



Stigmatization of Children and Adolescents with Autism Spectrum Disorders and their Families: a Scoping Study

Rinita Mazumder¹ · Sandra Thompson-Hodgetts²

Received: 16 August 2018 / Accepted: 14 December 2018 / Published online: 10 January 2019
© Springer Science+Business Media, LLC, part of Springer Nature 2019

Abstract

Introduction Individuals with autism spectrum disorder (ASD) and their families may experience high rates of stigmatization, including self-stigma, public stigma, stigma through association, and structural stigma.

Methods We conducted a scoping review of peer-reviewed publications to identify, describe, and summarize existing literature related to stigma and ASD.

Results Twenty-five articles met our inclusion criteria, including 14 qualitative, 9 quantitative, and 1 mixed method studies and 1 meta-synthesis. Four emergent themes include social perceptions of ASD, social isolation, well-being and responses to stigma, and stigma reduction.

Discussion Knowledge generated from this scoping review provides an overview of the influence that stigma may have on individuals with ASD and their families. Further research directions are suggested to address structural stigma and community inclusion.

Keywords Scoping review · Stigma · Public stigma · Children · Families · Caregivers · Autism spectrum disorders · ASD

Autism spectrum disorder (ASD) is a complex, neurodevelopmental disorder characterized by deficits in social development and communication, as well as repetitive and restricted behaviors (American Psychiatric Association 2013). As described by the diagnostic label, these characteristics fall on a spectrum and can present in a variety of ways. Often though, the individual living with ASD will present as having a “normal” physical appearance, leaving contrasting “abnormal” behaviors perplexing to onlookers. It can be difficult for some people to accept or understand that a child has ASD because of their “normal” appearance (Moysen and Roeyers 2011). People who do not know that a child has ASD will tend to judge certain ASD related behaviors as being problematic, yet are more lenient when they are told the child

has ASD (Chambres et al. 2008; Huws and Jones 2010). Individuals with ASD and their families experience judgment from others based on these behaviors and preconceived negative stereotypes about “normality” and “abnormality.” This stigmatization can present in different forms including self-stigma, public stigma, stigma through association, and structural stigma.

In his seminal work, *The Theory of Social Stigma*, Erving Goffman defined stigma as a social identity that is perceived to negatively deviate from societal norms and values (Goffman 1963). His work was instrumental in providing an initial conceptual framework for the analysis of stigmatizing conditions. Goffman recognized that stigma is enacted within social contexts and that perceptions of stigma can profoundly impact the quality of life and wellbeing of not only the person with disability, but also of close friends and family, known as courtesy stigma (Goffman 1963). While Goffman’s work remains one of the dominant theoretical foundations for examining and understanding stigma, more recent scholars have expanded on the concept of stigma (Farrugia 2009). For example, Pryor and Reeder depict four interrelated “types” of stigma in their *Four Manifestations of Stigma* (Pryor and Reeder 2011). These types of stigma include (1) public stigma, which represents people’s social and psychological

✉ Rinita Mazumder
mazumder@ualberta.ca

¹ Faculty of Rehabilitation Medicine, University of Alberta, 8205 114th St NW, Corbett Hall 3-75, Edmonton, Alberta T6G 2G4, Canada

² Department of Occupational Therapy, University of Alberta, 8205 114th St NW, Corbett Hall 2-16, Edmonton, Alberta T6G 2G4, Canada

reactions to someone they perceive to have a stigmatized condition. Public stigma may be related to innate beliefs and reactions, but is also informed by the presence of a diagnostic label, perceived severity of a condition, and media portrayals of that condition; (2) self-stigma, which reflects the social and psychological impact of possessing a stigma; in other words, of internalizing stigma; (3) stigma by association, which refers to social and psychological reactions to someone associated with a stigmatized person. For children, this may include parents and other family members, other caregivers, peers, or even professionals or programs that support people with the stigmatized condition. Finally, (4) structural stigma is defined as the legitimization and perpetuation of a stigmatized status by society's institutions and ideological systems. This type of stigma may include attitudes and practices of professionals or leaders, as well as other organizations' practices and policies. Bos et al. (2013), use Pryor and Reeder's (2011) articulation of the manifestations of stigma to theorize on the interrelatedness of the different forms of stigma, explore how stigma is rooted in social interactions, describe advancements in how we measure stigma, and provide recommendations for research related to stigma reduction.

There is currently a body of literature related to stigma and stigmatization of children and individuals living with other conditions including mental health disorders, epilepsy, attention deficit hyperactivity disorder (ADHD), and intellectual disability. Individuals and their families living with these conditions report feeling societal stigma, marginalization, and social exclusion from the community, extended family members, and friends (Ali et al. 2012; Benson et al. 2016; Green 2003; Kaushik et al. 2016; Wiener et al. 2012). Children with ASD are at a particularly high rate of experiencing stigma, even when compared to other disability groups (Cappadocia et al. 2012; Harandi and Fischbach 2016; Kinnear et al. 2016). ASD is diagnosed based on pervasive impairment in social interactions, social communication, and the presence of socially atypical behaviors (American Psychiatric Association 2013). Some scholars have proposed that these pervasive social impairments without a visible disability make the experience of stigma different for ASD than other disabilities (Gray 1993). Currently, however, there is no review of the existing literature around the stigmatization experienced by children with ASD and their families or caregivers. Therefore, the purpose of this scoping review is to (1) synthesize the existing literature related to stigmatization of children with ASD and their families and (2) identify gaps in the literature to inform future directions in the field.

Method

A scoping review was conducted as outlined by Arksey and O'Malley (2005). This type of review process allows us to

thoroughly examine, map, and identify gaps in the current existing literature regarding the broad topic of stigma and ASD, as opposed to empirically answering a well-defined research question and assessing the quality of the literature, like in a systematic review (Arksey and O'Malley 2005; Levac et al. 2010).

Arksey and O'Malley's (2005) five-stage methodological framework was utilized: (1) identifying the research question, (2) identifying relevant studies, (3) study selection, (4) charting the data, and (5) collating, summarizing, and reporting the results. In addition to this framework, recommendations to clarify and enhance each stage as suggested by Levac et al. (2010) were also taken into consideration. Suggestions made by Levac et al. (2010) incorporated into this study included collectively developing the data charting form and determining which variables to extract to answer the research question and breaking down step 5 of Arksey and O'Malley's framework (collating, summarizing, and reporting) into three distinct steps of analysis (a descriptive numerical summary analysis and a qualitative thematic analysis, reporting of the results, and consideration of the meaning of the findings).

Identifying the Research Question

The scoping review addresses the following question: what is known from the existing literature about the stigma and stigmatization associated with children and adolescents with autism spectrum disorder and their families?

Identifying Relevant Studies

Inclusion and exclusion criteria were defined for the study. Inclusion criteria were (1) a focus on stigma and/or stigmatization; (2) a focus on children or youth with a diagnosis of ASD (including previous terms used prior to the DSM-V, such as Asperger's) and/or their families or caregiver's; (3) publications in English; and (4) peer-reviewed literature. Studies that were related to (1) diagnoses other than ASD; (2) a focus on adults with an ASD diagnosis; (3) families of adult-aged children; and (4) stigma in the workplace related to adults, were excluded.

Study Selection

Four electronic databases, ERIC, MEDLINE, Child Development and Adolescent Studies, and CINAHL, were searched using search terms "autism, autism spectrum disorders, ASD, or Asperger's" AND "stigma or stigmatization." No date parameters were set and an initial search took place in January 2017 resulting in 107 peer-reviewed studies. All articles were screened by title and abstract, based on the clearly defined inclusion and exclusion criteria. Forty articles

potentially met the inclusion criteria based on abstract and title and were read in full. Nineteen of these articles clearly met inclusion criteria based on the full text. Four articles were unclear, so a second researcher independently screened these four articles based on the established inclusion and exclusion criteria, and an agreement was made for the inclusion of all four based on the full text. From this first search, 23 articles in total met the inclusion criteria based on the full text and were included in the study. A second search was conducted in December 2017 with date parameters set to the year 2017, which identified four potential new articles based on title and abstract. Upon reading in full, two of these articles also met inclusion criteria. Therefore, a total of 25 articles were identified for inclusion in this review.

Charting the Data

The final 25 articles were read in full and data were extracted in the following fields: author, year of publication, the location of study, title, participant information, study objective, methodology, outcomes and interpretation of methods, and main findings related to stigma. (See Table 1.)

Collating, Summarizing, and Reporting the Results

Information from the 25 articles were collated and analyzed thematically to map areas of interest related to stigma and ASD. Initial analysis of the data resulted in five themes: (1) judgment, (2) diagnostic label, (3) social isolation, (4) social well-being, and (5) fear of discrimination. These themes were organized using Scapple, an online mind-mapping application. Data charts were read and compared to the studies main findings to better formulate these themes and the information was further charted. Data were then thoroughly examined again by two reviewers; a process that revised our findings into four themes and two subthemes that better represent the data. (See Table 1.) The four final themes are (1) social perceptions of ASD, which includes two subthemes (i) invisibility and judgment and (ii) diagnostic labels; (2) social isolation; (3) well-being and response to stigma; and (4) stigma reduction.

Results

Overview of Results

The 25 articles included in the study were published between the years 1996 and 2017. Figure 1 shows the detailed flow of our study selection and results. Articles that were excluded focused on adult populations with ASD and workplace stigma, or individuals with diagnoses other than ASD.

The final studies selected used a variety of methods including qualitative ($n = 14$; 56%), quantitative ($n = 9$; 36%), mixed methods ($n = 1$; 4%), and one meta-synthesis ($n = 1$; 4%). Majority of the studies were conducted in the USA ($n = 9$) and Australia ($n = 9$), with two studies each from the UK ($n = 2$) and Israel ($n = 2$) and one study each from Serbia ($n = 1$), Pakistan ($n = 1$), and Canada ($n = 1$). Participants included those with lived experience of ASD, including parent's or caregivers of children with ASD ($n = 17$ articles) and adolescent's with ASD ($n = 2$ articles) and those without identified lived experience with ASD, including post-secondary students ($n = 3$ articles), high school students ($n = 2$ articles), and adults in the general public ($n = 1$ articles).

Thematic Analysis

Four major themes were identified, including (1) social perceptions of ASD (with two subthemes: invisibility and judgment, and diagnostic labels), (2) social isolation, (3) well-being and responses to stigma, and (4) stigma reduction.

Social Perceptions of ASD

The first theme relates to how others see people with ASD and perceive the diagnosis and how people with ASD and their families perceive that others see them and the diagnosis of ASD. Two distinct subthemes emerged that both directly relate to the primary theme.

Invisibility and Judgment Social perceptions and preconceived notions of individuals with ASD and those with whom they are associated are apparent in society, specifically around what it means to behave “normally.” Parents report how it can be “difficult for people in the public to ‘see’ Autism, (and how) all the public sees is a child acting out” (Neely-Barnes et al. 2011). Gray notes that “it is [a] combination of pervasive disability and apparent physical normality that gives the stigma experienced by families with autistic children its unique quality” (Gray 1993, p. 114). The invisibility of ASD in conjunction with challenging behaviors leads others to make assumptions about their child misbehaving and in turn make judgments about their parenting abilities (Broady et al. 2017; Farrugia 2009; Gray 2002a; Munroe et al. 2016; Neely-Barnes et al. 2011). From vignettes depicting a mother of a child with ASD and a mother of a child with asthma, the mother of the child with ASD was evaluated as being less valuable, illuminating the presence of associative stigma (Thibodeau and Finley 2017). Parents share how they are constantly judged and misunderstood by others in various settings (Broady et al. 2017) and that the resulting judgment can be embarrassing and contributes greatly to perceptions of stigma (Gray 2002a) Minhas et al. 2015). One mum reports negative judgment from her child's school, “school is judging

Table 1 Data Charting

Author, location	Title	Sample	Methodology	Outcomes/interpretation	Main findings related to stigma
Blanche et al. (2015); USA	Caregiving experiences of Latino families with children with autism spectrum disorder	<i>n</i> = 15 Latino parents of children with ASD	Semi-structured interviews	Thematic analysis	Theme of “dealing with stigma and social isolation” emerged from data; stigma led to changing social practices leading to social isolation
Broady et al. (2017); Australia	Understanding carers’ lived experience of stigma: the voice of families with a child on the autism spectrum	<i>n</i> = 15 carers’ of children with high functioning autism (HFA)	Semi-structured interviews	Thematic analysis	Four domains of stigmatizing experience: (1) lack of knowledge, (2) judgment, (3) rejection, (4) lack of support
Corcoran et al. (2015); USA	The lived experience of US parents of children with ASD: a systematic review and meta-synthesis	<i>n</i> = 14 papers	Meta-synthesis of literature	Identification of themes using the meta-synthesis framework	One of six major themes was stigmatization
Daniels et al. (2017); USA	Autism in Southeast Europe: a survey of caregivers of children with autism spectrum disorders	<i>n</i> = 758 caregivers of children with ASD	Surveys	Affiliate stigma scale	29% report worrying if others knew child had ASD; 41% report other people would discriminate against them; 42% report having child with ASD has negative impact on them
Farrugia (2009); Australia	Exploring stigma: medical knowledge and the stigmatization of parents of children diagnosed with ASD	<i>n</i> = 12 parents of children with ASD	Semi-structured interviews	Discourse analysis, deviant case analysis	Enacted stigma from friends affecting social circles; enacted stigma from public (staring, judging looks); invisibility of disability plays role in greater stigmatization; blamed/judged for bad parenting because of child’s behavior
Gill and Liamputtong (2011); Australia	Being the mother of a child with Asperger’s syndrome: women’s experiences of stigma	<i>n</i> = 15 mothers of children who have Asperger’s syndrome (AS)	Semi-structured interviews and narrative review of diary entries	Thematic analysis	The invisibility of disability with Asperger’s leads to more stigma; mothers avoid social situations to lessen stigma; dialog around learning to adapt to stigma
Gillespie-Lynch et al. (2015); USA	Changing college students’ conceptions of autism: an online training to increase knowledge and decrease stigma	<i>n</i> = 365 college students	Survey qualitative coding of open-ended questions	The demographic survey, pre-test measures, autism training, identical post-test measures	Gender differences in stigma rating; autism in the immediate family changed ratings of stigma; autism knowledge increase post-test and stigma decreased in post-test
Gray (1993); Australia	Perceptions of stigma: the parents of autistic children	<i>n</i> = 32 parents of children with ASD	Semi-structured interviews	Thematic analysis	55% identified as being stigmatized; parents report higher social withdrawal from social contact with the outside world; the discrepancy between normal physical appearance and reality of disability plays role in negative public encounters; courtesy stigma experienced by family
Gray (2002a, b); Australia	Ten years on: a longitudinal study of families of children with autism	<i>n</i> = 28 parents of children with ASD	Semi-structured interviews	Ethnography	Majority of parents still experienced stigma but impact of stigmatization declined for some over the years; some parents expressed continuation of stigma but how it mattered less to them

Table 1 (continued)

Author, location	Title	Sample	Methodology	Outcomes/interpretation	Main findings related to stigma
Gray (2002a, b); Australia	“Everybody just freezes. Everybody is just embarrassed”: felt and enacted stigma among parents of children with high functioning autism	$n = 53$ parents of children with high functioning autism (HFA)s	Semi-structured interviews	Thematic analysis	Parents felt others were critical of their parenting skills; embarrassment was a common manifestation of felt stigma; visibility and symptoms of the condition plays a role in stigma
Jones et al. (2015); USA	“Are you by chance on the spectrum?” Adolescents with autism spectrum disorder making sense of their diagnoses	$n = 10$ adolescents diagnosed with ASD	Semi-structured interviews	Phenomenological analysis	All adolescents referred to the social stigma of ASD, and describe struggling with how they and others with ASD are perceived in light of their diagnosis; feelings of frustration around social stigma experienced
Kinnear et al. (2016); USA	Understanding the experience of stigma for parents of children with ASD and the role stigma plays in families’ lives	$n = 502$ parents of children with ASD	Computer-assisted telephone interview, surveys/scales	Constructed scales: child’s autism-related behaviors; parent’s perceptions of public stereotypes; frequency of rejection; assessment of the difficulty of stigma in parent’s lives; the difficulty of raising a child with ASD	95.6% of parents reported that stigma was difficult in their lives from a little to extremely; stigma plays a significant role ($\hat{c} = 0.282, p < .001$) in predicting how challenging life is for parents.
Milacic-Vidojevic et al. (2014); Serbia	Tendency towards stigmatization of families of a person with ASD	$n = 181$ participants from the general public in Belgrade	Two questionnaires	Family Stigma Questionnaire (FSQ) and Level of Familiarity Questionnaire (LFQ)	Parents are blamed for the onset of condition; individuals with least education of ASD demonstrated higher tendency towards stigmatizing behaviors
Minhas et al. (2015); Pakistan	Parents’ perspectives on care of children with autistic spectrum disorders in South Asia—views from Pakistan and India	Study 1, $n = 15$ parents of children with autism spectrum disorder in Pakistan Study 2, $n = 5$ studies previously conducted in India	Semi-structured interviews and narrative review of previous studies	Thematic analysis of interviews Secondary narrative analysis of 5 previous studies	Parents found challenging behaviors were socially embarrassing and contributed to stigma towards their children and families; worry about mistreatment in the community; afraid to put children in mainstream education due to teachers’ attitudes; parents fear sending their children into public or for social celebrations
Mogensen and Mason (2015); Australia	The meaning of a label for teenagers negotiating identity: experiences with ASD	$n = 5$ teenagers with ASD	Participatory action research informed by phenomenology and ethnography The range of communication options given—face-to-face interview, drawings, photos, e-mails	Thematic analysis of interview transcripts, e-mails, and photos of a communication board	Participants were reluctant to disclose diagnosis due to stereotypes and negative public attitudes attached to the diagnosis in society; two participants feared sharing the diagnosis with friends would result in being treated differently; one participant comfortable with sharing the diagnosis, and being different helped him socially

Table 1 (continued)

Author, location	Title	Sample	Methodology	Outcomes/interpretation	Main findings related to stigma
Munroe et al. (2016); UK	The experiences of African immigrant mothers living in the United Kingdom with a child diagnosed with an autism spectrum disorder: an interpretive phenomenological analysis	<i>n</i> = 6 African immigrant mothers of children with ASD	Semi-structured interviews	Interpretive phenomenological analysis	One of the four themes identified was the pain of stigma and rejection
Neely-Barnes et al. (2011); USA	Parenting a child with as ASD: public perceptions and parental conceptualizations	<i>n</i> = 11 parents of children with ASD	Focus group interviews	Interpretive qualitative analysis	Difficult for people in public to “see” autism and they endure criticism because their child does not “act normal” (invisibility of ASD); public views them as bad parents
Obeid et al. (2015); USA	A cross-cultural comparison of knowledge and stigma associated with ASD among college students in Lebanon and the US	<i>n</i> = 675 post-secondary students from Lebanon and US	Pre-test and post-test questionnaires about knowledge and attitudes towards ASD Intervention: autism training program	Social Distance Scale; Autism Awareness Survey; Broad Autism Phenotype Questionnaire	Stigma lower at post-test relative to pre-test for both groups of students; women endorsed lower levels of stigma than men
Ranson and Byrne (2014); Australia	Promoting peer acceptance of females with high functioning autism in a mainstream education setting: a replication and extension of the effect of an anti-stigma program	<i>n</i> = 273 seventh-, eighth-, and ninth-grade female students	Pre-test and post-test (1 week and one term) of ASD knowledge and attitudes	Autism Knowledge Questionnaire; Adjective Checklist; Shared Activities Q; Similarity Ratings Form; Perceived responsibility Q	The positive influence of anti-stigma on knowledge and attitudes and to a lesser extent behavioral intentions
Russell and Norwich (2012); UK	Dilemmas, diagnosis, and de-stigmatization: parental perspectives on the diagnosis of ASD	<i>n</i> = 8 parents not seeking a diagnosis; <i>n</i> = 9 parents of children diagnosed with ASD	Semi-structured interviews	Thematic analysis	Parents fear the child will be discriminated against; parents may shy away from diagnosis because of negative perceptions
Stamland and Byrne (2013); Australia	The effects of a multicomponent high functioning autism anti-stigma program in adolescent boys	<i>n</i> = 395 seventh-, eighth-, and ninth-grade male students	Pre-test and post-test (1 week and one term) of ASD knowledge and attitudes	Autism Knowledge Questionnaire; Adjective Checklist; Shared Activities Q; Similarity Ratings Form; Perceived responsibility Q	The anti-stigma program improved knowledge and attitudes but did not improve behavioral intentions towards peers
Thibodeau and Finley (2017); USA	On associative stigma: implicit and explicit evaluations of a mother of a child with an autism spectrum disorder	<i>n</i> = 95 undergraduate students	2 × 3 between subject design: audio recorded vignette pertaining to a mother of a child with ASD or severe asthma	IAT (Implicit Association Test) score, social distance, stereotyped attitudes	Implicit evaluations of the mother of a child with ASD were less positive than implicit evaluations of the mother of a child with asthma
Werner and Shulman (2013); Israel	Subjective well-being among family caregivers of individuals with developmental disabilities: the role of affiliate stigma and psychosocial moderating variables	<i>n</i> = 176 family caregivers of individuals with ASD, ID, PD	Self-report questionnaire	Demographics, social well-being, affiliate stigma, positive meaning in caregiving, caregiving burden, self-esteem, social support	Affiliate stigma a predictor of subjective well-being for parents of children with ASD; greater levels of stigma associated with lower subjective well-being for ASD and not ID or PD
	Does the type of disability make a difference in affiliate stigma among	<i>n</i> = 170 family caregivers of	Self-report questionnaire	Affiliate stigma scale	

Table 1 (continued)

Author, location	Title	Sample	Methodology	Outcomes/interpretation	Main findings related to stigma
Werner and Shulman (2015); Israel	family caregivers of individuals with ASD, ID, or PD?	individuals with ASD, ID, PD			Higher levels of affiliate stigma for parents of children with ASD compared with ID or PD
Woodgate et al. (2008); Canada	Living in a world of our own: the experience of parents who have a child with autism	n = 21 parents from 16 families of children with ASD	Open-ended, in-depth qualitative interviews	Hermeneutic phenomenology	Parents expressed feeling social isolation and stigmatization

me, like I am some sort of crackpot...I have been through hell at this school with them pointing their finger”; three parents share how people in the general public, who, based on observing them and their child, comment, “control your (child)” or “that child just needs a good smack on the bum” and finally, from their own family members, “my family judges me all the time...commenting on how ‘some people shouldn’t be parents’”(Broady et al. 2017, p. 228).

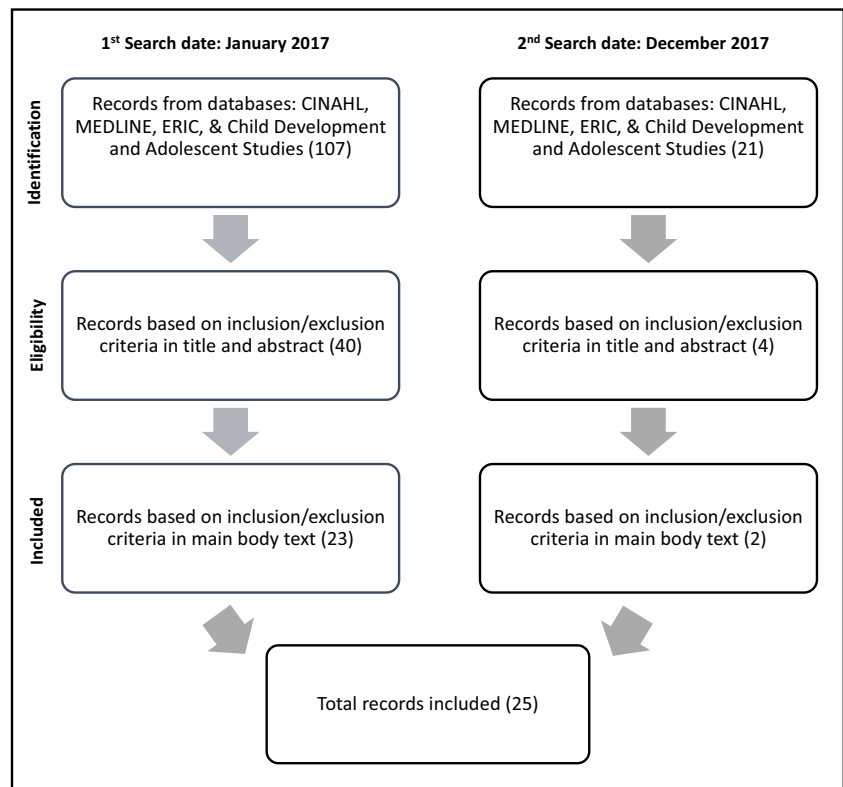
Diagnostic Label The preconceived social perceptions of how a “normal” looking child should behave are further complicated with the pervasive assumptions made around the specific label of ASD or Asperger’s. Parents of children with ASD and adolescents living with ASD report public social stigmatization specifically related to the diagnostic label of ASD or Asperger’s (Jones et al. 2015; Mogensen and Mason 2015; Russell and Norwich 2012) and higher levels of affiliate stigma than caregiver’s of children with an intellectual disability or physical disability (Werner and Shulman 2015).

Parents express how it is easy to refrain from sharing a diagnosis because of the negative preconceived perceptions that are associated with the ASD label and fear of their child experiencing discrimination (Russell and Norwich 2012). Adolescents living with ASD share mixed feelings about carrying an ASD label. In relation to sharing their diagnosis, some teens reported reluctance to share because of the negative stereotypes the public carries, which are directly related to negative experiences including being stigmatized and treated differently than non-diagnosed teens (Mogensen and Mason 2015). However, for some teens, a diagnosis improved understanding of themselves and helped them find belonging (Jones et al. 2015), with one teen reporting how he liked sharing his diagnosis because he was proud of being different and unique (Mogensen and Mason 2015).

Social Isolation Social isolation was reported from two different perspectives: parent reports of their own experiences and parent reports of their child’s experiences.

Parent reports of their experiences exposed two different causes of social isolation: social isolation due to rejection from others and social isolation due to their own avoidance of social situations. Parents’ felt rejected from various sources, including schools, other parents, and family members (Broady et al. 2017). Parents refrained from putting their children in mainstream education and avoided sending their children to public environments or out for social celebrations because of the way they may be treated (Minhas et al. 2015). Parents’ believed that the public held negative beliefs about their children, including that they would not be a good friend and that their children were socially isolated because other children thought they were weird (Kinnear et al. 2016).

One parent made clear that the school is stigmatizing their son, “the resource person said I should not expect other kids to

Fig. 1 Flowchart of study selection

buddy with him...they are saying, ‘why would another kid want to play with your kid’”(Woodgate et al. 2008). Additionally, parents felt isolated from extended family members who lacked an understanding of their child’s behaviors (Gray 1993; Kinnear et al. 2016; Munroe et al. 2016).

Caregiver’s described changing their social practices (Blanche et al. 2015) or avoiding certain social situations (Gill and Liamputtong 2011) as a strategy to avoid stigmatization. One mother shared, “you tend to limit your activities as well, either consciously or subconsciously, because it’s just hard to really, to go out and to be judged” (Munroe et al. 2016). However, this created feelings of guilt for some of the mothers because they worried they were limiting their child’s life experiences (Munroe et al. 2016).

Well-Being and Responses to Stigma The combination of social stigma experienced by individuals with ASD, the affiliated stigma experienced by families, and the resulting social isolation can greatly influence their well-being. Werner and Shulman (2013) highlighted that greater levels of stigma were associated with lower social well-being for caregivers of children with ASD, which was notably lower than for caregivers of individuals with an intellectual disability or physical disability. Parents’ report feeling helpless (Daniels et al. 2017), and how the stigma associated with having a child with ASD has a negative impact on them (Daniels et al. 2017) and their families (Corcoran et al. 2015). Peer rejection and negative stereotypes, along with the potential consequences of stigma

including isolation, exclusion, and loss of employment, were related to the parents’ ratings of how difficult stigma has been in their lives and how challenging it can be to raise a child with ASD (Kinnear et al. 2016). However, Gray (1993, 2002b) showed that responses to stigma and how it affects well-being can change over time. In 1993, Gray interviewed parents and asked them about their experiences of raising a child with ASD (Gray 1993). Ten years later, he performed a follow-up study with the same families and found that stigma did not affect them to the extent it had initially. Parents reported that over time, they had developed better coping strategies Gray 2002b. Parent reports in more recent studies also show that the ability to cope with stigma changes over time, and knowing that society was not going to change meant that they needed to adapt to the stigma and “stare it in the face” instead of allowing it to anger them (Gill and Liamputtong 2011, p. 718).

Stigma Reduction A lack of ASD knowledge and education feeds negative perceptions (Broady et al. 2017) and leads to greater levels of public (Farrugia 2009; Gill and Liamputtong 2011; Neely-Barnes et al. 2011) and affiliated stigma (Milacic-Vidojevic et al. 2014). Parents of children with ASD (Woodgate et al. 2008) and adolescents living with ASD (Jones et al. 2015) report that educating others about ASD could help mitigate enacted discrimination. A subset of the literature has begun to investigate the outcomes of stigma reduction programs for both adolescent and young adult

populations (Gillespie-Lynch et al. 2015; Obeid et al. 2015; Ranson and Byrne 2014; Staniland and Byrne 2013).

Staniland and Byrne (2013) developed an anti-stigma program to promote acceptance of peers with ASD in adolescent boys. Results from their study showed improvements in knowledge and attitudes, but did not show any change in behavioral intentions of non-autistic peers towards their peers with ASD. Ranson and Byrne (2014) updated the protocol and implemented the program in a group of adolescent girls. Similarly, knowledge and attitudes were improved, but in this group, the researchers also saw improvements in behavioral intention.

Working with US college-aged students, Gillespie-Lynch et al. (2015) reported lower stigma ratings on the Social Distance Scale, where students are asked how willing they are to engage with a certain type of person at varying levels of intimacy. In a replication study executed by Obeid et al. (2015), researchers found that, after a similar autism training program, students in both Lebanon and the USA reported similar improvements on the same measures. Both studies also reported increased knowledge and understanding of ASD (Gillespie-Lynch et al. 2015; Obeid et al. 2015).

Discussion

This scoping review examined the existing literature related to the stigmatization experienced by children and adolescents with ASD and their families or caregivers. Overall, the findings from this study situate closely with Pryor and Reeder's (2011) *Four Manifestations of Stigma*, centralized around public stigma. From the results of this study, we can see the impact that the invisible nature of ASD and the diagnostic label of ASD have on public perceptions and public stigma, the social behaviors and self-stigma that result from this judgment, the negative effects of stigma on well-being, and positive developments around education and awareness that can help those who stigmatize and those targeted by stigma. This study helps reinforce the multidimensional nature of stigma and our understanding that stigma can be experienced in different ways, affecting different facets of daily life. We discuss the implications of these results in relation to sensitivity and education and highlight gaps in the literature with suggestions for future research directions.

Potential Implications

Our findings highlight the impact that stigma has on the lives of individuals living with ASD and their parents or caregivers. Increased understanding of the perceptions and implications of the stigma experienced by people living with ASD has implications in professional practice, for building educational initiatives and in supporting policy

development. Professionals who display sensitivity, openness, and have inclusive practices may be better equipped for supporting families and children who are navigating services and able to build stronger relationships to best support their well-being.

The results from our review show that both caregivers and those living with ASD report difficulty in navigating spaces with others who lack knowledge of the disorder. This lack of knowledge includes a misunderstanding of the different behaviors children and adolescents with ASD may display. This has generally been reported to lead parents or caregivers of children with ASD to feel judgment and exclusion. Furthermore, people living with ASD report feeling stigmatized about their capabilities, which can lead to increased social isolation and decreased well-being. For these reasons, a fear of sharing a diagnosis or disclosing the label of ASD or Asperger's because of the way it may be perceived is understandable.

People living with ASD and their support networks report high levels of social isolation and judgment based on stigma. The potential benefits of stigma reduction strategies on decreasing these negative outcomes reinforce the importance of developing educational tools and specific interventions targeted at all individuals. Regardless of the setting (e.g., professional settings, community contexts, schools, targeting the general public), these strategies should focus on improving the acceptance and inclusion of children with ASD and their families. Importantly, this type of education would help raise awareness of stigma and social isolation experienced by people with invisible disorders, such as ASD. Similarly, youth with epilepsy maintain the invisibility of their disorder by not disclosing to others because they have experienced social exclusion and judgment based on stigma (Benson et al. 2016; Lewis and Parsons 2008). Youth with epilepsy expressed the need for educational strategies to improve understanding and accepting attitudes (Lewis and Parsons 2008). In addition to educational initiatives, it is paramount to improve inclusive practices and supports in our communities. These types of structural reforms are not easy to implement, but must be identified as a priority to move towards a culture of equal access, understanding, and acceptance of people with ASD.

Limitations and Future Directions

Stigma research related to ASD is a growing field. While many steps have been taken to increase the scope of research in the field, it is important to recognize the gaps in the literature and highlight areas for further research. Many of the studies in this scoping review were from the viewpoint of the parent ($n = 17$), which gives valuable insight to the lived experience of caregivers and parents,

whereas only two studies have examined experiences of stigma from the perspective of adolescent's, and the voice of younger children are completely missing from the picture. Including the voice of children as participants in research can be difficult. Directly involving children who may have limited verbal communication skills can add further challenges. However, it is possible. An emerging body of literature outlines the importance of hearing children's voices and delves into the methodological creativity required to engage participants and more specifically children with ASD (Danker et al. 2017; Gray and Winter 2011).

A small subset of the stigma literature ($n = 4$) is related to the development and assessment of educational programs that are intended to reduce stigma. These studies have opened a door to better understanding how increasing knowledge of ASD can influence more inclusive practices and behaviors that can decrease stigma. Outcomes of evaluations of educational programs targeting stigma reduction are encouraging, but there is a lack of cultural diversity within the educational initiatives and within their target populations. In line with considering targeted stakeholder groups, many ($n = 6$) of the studies in this scoping review represented non-Western cultures, taking into consideration that stigma contains a cultural context so addressing the roots of stigma and providing education and sensitivity training must be individualized in relation to each culture. A better understanding of how these promising interventions may generalize across cultures is warranted. For these programs to be effective, Bos et al. (2013) highlight the need for stigma reduction programs that identify specific manifestations for change—in other words, they should be directed towards a certain component of the stigma framework (self, affiliated, public, or structural stigma). Bos et al. (2013) also advise on the importance of targeting the level of intervention, whether it is intrapersonal, interpersonal, at the community level, or at the institutional level, and that this should be clearly identified at the initiation of the program.

It should also be noted that the majority of stigma literature in ASD is related to public stigma, self-stigma, and stigma by association. Structural stigma, the fourth category described by Pryor and Reeder (2011), has not been addressed. Because this form of stigma incorporates attitudes and practices of professionals and organizations, it is imperative to gain a clearer understanding of how structural stigma implicates individuals living with ASD. In addition to outcomes related to well-being, it is important to understand how it shapes opportunities for inclusion. Do structural policies play a role in the participation and inclusion of children and adolescents with ASD? Do the attitudes of individuals in organizational roles have implications in policy related to inclusion? By intervening at the structural level, would we see dynamic changes in public stigma and self-stigma?

Conclusion

Participation and inclusion are paramount to an individual's sense of self within a community. Stigmatizing behaviors deeply affect children and adolescents with ASD and diminish an individual's capacity to feel like a part of their community. Education around what stigma is, how it is experienced, and how the general public contribute and perpetuate stigma is an important first step in developing awareness and knowledge around developmental disabilities including ASD. It is clear that there remains a need for stigma reduction. Professionals supporting people living with ASD and their caregivers need to advocate for these changes both structurally in professional organizations as well as privately with the general public.

Compliance with Ethical Standards

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

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

References

- Ali, A., Hassiotis, A., Strydom, A., & King, M. (2012). Self-stigma in people with intellectual disabilities and courtesy stigma in family carers: a systematic review. *Research in Developmental Disabilities, 33*(6), 2122–2140. <https://doi.org/10.1016/j.ridd.2012.06.013>.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington: American Psychiatric Publishing.
- Arksey, H., & O'Malley, L. (2005). Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology: Theory and Practice, 8*(1), 19–32. <https://doi.org/10.1080/1364557032000119616>.
- Benson, A., O'Toole, S., Lambert, V., Gallagher, P., Shahwan, A., & Austin, J. K. (2016). The stigma experiences and perceptions of families living with epilepsy: implications for epilepsy-related communication within and external to the family unit. *Patient Education and Counseling, 99*(9), 1473–1481. <https://doi.org/10.1016/j.pec.2016.06.009>.
- Blanche, E. I., Diaz, J., Barretto, T., & Cermak, S. A. (2015). Caregiving experiences of Latino families with children with autism spectrum disorder. *American Journal of Occupational Therapy, 69*(5), 6905185010p1. <https://doi.org/10.5014/ajot.2015.017848>.
- Bos, A. E. R., Pryor, J. B., Reeder, G. D., & Stutterheim, S. E. (2013). Stigma: Advances in theory and research. *Basic and Applied Social Psychology, 35*(1), 1–9. <https://doi.org/10.1080/01973533.2012.746147>.
- Broady, T. R., Stoyles, G. J., & Morse, C. (2017). Understanding carers' lived experience of stigma: the voice of families with a child on the autism spectrum. *Health & Social Care in the Community, 25*(1), 224–233. <https://doi.org/10.1111/hsc.12297>.
- Cappadocia, M. C., Weiss, J. A., & Pepler, D. (2012). Bullying experiences among children and youth with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 42*(2), 266–277. <https://doi.org/10.1007/s10803-011-1241-x>.

- Chambres, P., Auxiette, C., Vansingle, C., & Gil, S. (2008). Adult attitudes toward behaviors of a six-year-old boy with autism. *Journal of Autism and Developmental Disorders*, 38(7), 1320–1327. <https://doi.org/10.1007/s10803-007-0519-5>.
- Corcoran, J., Berry, A., & Hill, S. (2015). The lived experience of US parents of children with autism spectrum disorders: a systematic review and meta-synthesis. *Journal Of Intellectual Disabilities: JOID*, 19(4), 356–366. <https://doi.org/10.1177/1744629515577876>.
- Daniels, A., Como, A., Hergüner, S., Kostadinova, K., Stosic, J., & Shih, A. (2017). Autism in Southeast Europe: a survey of caregivers of children with autism spectrum disorders. *Journal of Autism & Developmental Disorders*, 47(8), 2314–2325. <https://doi.org/10.1007/s10803-017-3145-x>.
- Danker, J., Strnadová, I., & Cumming, T. M. (2017). Engaging students with autism spectrum disorder in research through participant-driven photo-elicitation research technique. *Australasian Journal of Special Education*, 41(1), 35–50. <https://doi.org/10.1017/jse.2016.7>.
- Farrugia, D. (2009). Exploring stigma: medical knowledge and the stigmatisation of parents of children diagnosed with autism spectrum disorder. *Sociology of Health and Illness*, 31(7), 1011–1027. <https://doi.org/10.1111/j.1467-9566.2009.01174.x>.
- Gill, J., & Liamputtong, P. (2011). Being the mother of a child with Asperger's syndrome: women's experiences of stigma. *Health Care for Women International*, 32(8), 708–722. <https://doi.org/10.1080/07399332.2011.555830>.
- Gillespie-Lynch, K., Brooks, P. J., Someki, F., Obeid, R., Shane-Simpson, C., Kapp, S. K., ... Smith, D. S. (2015). Changing college students' conceptions of autism: an online training to increase knowledge and decrease stigma. *Journal of Autism and Developmental Disorders*, 45(8), 2553–2566. <https://doi.org/10.1007/s10803-015-2422-9>.
- Goffman, E. (1963). *Stigma: notes on the management of spoiled identity*. Eaglewood Cliffs: Prentice-Hall.
- Gray, D. E. (1993). Perceptions of stigma: the parents of autistic children. *Sociology of Health & Illness*, 15(1), 102–120. <https://doi.org/10.1111/1467-9566.ep11343802>.
- Gray, D. E. (2002a). Ten years on: a longitudinal study of families of children with autism. *Journal of Intellectual and Developmental Disability*, 27(3), 215–222. <https://doi.org/10.1080/136682502100000863>.
- Gray, D. E. (2002b). "Everybody just freezes. Everybody is just embarrassed": felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health & Illness*, 24(6), 734–749. <https://doi.org/10.1111/1467-9566.00316>.
- Gray, C., & Winter, E. (2011). Hearing voices: participatory research with preschool children with and without disabilities. *European Early Childhood Education Research Journal*, 19(3), 309–320. <https://doi.org/10.1080/1350293X.2011.597963>.
- Green, S. E. (2003). "What do you mean 'what's wrong with her?'": stigma and the lives of families of children with disabilities. *Social Science and Medicine*, 57(8), 1361–1374. [https://doi.org/10.1016/S0277-9536\(02\)00511-7](https://doi.org/10.1016/S0277-9536(02)00511-7).
- Harandi, A., & Fischbach, R. (2016). How do parents respond to stigma and hurtful words said to or about their child on the autism spectrum? *Austin Journal of Autism and Related Disabilities*, 2(4), 1030–1037.
- Huws, J. C., & Jones, R. S. P. (2010). "They just seem to live their lives in their own little world": lay perceptions of autism. *Disability & Society*, 25(3), 331–344. <https://doi.org/10.1080/09687591003701231>.
- Jones, J. L., Gallus, K. L., Viering, K. L., & Oseland, L. M. (2015). 'Are you by chance on the spectrum?' Adolescents with autism spectrum disorder making sense of their diagnoses. *Disability and Society*, 30(10), 1490–1504. <https://doi.org/10.1080/09687599.2015.1108902>.
- Kaushik, A., Kostaki, E., & Kyriakopoulos, M. (2016). The stigma of mental illness in children and adolescents: a systematic review. *Psychiatry Research*, 243, 469–494. <https://doi.org/10.1016/j.psychres.2016.04.042>.
- Kinnear, S., Link, B., Ballan, M., & Fischbach, R. (2016). Understanding the experience of stigma for parents of children with autism spectrum disorder and the role stigma plays in families' lives. *Journal of Autism & Developmental Disorders*, 46(3), 942–953. <https://doi.org/10.1007/s10803-015-2637-9>.
- Levac, D., Colquhoun, H., & Brien, K. K. O. (2010). Scoping studies: advancing the methodology. *Implementation Science*, 5(69). <https://doi.org/10.1186/1748-5908-5-69>.
- Lewis, A., & Parsons, S. (2008). Understanding of epilepsy by children and young people with epilepsy. *European Journal of Special Needs Education*, 23(4), 321–335. <https://doi.org/10.1080/08856250802387273>.
- Milacic-Vidojevic, I., Gligorovic, M., & Dragojevic, N. (2014). Tendency towards stigmatization of families of a person with autistic spectrum disorders. *International Journal of Social Psychiatry*, 60(1), 63–70. <https://doi.org/10.1177/0020764012463298>.
- Minhas, A., Vajaratkar, V., Divan, G., Hamdani, S. U., Leadbitter, K., Taylor, C., ... Rahman, A. (2015). Parents' perspectives on care of children with autistic spectrum disorder in South Asia – views from Pakistan and India. *International Review of Psychiatry*, 27(3), 247–256. <https://doi.org/10.3109/09540261.2015.1049128>.
- Mogensen, L., & Mason, J. (2015). The meaning of a label for teenagers negotiating identity: experiences with autism spectrum disorder. *Sociology of Health & Illness*, 37(2), 255–269. <https://doi.org/10.1111/1467-9566.12208>.
- Moyson, T., & Roeyers, H. (2011). The quality of life of siblings of children with autism spectrum disorder. *Exceptional Children*, 78, 41–55.
- Munroe, K., Hammond, L., & Cole, S. (2016). The experiences of African immigrant mothers living in the United Kingdom with a child diagnosed with an autism spectrum disorder: an interpretive phenomenological analysis. *Disability & Society*, 31(6), 798–819. <https://doi.org/10.1080/09687599.2016.1200015>.
- Neely-Barnes, S. L., Hall, H. R., Roberts, R. J., & Graff, J. C. (2011). Parenting a child with an autism spectrum disorder: public perceptions and parental conceptualizations. *Journal of Family Social Work*, 14(3), 208–225. <https://doi.org/10.1080/10522158.2011.571539>.
- Obeid, R., Daou, N., DeNigris, D., Shane-Simpson, C., Brooks, P., & Gillespie-Lynch, K. (2015). A cross-cultural comparison of knowledge and stigma associated with autism Spectrum disorder among college students in Lebanon and the United States. *Journal of Autism & Developmental Disorders*, 45(11), 3520–3536. <https://doi.org/10.1007/s10803-015-2499-1>.
- Pryor, J. B., & Reeder, G. D. (2011). HIV-related stigma. In C. J. Hall, J. C. Hall, & B. J. Cockerell (Eds.), *HIV/AIDS in the Post-HAART Era: manifestations, treatment, and epidemiology* (pp. 790–806). Shelton, PMPH-USA.
- Ranson, N. J., & Byrne, M. K. (2014). Promoting peer acceptance of females with higher-functioning autism in a mainstream education setting: a replication and extension of the effects of an autism anti-stigma program. *Journal of Autism and Developmental Disorders*, 44(11), 2778–2796. <https://doi.org/10.1007/s10803-014-2139-1>.
- Russell, G., & Norwich, B. (2012). Dilemmas, diagnosis and de-stigmatization: parental perspectives on the diagnosis of autism spectrum disorders. *Clinical Child Psychology & Psychiatry*, 17(2), 229–245. <https://doi.org/10.1177/1359104510365203>.
- Staniland, J. J., & Byrne, M. K. (2013). The effects of a multi-component higher-functioning autism anti-stigma program on adolescent boys. *Journal of Autism & Developmental Disorders*, 43(12), 2816–2829. <https://doi.org/10.1007/s10803-013-1829-4>.

- Thibodeau, R., & Finley, J. (2017). On associative stigma: implicit and explicit evaluations of a mother of a child with autism spectrum disorder. *Journal of Child and Family Studies*, 26(3), 843–850. <https://doi.org/10.1007/s10826-016-0615-2>.
- Werner, S., & Shulman, C. (2013). Subjective well-being among family caregivers of individuals with developmental disabilities: The role of affiliate stigma and psychosocial moderating variables. *Research in Developmental Disabilities*, 34(11):4103–4114. <https://doi.org/10.1016/j.ridd.2013.08.029>.
- Werner, S., & Shulman, C. (2015). Does type of disability make a difference in affiliate stigma among family caregivers of individuals with autism, intellectual disability or physical disability? *Journal of Intellectual Disability Research*, 59(3), 272–283. <https://doi.org/10.1111/jir.12136>.
- Wiener, J., Malone, M., Varma, A., Markel, C., Biondic, D., Tannock, R., & Humphries, T. (2012). Children's perceptions of their ADHD symptoms: positive illusions, attributions, and stigma. *Canadian Journal of School Psychology*, 27(3), 217–242. <https://doi.org/10.1177/0829573512451972>.
- Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: the experience of parents who have a child with autism. *Qualitative Health Research*. <https://doi.org/10.1177/1049732308320112>.