, improved clarity of the quantitative and qualitative survey questions, and helped ensure that the questions directly accessed the content we sought to obtain. Minor revisions were made based on the cognitive testing. After incorporating these changes, we pilot tested the revised CATI on a sample of 20 individuals from the target sample group.

After completing these interview construction steps, we conducted 502 phone interviews that lasted approximately 20–30 min each. Data collection was completed by the end of December 2012. Verbal informed consent was obtained from all individual participants included in the study. Respondents who completed the interview received a \$25 check or international postal order. All focus groups and the implementation of the CATI were approved by the Institutional Review Boards at Columbia University Medical Center, Yale University, University of Michigan, and UMASS Boston.

## Measures

In this study, stigma was defined for the participants as when “individuals are made to feel inferior, shamed, isolated, or their self-image is damaged.” We assessed the psychometric properties of the measures beginning with exploratory factor analysis to determine whether the questions representing domains of child behaviors, stereotypes, and rejection clustered as expected and thus could be represented by separate factors. Based on the results of the factor analysis, we constructed scales consisting of questions that strongly loaded on the same factor. Cronbach’s (1951) alpha ( $\alpha$ ) was used to assess that the formed scales had adequate internal consistency and reliability. We present example items from each scale in the text and provide the wording and frequency distributions of all scale items are included in the tables of the “Appendix”.

## Constructed Scales

*Child’s Autism-related Behaviors* involves questions designed to capture variation in symptoms and behaviors associated with ASD (see Table 6 in “Appendix”). The 7-item scale ( $\alpha = .69$ ) includes items such as “trouble making eye contact” and “became visibly upset with change in routine”. Example questions are—“In the last 6 months, how often has [CHILD] been a threat or aggressive towards others—often, sometimes, rarely, or never?” and “...done repetitive behaviors such as hand flapping or rocking that was noticeable to others”.

*Parent’s Perception of Public Stereotypes* includes two scales that emerged from an exploratory factor analysis that describe stereotypes that parents believe the lay public holds about individuals on the autism spectrum. The first scale, entitled *Competence in Social Roles*, is based on a 3-item scale ( $\alpha = .84$ ) that measures stereotypes regarding “marriage”, “holding a job”, and “living independently.” An example item is: “Individuals with autism will never be able to hold a job. Do you think most people believe that, some people believe that, or only a few people believe that?” (see Table 7 in “Appendix”).

*Autism Causes and Characteristics* is the second stereotype scale that contains 5 items ( $\alpha = .62$ ). As examples, parents are asked to respond whether they believed most, some, or only a few people believe the following statements: “Individuals with autism cannot be a good friend because of their autism”; “Parents can cause their children’s autism because of their parenting style”; and “Individuals with autism are ‘mentally ill’” (see Table 8 in “Appendix”).

*Frequency of Rejection of Child by Peers* is a 7-item scale ( $\alpha = .81$ ) that assesses the frequency that the child was rejected by his/her peers. An example item is “To the best of your knowledge, in the past 6 months, how often has [CHILD] been teased or called an insulting name by other children because of (his/her) autistic behaviors—often, sometimes, rarely, or never?” (see Table 9 in “Appendix”).

*Isolation from Friends and Family* is a single item measure assessing how often the parents isolated themselves from their friends and family because of their child’s autistic behaviors. The item reads: “In the past 6 months, how often have you decided not to spend time with friends and family because of [CHILD]’s autistic behaviors—was that often, sometimes, rarely, or never?” (see Table 10 in “Appendix”).

*Exclusion by Friends and Family* is a single item measure assessing how often parents felt actively excluded because of their child’s autistic behaviors. The question reads “In the past 6 months, how often have you felt that you and your family were excluded from events or

activities because of [CHILD]’s autistic behaviors”— was that often, sometimes, rarely, or never?” (see Table 10 in “Appendix”).

*Impact of Autism on Parent’s Work Hours* is a single item measure assessing whether parents had to cut back on work hours because of their child’s autism. The precise wording of the question was “Sometimes parents of children with health conditions have problems in their own lives because of their child’s condition. Have any of the following happened to you or [CHILD]’s other parent because of [CHILD]’s autism and having to take care of him/her? Have you or [CHILD]’s other parent had to cut back on work hours or stop working?” Parents were asked to respond “yes” or “no” (see Table 10 in “Appendix”).

*Overall Assessment of Difficulty of Stigma in Parent’s Lives* was assessed by asking, “How difficult has the stigma that is often associated with autism been for you and your family—extremely difficult (5), very difficult (4), somewhat difficult (3), a little difficult (2), not at all difficult (1), or have you not experienced stigma (0)? (see Table 11 in “Appendix”).

*Overall Difficulty of Raising a Child with Autism Spectrum Disorder* was assessed by the question, “Overall, how difficult would you say it has been for your family to have a child on the autism spectrum?” Parents were asked to respond—extremely difficult (5), very difficult (4), somewhat difficult (3), a little difficult (2), or not at all difficult (1) (see Table 11 in “Appendix”).

Parents were also asked a general question about their perception of the prevalence of stigma. The precise wording of the question was: “Do you think individuals with autism are stigmatized? Would you say definitely yes, probably yes, probably no, or definitely no?” (see Table 11 in “Appendix”).

## Analysis

We used multiple regression for our continuously distributed outcome variables and logistic regression for the only dichotomous dependent variable in our model (impact on employment) to investigate variables of interest while statistically controlling for potential confounding variables. All analyses statistically controlled for certain sociodemographic controls including child’s age, gender, diagnosis, verbal ability, education, and physical characteristics, as well as parent’s race, education, and age (regression coefficients not reported).

Analyses closely follow the conceptual model in Fig. 1. We developed and tested the model to determine if the data would support or disconfirm what we expected. The data could disconfirm the model by showing no relationship where one was expected or even a relationship in the opposite direction of what was expected.

Specifically, we begin with analyses in which stereotyping and peer rejection are dependent variables and then move to the right in our model to analyses in which isolation and exclusion are the dependent variables. This is followed by equations in which the difficulty of stigma and finally, the overall challenge of raising a child with ASD, are the dependent variables.

## Results

In order to provide information about the frequency of each of the stigma-related measures and outcomes, we provide descriptive results for each measure (see “Appendix” for providing frequencies for all of the measures).

### Descriptive Findings: How Common are Stigma-related Perceptions and Experiences?

#### *Child’s Autism-related Behaviors*

All study participants reported that at some point over the last 6 months their child often or sometimes exhibited at least one autism-related behavior listed in the 7-item scale (see Table 6 in “Appendix”). Regarding specific questions in this domain, 78.7 % of parents reported that their child had trouble making eye contact, 44.6 % reported their children had serious tantrums or meltdowns, and 20.8 % reported their child had trouble with bladder or bowel control.

#### *Stereotypes Concerning Competence in Social Roles*

Over 90 % of parents think that most or some (as opposed to only a few) of the general public believe that a child with ASD will never hold a job, marry, or live independently (see Table 7 in “Appendix”).

#### *Stereotypes Concerning Autism Causes and Characteristics*

Once again, parents thought that most or some of the public (as opposed to only a few) believe that a person with ASD cannot be a good friend (86.5 %), that individuals with autism are mentally ill (73.7 %), are dangerous or a threat to others (60.8 %), have intellectual disabilities (94.6 %), or that the person’s ASD was caused by the way they were parented (40.3 %) (see Table 8 in “Appendix”).

#### *Frequency of Rejection of Child by Peers*

To offer evidence concerning the frequency of rejection, we provide the percent of parents reporting that an

experience of rejection occurred often or sometimes as opposed to rarely or never in the 6 months prior to interview (see Table 9 in “Appendix”). Having difficulty making friends (82.9 %), being regarded as “weird” (76.1 %), being left out of activities by other children (74.5 %), and being avoided by other children (69.2 %), were more common experiences reported by parents whereas actively being teased or insulted (36.5), hearing your child called hurtful words (21.9 %), and being physically bullied (12.8 %) were less common.

*Isolation from Friends and Family, Exclusion by Friends and Family, and Impact of Autism on Parent’s Work Hours Because of Child’s ASD (see Table 10 in “Appendix”)*

Many parents (40.4 %) reported isolating themselves from friends and family often or sometimes in the past 6 months by deciding not to spend time with them because of the autistic behaviors of their child. Exclusion was also reported with some frequency with 31.7 % of parents indicating that they were often or sometimes excluded from events and activities by others. Finally, 55.4 % of parents indicated that they or their spouse had to cut back on work hours because of their child’s ASD.

*Overall Assessment of Difficulty of Stigma and Overall Difficulty of Raising a Child with ASD*

When asked how difficult stigma had been in their lives, 9.0 % reported “extremely,” 22.2 % “very,” 47.5 % “somewhat”, 16.0 % “a little,” and only 4.4 % reported “not at all” (see Table 11 in “Appendix”).

Thus, the overall impact of stigma varies substantially across parents, leading to questions about why such variations might be evident and what the consequences of this variation might be. When asked “How difficult it had been for you and your family to have a child on the autism spectrum?”, 18.3 % indicated extremely,” 31.9 % “very,” 39.4 % “somewhat,” 9.0 % “a little,” and only 1.4 % stated “not at all difficult” (see Table 11 in “Appendix”). This variation in the level of difficulty of raising a child with ASD led us to consider whether, and to what extent,

the experience of stigma plays a role in the level of reported difficulty.

**Evaluating the Conceptual Model**

The descriptive findings reported show that almost all parents experienced stigma but the extent to which they did so varied. The conceptual model (Fig. 1) proposes a way of understanding some of the sources of that variation and some of its consequences. Our analyses begin at the left hand side of the model by assessing child autism-related behaviors as potential determinants of stereotyping and reports of rejection.

Are *Child’s Autism-related Behaviors* associated with *Stereotypes of Adult Competence*, *Stereotypes of Autism Causes and Characteristics*, and *Frequency of Rejection of Child by Peers*? Table 1 presents three regression analyses evaluating the potential impact of child’s autism-related behaviors on stigma related variables:

- 1) Stereotypes of Adult Competence in Social Roles
- 2) Stereotypes of Autism Causes and Characteristics, and
- 3) Frequency of Rejection of Child by Peers.

Each analysis controls for child’s age, gender, education, diagnosis, verbal ability, physical characteristics, and parents’ race, age, and education (summarized as “sociodemographic controls” in the conceptual model, Fig. 1). None of these control variables showed a strong or consistent pattern of association with the dependent variables and are therefore not shown in Table 1.

Consistent with the conceptual model, Table 1 shows that the child’s autism-related behaviors predict the extent of the stereotypes parents perceive of adult competence in social roles and how frequently their child was rejected by his/her peers. The child’s autism-related behaviors played the largest role in predicting the child’s frequency of rejection by peers ( $\beta = .438, p \text{ value} < .001$ ) such that a one standard deviation unit change in autism behaviors is associated with a .438 standard deviation unit change in the child’s rejection. Autism-related behaviors have smaller, but significant roles in predicting stereotypes of adult

**Table 1** Regression analyses showing effects of child’s autism-related behaviors on (1) stereotypes of adult competence in social roles (2) stereotypes of autism causes and characteristics, and (3) reports of rejection of child by peers (N = 502)

	Stereotypes of adult competence	Stereotypes of autism and characteristics	Rejection of child by peers
Child’s autism-related behaviors	.158**	.181***	.438***
R-square	.035**	.045**	.227***

Standardized coefficients with associations adjusted for child’s age, gender, diagnosis, verbal ability, education, physical characteristics, and parent’s race, education, and age

+  $p < .10$ ; \*  $p < .05$ ; \*\*  $p < .01$ ; \*\*\*  $p < .001$

competence in social roles ( $\beta = .158$ ,  $p$  value  $<.01$ ) and stereotypes of autism causes and characteristics ( $\beta = .181$ ,  $p$  value  $<.001$ ).

*Are Child's Autism-related Behaviors, Stereotypes of Adult Competence, Stereotypes of Autism Causes and Characteristics, and Frequency of Rejection of Child by Peers associated with Family's Isolation and Exclusion?*

Table 2 shows results for two dependent variables: (1) family isolation and (2) family exclusion with autism-related behaviors, stereotypes of adult competence in social roles, stereotypes of autism causes and characteristics and rejection of child by peers as predictor variables. For each dependent variable, we present two regression equations, the first includes *child autism-related behaviors* (Eq. 1) and the second adds *stereotypes of adult competence and autism causes and characteristics, and frequency of rejection of child by peers* (Eq. 2). The equations help to determine whether the effect of the *child's autism-related behaviors* is partially or wholly accounted for by adding the two variables for *stereotyping* and the *child's rejection by peers*.

The child's autism-related behaviors are strongly related to both isolation and exclusion; the more such behaviors a child exhibits, the more isolation and exclusion a family experiences. Table 2 also shows that neither measure of stereotyping of adult competence or autism causes and characteristics is independently associated with either family isolation or exclusion but the child's rejection by peers is significantly related to both, suggesting that the child's rejection may be one factor leading to the family's isolation and exclusion.

The third finding refers to the effect that controlling stereotypes of adult competence and child's rejection by peers have on the coefficients for the child's autism-related

behaviors. By comparing the coefficient of *autism-related behaviors* in the first equation for each dependent variable to its coefficient in the second, when the two *stereotypes and child's rejection by peers* are added to the equation, we observe that while the coefficient for *autism-related behaviors* remains significant for each dependent variable, it is diminished in magnitude. Specifically, when *isolation* is the dependent variable, the standardized regression coefficient for *child's autism-related behaviors* declines by 25 % from  $\beta = .400$ ,  $p < .001$  in Eq. 1 to  $.301$ ,  $p < .001$  in Eq. 2. When *exclusion* is the dependent variable, the coefficient for *child's autism-related behaviors* declines by 52 % from  $\beta = .359$ ,  $p$  value =  $.001$  to  $\beta = .175$ ,  $p$  value  $<.001$ . These results are important as they suggest that part of the reason the child's *autism-related behaviors* affect *isolation* and *exclusion* is the rejecting responses to those behaviors.

*Are Child's Autism-related Behaviors, Stereotypes of Adult Competence, Stereotypes of Autism Causes and Characteristics, and Frequency of Rejection of Child by Peers associated with the Impact of Autism on Parent's Work Hours?* As shown in Eq. 1 of Table 3, each one unit increase in *child's autism-related behaviors* is associated with more than a doubling (OR = 2.13) of the odds ratio of *loss of work hours* due to having a child with autism.

Equation 2 adds the two measures of *stereotyping* and *child's rejection by peers* to the model. As the equation shows, *peer rejection* (but neither of the measures of *stereotyping*) is independently associated with *parent's loss of work hours*. Each one unit change in *peer rejection* is associated with a 1.70 increase in the odds of employment cut back. Moreover, the odds ratio associated with *child's autism-related behaviors* drops from 2.13 in Eq. 1 to 1.70 in Eq. 2 after *child's rejection by peers* is controlled. This finding is consistent with the possibility that *peer rejection* is one reason that the child's *autism-related behaviors* leads to a cut back in parent's work hours.

**Table 2** Regression analyses showing effects of *child's autism-related behaviors, stereotypes and rejection* on variables describing *isolation and exclusion* of family (N = 502)

	Isolation		Exclusion	
	Equation 1 <sup>a</sup>	Equation 2 <sup>a</sup>	Equation 1 <sup>a</sup>	Equation 2 <sup>a</sup>
Child's autism-related behaviors	.400***	.301***	.359***	.175***
Stereotypes of adult competence	–	.079 <sup>+</sup>	–	.008
Stereotypes of autism causes and characteristics	–	–.040	–	.081 <sup>+</sup>
Rejection of child by peers	–	.214***	–	.386***
R-square	.241***	.276***	.192***	.321***

Standardized coefficients with associations adjusted for child's age, gender, diagnosis, verbal ability, education, physical characteristics and parent's race, education and age

<sup>+</sup>  $p < .10$ ; \*  $p < .05$ ; \*\*  $p < .01$ ; \*\*\*  $p < .001$

<sup>a</sup> "Eq." is an abbreviation for "Equation" and refers to regression equations with different variables added

**Table 3** Logistic regression analyses showing effects of *child's autism-related behaviors, stereotypes of adult competence, stereotypes of autism causes and characteristics, and rejection of child by peers on parent's loss of employment: regression coefficients and (odds ratios) (N = 502)*

	Parents loss of employment	
	Equation 1 <sup>a</sup>	Equation 2 <sup>a</sup>
Child's autism-related behaviors	.757 (2.133)***	.482 (1.619)*
Stereotypes of adult competence in social roles	–	.202 (1.224)
Stereotypes of autism causes and characteristics	–	.024 (1.025)
Rejection of child by peers	–	.532 (1.703)**
Nagelkerke R square/cox and Snell R square	.128/.096	.153/.115

Standardized coefficients with associations adjusted for child's age, gender, diagnosis, verbal ability, education, physical characteristics and parent's race, education and age

<sup>+</sup>  $p < .10$ ; \*  $p < .05$ ; \*\*  $p < .01$ ; \*\*\*  $p < .001$

<sup>a</sup> "Eq." is an abbreviation for "Equation" and refers to regression equations with different variables added

*What are the Factors Associated with the Overall Level of Difficulty that Stigma Causes?*

Table 4 presents 3 equations that sequentially add variables to regression equations explaining the *overall level of difficulty that stigma causes* in parents' lives. The first equation includes *child's autism-related behaviors* and control variables, the second adds *rejection of child by peers* and *stereotypes*, and the third adds measures of *isolation, exclusion, and parent's loss of work hours*. As shown in Eq. 1 of the Table, the child's autism-related behaviors are significantly related (standardized regression coefficient .210;  $p < .001$ ) to the level of difficulty parents report stigma to be. Equations 2 and 3 show that stigma-related experiences (stereotypes and peer rejection) and potential consequences of stigma (isolation, exclusion, and employment loss) are each uniquely and significantly associated with the parents' rating of how difficult stigma has been for them.

**Table 4** Regression analyses showing effects of *child's autism-related behaviors, stereotypes and rejection of child by peers, and isolation and exclusion of family on variables describing difficulty of stigma for parents (N = 498)*

	Difficulty of stigma		
	Equation 1 <sup>a</sup>	Equation 2 <sup>a</sup>	Equation 3 <sup>a</sup>
Child's autism-related behaviors	.210***	.054	–.032
Stereotypes of adult competence in social roles	–	.010	–.009
Stereotypes of autism causes and characteristics	–	.196***	.182***
Rejection of child by peers	–	.276***	.150**
Frequency of isolation	–	–	.124*
Frequency of exclusion	–	–	.211***
Impact on parent's work hours	–	–	.119**
R-square	.071***	.183***	.254***

Standardized coefficients with associations adjusted for child's age, gender, diagnosis, verbal ability, education, physical characteristics and parent's race, education and age

<sup>+</sup>  $p < .10$ ; \*  $p < .05$ ; \*\*  $p < .01$ ; \*\*\*  $p < .001$

<sup>a</sup> "Eq." is an abbreviation for "Equation" and refers to regression equations with different variables added

*How Important are Stigma-related Processes and Experiences in Influencing Parents' Reports of the Difficulty of Raising a Child with ASD?*

Table 5 shows results for the final outcome variable represented in our conceptual model: the *overall reported difficulty of raising a child with ASD*. The Table includes four equations that sequentially add variables related to stigma. In the first equation we see that the *child's autism-related behaviors* are, as expected, strongly related (standardized regression coefficient .363;  $p < .001$ ) to the *difficulty of raising a child with ASD*—the more such behaviors, the greater the experienced difficulty.

Interestingly, Table 5 also reveals that as we add measures assessing *rejection* (Eq. 2), *isolation, exclusion, cut back in work hours* (Eq. 3) and the *overall level of difficulty of stigma* (Eq. 4), these are independently and significantly associated with the overall challenge of raising a



**Table 5** Regression analyses showing effects of *child's autism-related behaviors* and *stereotypes* and *rejection of child by peers* on variables describing *isolation* and *exclusion* of family, impact of autism on parent's work hours, and difficulty of stigma (N = 502)

	Difficulty of having a child with autism			
	Equation 1 <sup>a</sup>	Equation 2 <sup>a</sup>	Equation 3 <sup>a</sup>	Equation 4 <sup>a</sup>
Child's autism-related behaviors	.363***	.304***	.196***	.206***
Stereotypes of adult competence in social roles	–	.003	–.018	–.016
Stereotypes of autism causes characteristics	–	.061	.045	–.007
Rejection of child by peers	–	.109*	–.041	–.084 <sup>+</sup>
Frequency of isolation	–	–	.154**	.119*
Frequency of exclusion	–	–	.250***	.191***
Impact of autism on parent's work hours	–	–	.142***	.109**
Difficulty of stigma	–	–	–	.282***
R-square	.142***	.152***	.256***	.314***

Standardized coefficients with associations adjusted for child's age, gender, diagnosis, verbal ability, education, physical characteristics and parent's race, education and age

<sup>+</sup>  $p < .10$ ; \*  $p < .05$ ; \*\*  $p < .01$ ; \*\*\*  $p < .001$

<sup>a</sup> "Eq." is an abbreviation for "Equation" and refers to regression equations with different variables added

child with ASD. In fact, the explained variance more than doubles from Eq. 1 (14.2 %) where stigma-related factors are not considered, to Eq. 4 (31.4 %) where they are. Moreover, the coefficient for the child's *autism-related behaviors* drops by a substantial 43 % as we move from Eq. 1 (standardized regression coefficient = .363) to Eq. 4 (standardized regression coefficient = .206).

## Discussion

We set out to determine the extent to which parents of children with ASD find stigma to be a problematic aspect of their lives and why. Almost universally (95 %), parents in the sample think that individuals with autism are stigmatized (see Table 11 in "Appendix"). Further, we wondered whether stigma processes contributed to parents' overall assessment of how difficult it is to raise a child with ASD. We conceptualized and measured key domains of autism stigma and explored how useful they were in explaining the phenomena in a large sample of parents of (well-defined) children on the autism spectrum.

Our data show empirically what we speculated to be true. Of the variables tested in this study, stigma and the child's autism-related behaviors play the largest roles in making parents' lives challenging overall. While stereotypes and peer rejection are not significant predictors of the difficulty of having a child with ASD, the difficulty of stigma plays a large, significant role ( $\alpha = .282$ ,  $p < .001$ ) in predicting how challenging life is for parents. The influence of the child's autism-related behaviors was also seen to have a strong and significant direct impact (.206,  $p < .001$ ) on how difficult it is to raise a child with autism, independent of the stigma these behaviors are associated with.

We adopted the Link and Phelan (2001, 2006) model to explain how different factors may contribute to stigma and the roles that each might play in the lives of ASD parents. Our analyses were designed to address two questions. First was whether parents would report encountering stigma processes with some frequency. Second was whether stigma processes add on to the difficulty of raising a child on the autism spectrum.

With respect to the first question raised, it is clear that almost all parents reported stigma processes, and the majority experienced feelings of isolation and exclusion from friends and family (see Table 10 in "Appendix"). Nearly all parents perceived both negative stereotypes related to the ability of someone with ASD to be an independent adult (see Table 7 in "Appendix") and beliefs about autism causes and characteristics (see Table 8 in "Appendix"), but they did so to varying degrees. Parents reported their children demonstrated many of the behaviors commonly used to characterize ASD (see Table 6 in "Appendix") and almost all of them experienced some rejection by their peers (see Table 9 in "Appendix").

With respect to the second question, we found associations that are consistent with the idea that stigma processes add to the difficulty of raising a child with ASD. The symptoms and behaviors of autism are significantly associated with the stigma components of stereotyping, rejection, and exclusion. These experiences, in turn, are moderately to strongly associated with the difficulty of stigma in parents' lives.

Our data suggest that parents believe the difficulty they experience because of stigma is rooted in experiences of stereotyping, rejection, and exclusion. The coefficients for the child's autism-related symptoms and behaviors are reduced when stereotyping, rejection, and exclusion are entered into the regression analyses, assessing the overall

difficulty level of stigma (Table 4, Eq. 1 vs. Equations 2 and 3). This suggests that the reason the child's autism-related behaviors may be important for overall difficulty with stigma is because of their impact on social processes of stereotyping, rejection, isolation, and exclusion. Once these later factors are taken into account, the child's autism-related behaviors have no independent effect on parents' reported difficulty with stigma.

Finally, the parents' report of the difficulty of stigma, along with associated domains of isolation and exclusion, play a strong role in how challenging parents report it has been for them to raise a child with ASD. Indeed, judging from the increment to explained variance (Table 5, Eq. 1 vs. Equations 2–4), stigma-related processes account for a large fraction of this difficulty. This finding is similar to Gray's (1993) qualitative report that parents who *believed* their child and family were stigmatized also experienced a high degree of difficulty in raising their child.

### Limitations and Recommended Next Steps

Our study sample of 502 families is the largest quantitative study we found that addresses stigma associated with autism. The SSC sample was limited, however, to families with one child with ASD. Stigma might be different, perhaps enhanced, in families with more than one child on the spectrum. Autism and associated stigma should not be seen as a snapshot in time. A longitudinal study is needed to define add-on effects or, hopefully, a decrease in stigma over time. In addition, the conceptual model we tested is limited as this study is a cross-sectional design and so cannot prove causation. While our data did not show this, it is possible, for example, that instead of the child's autism-related behaviors impacting stereotypes and rejection, which in turn impact isolation and exclusion, that isolation and exclusion impact a child's behaviors instead. Finally, even though there was broad geographic distribution, diversity in terms of parents' education and race was more limited. A subsequent study that includes a wider spectrum of families would be informative. Measures (scales) developed for this study should be tested in other samples to further confirm reliability and validity in a broader and diverse population.

In conclusion, our goal in this study was to understand the process through which parents feel that stigma is a challenge in their lives. We developed a conceptual model to assess how important stigma is in making parents' lives

difficult and found evidence to support our model in almost all of the associations between variables.

While stigma is certainly not the only factor that played a role in making lives difficult for parents of a child with ASD, it played a major and significant role in our conceptual model. While we are aware that children's behaviors are generally important in determining how they are perceived, we see more clearly now how reducing stigma associated with these behaviors could help to diminish the family's overall burden. Our findings underscore that efforts to increase the public's understanding and acceptance of the child's autism-related behaviors could help to both mitigate the stigma that many parents experience and the difficulties they may contend with raising a child with autism spectrum disorder.

### Supplementary Data

In the Online Supplement, readers can find a detailed description of the development of the interview, the development of the four multiple-item scales, and the factor analysis (rotated factor matrix) that led to the creation of the four scales that together explain 54 % of the common variance.

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### Compliance with Ethical Standards

**Ethical Statement** All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

**Conflict of interest** The authors declare that they have no conflict of interest.

### Appendix

See Tables 6, 7, 8, 9, 10 and 11.

**Table 6** Measures: child's autism-related behaviors ( $\alpha = 0.69$ )

How often during the past 6 months	Often (4) %	Some times (3) %	Rarely (2) %	Never (1) %
Head banging	2.0	5.6	11.2	81.3
Threat or aggressive toward others	6.4	19.7	27.3	46.6
Noticeable repetitive behaviors	33.7	22.5	15.5	28.3
Trouble making eye contact	42.6	36.1	16.7	4.6
Trouble with bladder or bowel control	9.8	11.0	13.1	66.1
Serious tantrums or meltdowns	14.5	30.1	32.5	22.9
Became upset with change in routine	22.5	43.0	26.9	7.6

**Table 7** Measures: stereotyped beliefs—competence in social roles ( $\alpha = 0.84$ )

Individuals with autism will never be able to____. Do you think most people believe that, some people believe that, or only a few people believe that?	Most (3) %	Some (2) %	A Few (1) %
Hold a job	35.9	58.6	5.6
Live independently	37.5	57.4	5.2
Marry	47.4	43.0	9.6

**Table 8** Measures: stereotyped beliefs about autism causes and characteristics ( $\alpha = 0.62$ )

Do most people, some people, or only a few people believe	Most people believe (3) %	Some people believe (2) %	A few people believe (1) %
Individuals with autism cannot be a good friend because of their autism	34.1	52.4	13.3
Parents can cause their children's autism because of their parenting style	3.8	36.5	58.2
Individuals with autism are 'mentally ill'	25.5	48.2	26.1
Individuals with autism are dangerous or a threat to others	6.2	54.6	38.4
Individuals with autism have intellectual disabilities	47.6	47.0	5.4

**Table 9** Measures: rejection of child by peers ( $\alpha = 0.81$ )

How often during the past 6 months child	Often (4) %	Some times (3) %	Rarely (2) %	Never (1) %
Teased or called an insulting name	9.0	27.5	36.7	26.1
Left out of activities by other children	43.2	31.3	17.5	7.4
Physically bullied by other children	3.2	9.6	25.5	60.8
Avoided contact by other children	32.1	37.1	21.5	8.6
Heard child called hurtful names or words	3.4	18.5	39.4	38.6
Regarded as weird or odd by other children	37.5	38.6	17.1	5.0
Had difficulty making friends	54.8	28.1	11.2	5.0

**Table 10** Measures: family isolation and exclusion and impact on parent's work hours

How often during the past 6 months parent...	Often (4) %	Some times (3) %	Rarely (2) %	Never (1) %
Decided not to spend time with friends and family	14.9	25.5	25.7	33.9
Felt you and your family were excluded	8.4	23.3	29.1	39.2
Impact on parents' work hours		Yes %		No %
Cut back on work hours because of child's autism		55.4		44.4

**Table 11** Measures: overall stigma and difficulty raising child with ASD

	Extremely (5) %	Very (4) %	Some what (3) %	A Little (2) %	Not at All (1) %
How difficult has the stigma that is often associated with autism been for you and your family?	9.0	22.2	47.5	16.0	4.4
How difficult has it been for your family to have a child on the autism spectrum?	18.3	31.9	39.4	9.0	1.4
	Definitely yes %	Probably yes %	Probably no %	Definitely no %	
Individuals with autism are stigmatized	59.4	35.3	4.6	0.6	

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