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ORIGINAL ARTICLE

A Systematic Review of the Stigma Experienced by People with Autism Spectrum Disorder Associated with Intellectual Disabilities and by Their Family Caregivers

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Abstract

The purpose of this paper was to explore the social stigma experienced by individuals diagnosed with ASD+ID, and to identify knowledge gaps for future studies by conducting a systematic review of peer-reviewed literature. In this systematic review, we included 12 studies exploring the experience of stigma among people with ASD+ID and/or their caregivers. Our aim was to better understand this experience, but also to explore the strategies used to cope with stigma in this population. Our results confirmed that people with ASD+ID and their caregivers experience at least low to moderate levels of stigma, and that this experience is modulated by internal and external factors (such as parental age, mindfulness traits, ASD symptoms…). In addition, our results show the impact of stigma on community integration, psychological well-being and help-seeking behaviour. The role of family, friends and professional support, as well as the formation of networks to share information, appear in our results to be protective factors against stigma. To our knowledge, this study is the first systematic review to examine the stigmatisation of people with ASD+ID and/or their caregivers. Further research is needed to understand the perspective of people with ASD+ID themselves and to explore other factors that modulate this experience, in particular gender and ethnicity.

Keywords Autistic spectrum disorder · Intellectual disability · Stigma · Neurodevelopment · Mental health · Systematic review

Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental condition reported in 1.70 and 1.85% in US children aged 4 and 8 years respectively, while prevalence in Europe ranged between 0.38 and 1.55% (Bougeard et al., 2021). According to the current DSM5 definition of ASD (American Psychiatric Association, 2013) there is a spectrum of how autism presents depending on level of required support and on co-occurring condition including intellectual impairment, language deficit, psychological and medical conditions (American Psychiatric Association, 2013).

The elevated prevalence of ASD, associated with its variable but sometimes negative impact on individuals' daily lives, makes early diagnosis and intervention important. To address the negative impact experienced by autistic people existing in neurotypical settings that can be disabling (when acceptance, supports, and accommodations are absent), we must recognize how they are considered by the society in which they live.

Several surveys conducted in Australia (Jones et al., 2021), Denmark (Jensen et al., 2016), France (Durand-Zaleski et al., 2012), Korea (Park et al., 2018), the United Kingdom (UK) (Cage et al., 2019), the United States (US) (Baio, 2012), and Canada (Mitchell & Locke, 2015) all suggest that the general population is now more aware of what autism actually is. This growing awareness is enhanced by the fame of public figures with autism (for instance, Greta Thunberg), and is translated by a strong

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activity on social networks and Internet (Skafle et al., 2021).

However, a recent survey (Jones et al., 2021) highlights discrepancies between knowledge of autism in the general population and the lived experience of individuals with autism themselves. This suggests that the general population's knowledge of autism remains superficial. Other surveys suggest stigma in autism, with the existence of misconceptions and myths (Jensen et al., 2016; Park et al., 2018), as well as a reticence of neurotypical people to interact with autistic people.

Stigma was first defined by sociologist Erving Goffman (2009) as a spoiled identity that discredits a person in society. Link and Phelan suggest that there are several conditions for stigma, namely labelled differences, stereotypes, separation, status loss and discrimination of the stigmatized individuals (Link & Phelan, 2001).

Research on stigma associated with ASD us expanding. Recent studies on stigma, which often explore multiple dimensions including experienced and internalized stigma, were discussed in a systematic review of 27 studies (Han et al., 2022). The reviewed literature demonstrates that individuals with ASD are aware of being stereotyped, judged, and discriminated against by others. Additionally, these individuals often exhibit signs of internalizing stigma, which increases their vulnerability to low self-worth and poorer mental health. Han et al. (2022) analysis suggests that autistic individuals employ various strategy to cope with stigma, including concealment and camouflaging, selective disclosure and self-advocacy, as well as positive reframing and identity reconstruction. Autistic individuals may choose to hide their diagnosis or mask their symptoms. Alternatively, they might disclose their condition selectively and integrate it into their identity, fostering a sense of belonging and community. However, the evidence regarding the effectiveness of these strategies is limited and mixed, and most data were gathered from individuals with proficient verbal and intellectual abilities (predominantly, those with an IQ above 100), despite reports that intellectual disability (ID) occurs in 50% of autistic individuals (NICE, 2011, 2017). Consequently, Han and colleagues' (2022) recommend that future research should include populations with ASD across a broader range of intellectual abilities, and explore interventions that could aid in managing stigma.

It seems quite intuitive to assume that combining ASD with ID would lead to greater vulnerability, especially given that ID is often associated with additional co-occurring conditions, and that individuals with these conditions may fewer adaptive abilities compared to those with higher cognitive functioning. Logically, these factors would make these individuals more susceptible to misunderstanding and rejection by their peers.

Our study aims to explore the social stigma experienced by individuals diagnosed with ASD+ID, and identify knowledge gaps for future studies by conducting a systematic review of peer-reviewed literature. The primary research question that guided this study was: "What is the stigma perceived and experienced by people with ASD+ID and their caregivers?" Another research question was: "What are the factors that help people with ASD+ID and their caregivers to deal with stigma?".

Method

A systematic literature review on stigma in ASD+ID was performed to summarize the research published before March 2023.

Search Strategy

We used Medline (Pubmed) and psychinfo databases, with the following search terms: stigma AND ASD AND ID, and MESH terms: "("Autistic Disorder"[Mesh] OR "Autism Spectrum Disorder"[Mesh]) AND ("Intellectual Disability"[Mesh] OR "Persons with Mental Disabilities"[Mesh]) AND ("social stigma" [Mesh]); ("Autistic Disorder"[Mesh] OR "Autism Spectrum Disorder"[Mesh]) AND ("Intellectual Disability"[Mesh] OR "Persons with Mental Disabilities"[Mesh]) AND ("Social Stigma"[Mesh]); ("Autistic Disorder"[Mesh] OR "Autism Spectrum Disorder"[Mesh]) OR ("Intellectual Disability"[Mesh] OR "Persons with Mental Disabilities"[Mesh]) AND ("Social Stigma"[MESH]) NOT ("Asperger syndrome"[Mesh]) NOT ("Down syndrome"[Mesh]).

Study Selection

All types of studies (qualitative, quantitative, and mixed-methods) were considered to extract the relevant articles. The included studies fulfilled the following eligibility criteria: (1) published before March 2023 in peer-reviewed journals, (2) written in either English or French, (3) reporting on stigma experienced by individuals with ASD+ID or their caregivers, (4) original research irrespective of its design or country of origin.

Exclusion criteria covered: (1) studies focusing on ASD alone or ID alone, (2) studies focusing on people that were not caregivers of individuals with ASD+ID (such as teachers or classmates), (3) reviews, books, and essays.

Data Extraction

The first author of this paper screened the titles and the abstracts against the inclusion criteria. The full-texts deemed relevant were retrieved and reviewed. The two authors independently assessed the full text articles to confirm eligibility and reconcile any discrepancies. For charting, data were extracted according to study author and year of publication, study design, sample size and sampling characteristics, type of stigma measured (perceived, anticipated, internalized, experienced), strength and significance (if applicable) of the stigma and health outcome association, and mediators and moderators.

Quality Appraisal

The two authors evaluated the quality of the studies using the STROBE checklist for quantitative or mixed design studies, and the COREQ checklist for qualitative studies. Discrepancies were resolved through discussion.

The STROBE criteria were analyzed according to three levels (A, B, and C): A—when at most one criterion was missing; C—when more than two criteria were not met; B—in other cases.

The overall quality of each study was assessed according to three levels (A, B, and C): A—when there were at least ¾ items A and less than 10% items C in the method and analysis parts; C—when there were less than 50% items A and at least 10% items C; B—in other cases.

Patient and Public Involvement

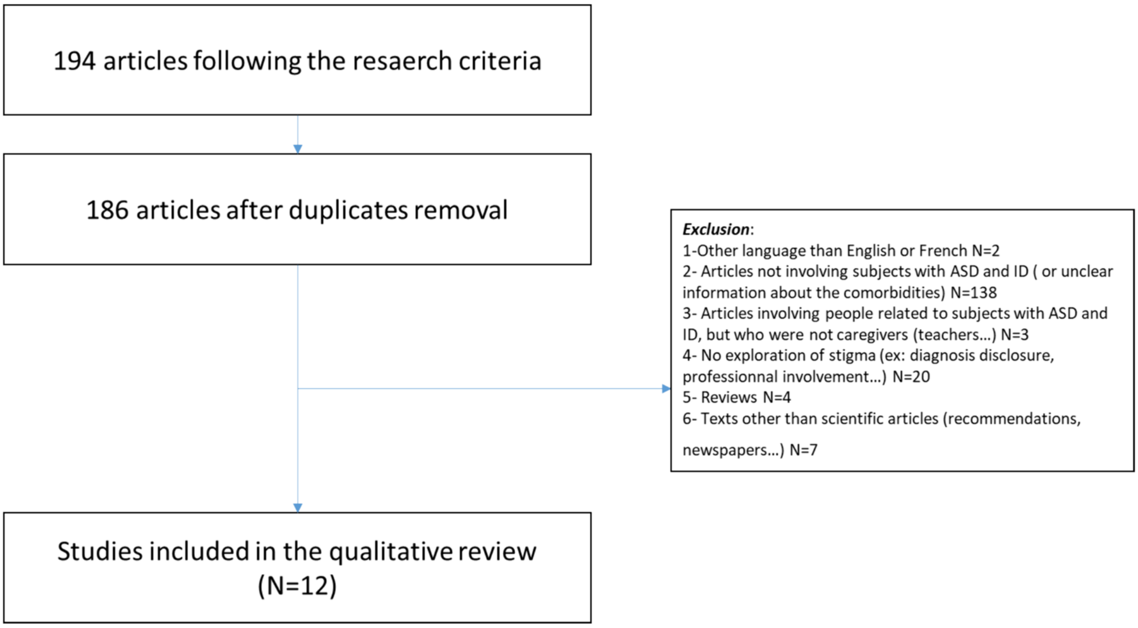
We did not engage with patients or the public during the development of this review.

Results

Figure 1 summarizes the selection process. After removing 8 duplicate articles, 162 were not included among the total 186 studies (139 because they did not target people with ASD+ID, 3 because they targeted peers and not family and/or caregivers, and 20 because they did not specifically focus on stigma). Following the exclusion criteria, 4 reviews and 7 texts that were not scientific studies (for instance, guidelines or journalistic work) were excluded. The remaining 12 articles were included in this review.

Characteristics of Included Studies

The study characteristics are detailed in Tables 1 and 2. Apart from one (which was published in 2010), all of the studies were published after 2016, and most of them (n = 8) after 2019. Six studies were conducted in Asia (five in Hong-Kong, and one in China), two in the United Kingdom, two in the US, one in Ethiopia, and one in Israel. Ten studies had a cross-sectional design, and two had a longitudinal design. Three studies used a qualitative design, eight a quantitative design, and one a mixed design.



Exclusion:
1-Other language than English or French N=2
2- Articles not involving subjects with ASD and ID (or unclear information about the comorbidities) N=138
3- Articles involving people related to subjects with ASD and ID, but who were not caregivers (teachers…) N=3
4- No exploration of stigma (ex: diagnosis disclosure, professionnal involvement…) N=20
5- Reviews N=4
6- Texts other than scientific articles (recommendations, newspapers…) N=7

Fig. 1 [TOP]: PRISMA flow diagram showing study selection

Table 1 Characteristics of included studies

	Years	Countries	Study design	Diagnoses ascertainment and recruitment	Sample size (participants with ASD + ID)	Gender (participants with ASD + ID)	Age (participants with ASD + ID)	Caregivers' sample size	Caregivers' age	Caregivers' gender	Socio economic level	Education level	Stigma dimension	Mesure of stigma (type and validity)
Mitter et al.	2018	United Kingdom	Cross sectional	Online survey of family members (recruitment by UK-based organizations working with caregivers of children with IDD)		68% male	Not specified	407 family members of children with intellectual disability (including 215 children with comorbid ASD)	38% between 45 and 54 and 28% between 31 and 44	Mothers (79%), 7% fathers	Unknown	53% educated until 18 years old	Family and affiliate stigma	FAMSI (26-item scale based on 11 scales including Affiliate Stigma Scale), revised by clinicians Piloted by 10 caregivers; good internal consistency (Cronbach alpha = 0.84)
Tilahun et al.	2016	Ethiopia	Cross sectional facility based study carried out using a structured questionnaire administered to caregivers	Following DSMIV criteria after clinical observation by psychiatrist and caregiver interview	102	Boys 75.5%	8 years in mean	102	36 years	Unknown		61% have received at least some formal education	Community stigma	Structured questionnaire adapted from the FIS originally developed for relatives of people with SZ; good internal consistency (Cronbach Alpha = 0.92)
Winnie et al.	From November 2008 to March 2009 (study published in 2010)	Hong Kong	Cross sectional study	Questionnaire sent to children recruited through non-governmental organizations (NGOs) and special schools	179 children with ASD, including a population of 73 children with ASD and ID (8 with ASD and borderline ID, 43 with mild ID, 20 with moderate ID, 2 with Asperger's with ID)	158 boys (88.3%)	9.82 years in mean	188	42.56 years	Female (84.3%)	Not specified	50% senior secondary school	Relationship between courtesy stigma and affiliate stigma	Devaluation of Consumer Families Scale (DCFS) for courtesy stigma with 7 original items + 2 more items (Cronbach's alpha = 0.86); Affiliate Stigma Scale (ASS) with good internal consistency (Cronbach's alpha = 0.94)

Table 1 (continued)

	Years	Countries	Study design	Diagnoses ascertainment and recruitment	Sample size (participants with ASD + ID)	Gender (participants with ASD + ID)	Age (participants with ASD + ID)	Caregivers' sample size	Caregivers' age	Caregivers' gender	Socio economic level	Education level	Stigma dimension	Mesure of stigma (type and validity)
Charles et al.	2021	Hong Kong	One year, two-wave longitudinal design	Recruitment from four autism service centers and 14 special schools in Hong Kong, diagnosis based on DSM-5	Around 79% of ASD + ID	84% boys	12.63 years in mean	389 parents at T1; 372 at T2 (retention rate of 95,6%)	46.83 years in mean	82% mothers	20,001–25,000 HK dollars median monthly family income		At T1: public, courtesy stigma; at T2: self-stigma content, self-stigma process	Perceived Public Stigma Scale and Perceived Courtesy Stigma Scale, both with good internal consistency (Cronbachs alpha = 0.90); Affiliate Stigma Scale (Cronbach's alpha = 0.94), Self-stigmatizing Thinking's Automaticity and Repetition Scale (Cronbach's alpha = 0.95)
McGarty et al.	2020	UK	Qualitative study	Based on parents' report	Seven children (3 with ASD and ID)	6 males, one female	Aged from 10 to 18 (14.71 years in mean)	7 parents + 1 stepfather	45.63 years in mean	4 mothers, 3 fathers + 1 stepfather	5 deprived areas	High school	Courtesy stigma	Face-to-face semi-structured interviews
Chan et al.	2022	Hong Kong	2-year, two-wave prospective longitudinal design	Recruitment from four autism service centers and 14 special schools in Hong Kong, China; ASD had to be diagnosed by a clinician, based on the DSM-5 criteria	Around 79% with ASD and ID	84% boys	11.61 years in mean	441 parents at T1, 381 parents at T2 (86% retention rate)	45.78 years in mean	81% mothers	20,001–25,000 HKD median monthly household income	Secondary education or above (96%)	Courtesy stigma (at T1), self-stigma (= affiliate) (at T2)	Parental Stigma Scale (PSS), good internal consistency (Cronbach's alpha 0.94), Parents' Self-Stigma Scale (PSSS), good internal consistency (Cronbach's alpha 0.94)

Table 1 (continued)

	Years	Countries	Study design	Diagnoses ascertainment and recruitment	Sample size (participants with ASD + ID)	Gender (participants with ASD + ID)	Age (participants with ASD + ID)	Caregivers' sample size	Caregivers' age	Caregivers' gender	Socio economic level	Education level	Stigma dimension	Mesure of stigma (type and validity)
Feaster and Franzen	2019	China	Exploratory qualitative cross-sectional design	Unspecified (probably parent's report); patients were selected from a religious organization for children with special needs, attending a summer program	Unspecified	Unspecified	From 6 years old to 19 years old	14 parents for individual or couple interviews, 24 parents in group sessions	Unspecified	Unspecified	Few were wealthy or poor, most in-between	Unspecified	Social stigma and cultural stigma	Semi-structured interviews
Ng et al.	2020	Hong Kong	Cross-sectional quantitative study	Recruitment from four early education and training centers and 3 special child-care centers from local ONG in HongKong; diagnosed by pediatricians or psychologists in hospitals	63 children (4 with ASD and ID)	85% boys	5.45 years in mean	63 caregivers	39 years in mean	48 mothers (76%)	Superior to 20,000HKD (71%)	Senior high school (54%)	Affiliate stigma	Affiliate Stigma Scale (ASS), good internal consistency (Cronbach's alpha = 0.94)
Habayeb et al.	2019	USA	Mixed method study	Parents' report through a demographic questionnaire	20 (1 with ASD and ID)	Unknown	9 years and 4 months	20 (9 participants completing a follow-up phone interview)	38 years and 5 months	75% mothers	30% with a yearly family income between 100,000–150000; 40% with a full-time employment	50% bachelors, 25% with a master level	Perceived stigma	Adapted Perceived Stigma Scale (APSS), acceptable internal consistency (Cronbach's alpha = 0.76) and test–retest reliability (Cronbach's alpha = 0.78)

Table 1 (continued)

	Years	Countries	Study design	Diagnoses ascertainment and recruitment	Sample size (participants with ASD + ID)	Gender (participants with ASD + ID)	Age (participants with ASD + ID)	Caregivers' sample size	Caregivers' age	Caregivers' gender	Socio economic level	Education level	Stigma dimension	Mesure of stigma (type and validity)
Werner et al.	2019	Israel	Cross-sectional quantitative design	Recruitment from National ID registry, social media, clinics, schools, social services, newsletters	187 (40 with ID and ASD)	55% boys	17 years in mean	187 caregivers (all parents, except for an aunt)	48 years in mean	83% female	73% below average	12 years in mean	Family stigma and help-seeking stigma	Devaluation of Consumers Family Scale, modified for the study with Cronbach's alpha = 0.75; Stigmatization subscale of the Parental Attitudes Toward Psychological Services Inventory, Cronbach's alpha = 0.80
Marsack and Perry	2018	USA	Qualitative study (follow-up of a larger web-based study)	Unknown (probably parent's report, participants were recruited from members of ASD support groups and national organizations; snowball sampling was also attempted); high levels of comorbidity between ID and ASD (no clear percentage)	Not clearly specified	Majority of boys (only 10 girls)	18–44 years old	51 parents	From early 50 s to 70 s	46 mothers, 5 fathers	Not clearly specified (higher family income than the average American)	Not clearly specified (higher education levels than the average American)	Social stigma	Qualitative semi-structured interview (questions read by 8 professionals with critical feedback and suggestions to improve the readability of some items and improve their phraseology)

Table 1 (continued)

	Years	Countries	Study design	Diagnoses ascertainment and recruitment	Sample size (participants with ASD + ID)	Gender (participants with ASD + ID)	Age (participants with ASD + ID)	Caregivers' sample size	Caregivers' age	Caregivers' gender	Socio economic level	Education level	Stigma dimension	Mesure of stigma (type and validity)
Chan and Leung	2020	Hong Kong	Cross-sectional study using a questionnaire administered to caregivers	Recruitment from 4 autism service centers and 14 special schools in Hong Kong, China; ASD diagnosed by clinician, based on the DSM-5 criteria	Unspecified (77% with ASD + ID)	Majority of boys (83%)	11.47 years in mean	441 parents	45.64 years in mean	82.1% female	Median monthly household income between HK$20,001 and HK$25,000 (or about US$2,568 and US$3,210)	95% pursued high school levels	Public stigma, Courtesy stigma, Vicarious stigma, Parents' self-stigma (affiliate)	Child Stigma Scale for public stigma, good internal consistency (Cronbach's alpha = 0.92); Parental Stigma Scale for courtesy stigma, good internal consistency (Cronbach's alpha = 0.94); adapted version of the Vicarious Affiliate Stigma Scale for vicarious stigma, good internal consistency (Cronbach's alpha = 0.95); Affiliate Stigma Scale for parental self-stigma, good internal consistency (Cronbach's alpha = 0.94)

Table 2 Results of included studies

References	Data analysis	Main results	Bias and limitations
Mitter et al. (2018)	Regression analyses	The FAMSI has a good reliability; perceived family stigma, caregiver burden and subjective well-being are the strongest predictors of family stigma	Data pursued online, selection bias (older age or minorities excluded), questionnaires in English, original Challenging Behavior Interview modified from the original, uncertainty with additional diagnosis, no clinical assessment, no analyses of the variance across the groups and other covariates
Tilahun et al. (2016)	Parametric and non-parametric analyses	43% of caregivers reported stigma; stigma didn't depend on age, neurodevelopmental disorder type, gender and caregiver education level; higher stigma in those who search for traditional help or havesupernatural beliefs	Limited sample size; cross sectional study, population bias (more that 80% urban residents)
Winnie et al.	Pearson's correlation analysis	Courtesy stigma positively associated with perceived responsibility/blame and affiliate stigma; it was also negatively related to perceived controllability. Perceived controllability negatively related to affiliate stigma and perceived responsibility/blame was positively related to affiliate stigma Affiliate stigma negatively related to psychological well-being	Cross-sectional study; no specific information about instrumental and emotional support
Charles et al.	Descriptive statistics, bivariate correlations, hierarchical regression, then simple slope tests	Public and courtesy stigma at T1 were positively correlated with self-stigma (affiliate stigma) process, perceived stress, and symptoms of depression and anxiety at T2; mindfulness was negatively correlated with self-stigma content and process, perceived stress, and symptoms of depression and anxiety at T2	No possibility to make causal relations, measures made with self-reports, no gender diversity (mothers and sons mostly),
McGarty et al. (2021)	Thematic analysis conducted in a six-phase approach	Parents have a positive view of physical activity but experience several barriers. Social and informational support positively influence the research of physical activities. Parents report high levels of exclusion due to having a child with ID and felt they did not receive enough support. Parents are also aware of the stigma (negative attitudes and prejudice) their child faced because of their condition, which negatively impacted they promotion of physical activity	Selection bias, small sample size, demographic data based on parents' report

Table 2 (continued)

References	Data analysis	Main results	Bias and limitations
Chan et al. (2022)	Descriptive statistics, correlation analyses, then hierarchical regression analyses, simple slope analyses	Courtesy stigma interacted with self-compassion at T1 in predicting self-stigma, depressive and anxiety symptoms and parent–child and inter-parental conflicts at T2. Specifically, the associations of courtesy stigma with the adverse psychological consequences were weaker for parents with high self-compassion than for those with low self-compassion	Measures based on participants' self-reports, correlational data with no possibility to determine causal relations, no possibility to differentiate the stigmatizing experiences instigated by the different psychiatric conditions (ASD, ID, ADHD…)
Feaster and Franzen (2021)	Open and axial coding iterations (coder triangulation and data charts)	Families identify experiences of stigma and acceptance related to traditional and alternative social constructions of intellectual and developmental disabilities, and how they use social networks and information-sharing to help develop community-based services	Qualitative method, convenience sample, researcher from outside the community, participants engaged in the organization providing the summer program
Ng et al. (2020)	Parametric (univariate, hierarchical multiple linear regression analyses, bootstrapping methods) and non-parametric analysis	Parents had a moderate level of affiliate stigma, which did not correlate with the frequency of their children's participation in activities. The parents' affiliate stigma was found to have negative impacts on their children's involvement in overall community participation and participation in one particular activity at home	Convenience sampling with probable exclusion of parents whose children suffer from severe affiliate stigma, exclusion of children with ASD who had serious illnesses or physical impairments (selection bias), small sample size, gender bias toward boys with ASD
Habayeb et al. (2020)	Descriptive statistics + linear regression analyses (quantitative date); grounded theory analytic procedures (qualitative date)	Results indicated low to moderate levels of perceived stigma; no significant predictors of perceived stigma found, nor intergroup differences; most participants reported disability- related stigma among Arab American communities including from their own family	Sampling bias, small sample size, privacy concerns limiting the sharing of personal information from the participants
Werner et al. (2019)	Multiple regression analyses, bootstrapping, path analyses	Lower family stigma related to higher personal enabling factors (e.g. knowledge about services and previous experience seeking help), which in turn was related to higher help-seeking behaviors. Higher professional enabling factors (e.g. attitude of the professional, services in the vicinity) were related to higher intentions to seek help, which were related to higher help-seeking behaviors	Convenience sample, help-seeking stigma was explored as an overall construct (no exploration of specific services), no exploration of the objective usefulness of provided services
Marsack and Perry (2018)	Grounded therory approch, line-by-line analysis	Many participants recounted the misunderstanding that comes from lack of knowledge of ASD, leading to stigma. ASD behaviors can be considered as reflections of parenting ability. Resistance from the school system reported. Parents encounter complex caregiving burdens and daily life impacts (lack of services, financial strain)	Overrepresentation of people who had high family incomes and education levels than the average American, female caregivers oversampled most autistic individuals males, no exploration of gender role

Table 2 (continued)

References	Data analysis	Main results	Bias and limitations
Chan and Leung (2021)	Descriptive statistics, correlation analyses, path analyses and path model, bias corrected boostrap method	Social communication and interaction deficits and restricted and repetitive behaviors in childhood positively associated with public and courtesy stigma. While public stigma was positively associated with parental vicarious stigma, courtesy stigma was positively associated with parental self-stigma. Both vicarious and self-stigma positively associated with depressive and anxiety symptoms among parents	Cross-sectional design, majority of male children and mothers

In 12 studies, individuals with ASD+ID were a subgroup of the whole sample. The exact sample size of individuals with ASD+ID was not clearly specified in six of the studies. One study had a sample size of 102 children, one of 179 (including 73 children with ASD+ID), one with seven children, one with 63 children (including four children with ASD+ID), one with 20 children (including only one child with ASD+ID), and one with 187 participants (including 40 children with ASD+ID). The majority of these subjects were males (55–88% of the sample). All of the studies reported a mean age of below 18 years, except one which focused on aging (Marsack & Perry, 2018).

All 12 studies included caregivers, mostly mothers, although one included an equal number of fathers (or stepfathers) and mothers (McGarty et al., 2021). Eight studies had a sample size of under 188 participants with ASD. The other sample sizes were respectively 389 (one study), 407 participants (one study), and 441 ($n=2$). The majority of the caregivers were aged 35–50 years. The number of caregivers was as follows: over 250 for three studies, 100–250 for three studies, and under 100 for the remaining five. The socio-economical level, which was not systematically reported, was heterogeneous. Four studies reported a median family income of 20,001–25,000 HK dollars per month (about US$ 2568 to US$ 3210), or superior to 20,000 HK dollars. One study reported that 30% of their participants had a yearly family income of between 100,000 and 150,000, while 40% of them were in full-time employment. Two studies gave imprecise information, one reporting “a higher family income” among their participants “than their country’s average”, while the other reported that “Few [of their sample size] were wealthy or poor, most in-between”. One study reported that 73% of their participants had a family income below the average of their country, and another that their population stemmed from “five deprived areas”. Finally, three studies did not give information regarding socio-economical level. Most caregivers pursued at least secondary education (50–95% of the samples), although one study did not specify their educational level, and another reported “at least some formal education”.

Description of Stigma in ASD+ID

Our reviewed articles refer to a wide range of stigma (defined in Table 3): courtesy stigma (defined as the stigma experienced by families, and also known as family stigma), affiliate stigma (referring to the perception and the interiorization of stigma experienced by families, and also labelled “self-stigma” in two studies), vicarious stigma (describing the distress families feel in response to perceiving stigma directed at their child), help-seeking stigma, public stigma (also called social stigma), community, cultural and perceived stigma (ambiguous regarding the targeted individuals).

Table 3 Overview of types of stigma

Type of stigma	Definition	Articles
Public (or social) stigma	Corresponds to the general public's stereotyping, prejudice, and discrimination toward people with discredited characteristics (Corrigan & Watson, 2002)	N = 4 (Chan & Leung, 2021; Feaster & Franzen, 2021; Marsack & Perry, 2018; Yip & Chan, 2022)
Courtesy (or family) stigma	Abuse experienced by parents of children with disabilities, who are considered by their peers as blamable (Goffman, 1963) and unable to educate and control their children due to a lack of competence (Chan et al., 2022)	N = 7 (Chan & Leung, 2021; Chan et al., 2022; Mak & Kwok, 2010; McGarty et al., 2021; Mitter et al., 2018; Werner et al., 2019; Yip & Chan, 2022)
Affiliate stigma (referred to in two articles as "self-stigma")	The perception of family stigma may lead to affiliate stigma, which represents self-stigma experienced by the family and caregivers of individuals with disabilities (Ng et al., 2020)	N = 6 (Chan & Leung, 2021; Chan et al., 2022; Mak & Kwok, 2010; Mitter et al., 2018; Ng et al., 2020; Yip & Chan, 2022)
Help-seeking stigma	Negative perception of the general population regarding those who seek help from mental health services	N = 1 (Werner et al., 2019)
Community stigma	Stigma experienced within the community	N = 1 (Tilahun et al., 2016)
Cultural stigma	Stigma influenced by culture-specific constructs (Yang et al., 2014)	N = 1 (Feaster & Franzen, 2021)
Perceived stigma	Perceptions of societal stereotypes, prejudice, and discrimination (Han et al., 2022)	N = 1 (Habayeb et al., 2020)
Vicarious stigma	Psychological pain experienced by family members when they realize the detrimental impact of stigma on their relatives (Corrigan & Miller, 2004)	N = 1 (Chan & Leung, 2021)

Among all studies, seven articles focused on family stigma, one with a specific focus, while the six remaining articles investigated other types of stigma. Three studies examined both family stigma, and affiliate stigma. One study focused on affiliate stigma only. Two articles explored social stigma (one also cultural stigma): one community stigma, and one perceived stigma.

The measurements of stigma varied from one study to the next, depending on the type of stigma analyzed and the study's design. The three qualitative studies used semi-structured interviews to analyze stigma, and the nine quantitative studies used standardized but heterogeneous scales. Definitions of stigma used by the reviewed studies are shown in Table 3.

One study (Mitter et al., 2018) used the Family Stigma Instrument (FAMSI) to measure stigma among families of people with ID. Three studies used the Affiliate Stigma Scale to assess affiliate stigma. One study (Tilahun et al., 2016) used an adapted version of the Family Interview Schedule, primarily designed for relatives of people with schizophrenia, to assess the experience of stigma in the community. Two studies (Mak & Kwok, 2010; Werner et al., 2019) used an adapted version of the Consumers Family Scale to explore courtesy stigma. One study (Yip & Chan, 2022) used the Affiliate Stigma Scale (ASS) combined with three other scales: the Perceived Public Stigma Scale, the Perceived Courtesy Stigma Scale, and the Self-Stigmatizing Thinking's Automaticity and Repetition Scale (Cronbach's alpha = 0.95). One study (Chan et al., 2022) used the Parental Stigma Scale (PSS) and the Parents' Self-Stigma Scale (PSSS) to assess respectively the courtesy stigma and the self-stigma experienced by families. One study (Chan & Leung, 2021) used the Child Stigma Scale to assess public stigma, the Parental Stigma Scale to assess the caregivers' experience of courtesy stigma, the ASS to assess the affiliate stigma, and the Vicarious Stigma Scale to assess vicarious stigma. Finally, one study (Habayeb et al., 2020) used an adaptation of the Perceived Stigma Scale to study parents' perceived stigma. Internal consistency of the standardized scales used in the studies ranged from moderate to good, with a Cronbach's alpha ranging from 0.75 to 0.95.

Stigma Perceived and Experienced by People with ASD+ID or Their Caregivers

Eight studies provided information on the perception and the experience of stigma, all of them questioning caregivers only, with no clear information from the perspective of individuals with ASD+ID.

Three studies (Habayeb et al., 2020; Ng et al., 2020; Werner et al., 2019) described the level of experienced stigma. Habayeb et al. (2020) reported low to moderate levels of perceived stigma among their participants. In Werner et al.

(2019), participants reported very low levels of help-seeking stigma and higher levels of courtesy stigma. Ng et al. (2020) reported a moderate level of affiliate stigma, with a mean ASS score of 2.21 (SD = 0.48).

Only the study conducted by (Mitter et al., 2018) provided data on the proportion of participants who experienced stigma. In this study, of the 407 family caregivers (53% of whom had children with ASD along with intellectual disabilities) who completed the 28-item Family Stigma Instrument, 59.3% perceived family stigma. Additionally, 34.5% reported experiencing affiliate stigma, with 11.4% associated with the affective dimension (which measures the emotional responses, such as feelings of shame, guilt or embarrassment), 65.9% with the cognitive dimension (which includes beliefs and thoughts held by family members about the stigma, such as perceived judgment from others), and 5.7% with the behavioral dimension (which assesses the actual behaviors or actions taken by family members in response to stigma, like withdrawing from social interactions).

Two studies (Marsack & Perry, 2018; Mitter et al., 2018) described caregivers of people with autism feeling judged when in public with their child. Mitter et al. (2018) reported that 79% feel “looked at differently” when they were with their child, and Marsack and Perry (2018) that they felt “stared at and judged”. Three studies have also reported that caregivers seek to hide from their peers. In the study by Tilahun et al. (2016), around 43% of caregivers reported being often and very much worried about being treated differently, and 45% ‘ashamed’ or ‘embarrassed’ by their child’s condition, with 26.4% feeling the need to hide the issue from their community (26.4%), or keep their child’s condition a secret (26.7%). In addition, 47.1% of caregivers said they felt their child’s condition was their fault. In the study by Habayeb et al. (2020), caregivers recounted an experience of disability-related stigma, sometimes with injunctions from their community to keep their child’s condition secret. In the study by Feaster and Frazen (2021), parents reported having to keep their disabled child within the ‘family living space’, forcing them to avoid interactions outside the direct family. Notions of misunderstanding and blame from relatives were also cited as sources of caregiver stigma in two studies (Feaster & Franzen, 2021; Marsack & Perry, 2018). According to Feaster et al. (2021), some parents also reported a lack of support and understanding from their family and the wider community.

The notion of exclusion was found in four studies (Feaster & Franzen, 2021; Marsack & Perry, 2018; McGarty et al., 2021; Mitter et al., 2018). In the Mitter et al. (2018) study, 66% of caregivers described that their family was not invited to social events, and 52% felt excluded from activities due to their child’s health condition. The qualitative study by McGarty et al. (2021), which explored caregivers’ experiences of promoting physical activity for their child, identified several barriers including social exclusion and stigma and lack of understanding. In the study, parents reported feeling excluded from mainstream sports clubs, coupled with negative attitudes and prejudice towards their child or themselves. Some parents stated that they isolate themselves in reaction to the judgment of others, and fear that the negative attitudes of other children will lead to their son or daughter being bullied. In the qualitative study by Feaster et al. (2021), caregivers reported that rejection by their peers affected their social life on multiple levels. Finally, Marsack et al. (2018) reported that the combination of misunderstanding and stigma towards ASD and the burden of inadequate care provision were associated with social rejection. In two studies (McGarty et al., 2021; Ng et al., 2020), caregivers also reported that stigma limited their children’s involvement in community (Ng et al., 2020) or physical activities (McGarty et al., 2021). In Marsack et al. (2018), some caregivers reported difficulties at school (particularly in the allocation of individual education plans) as additional sources of stigma.

Factors that Help People with ASD+ID or Their Caregivers to Deal with Stigma

Seven studies explore factors moderating or predicting stigma. Four multivariate linear regressions were used in the paper by Mitter et al. (2018), each calculated with affective affiliated stigma, cognitive affiliated stigma, and global affiliated stigma as outcome variables. After corrections, the predictors of these dimensions were evaluated. For affective affiliated stigma, 3% of the variance was predicted by three factors: perceived family stigma, ethnicity, and burden. In addition, 31% of the variance in cognitive affiliated stigma was influenced by perceived family stigma, caregiver age and subjective well-being. For behavioral affiliated stigma, 7% of the variance was predicted by perceived family stigma and burden. Finally, the strongest predictors of total affiliated stigma were perceived family stigma, caregiver burden, and subjective well-being.

The aim of Mak et al. (2010) was to propose an integrated model investigating the process of internalization from courtesy stigma to affiliate stigma among the caregivers of people with ASD, using attributions of perceived controllability, perceived responsibility, and self-blame. They also sought to investigate the negative impact of three types of support (family, friends, and professional support) on affiliate stigma and the effects of affiliate stigma, as well as the three types of support on psychological well-being. In this study, the analysis revealed a positive association between courtesy stigma and perceived responsibility and affiliate stigma, and a negative relationship with perceived controllability. Perceived controllability appeared to be negatively related to affiliate stigma, and perceived responsibility/blame positively related to affiliate stigma. While affiliate stigma was negatively related to psychological well-being, support from friends, family and professionals was positively related to psychological well-being. Only support from friends was negatively related to affiliation stigma. Yip et al. (2022) proposed a descriptive and correlation analysis, aiming to (i) investigate the links between public and courtesy stigma, and adverse cognitive and affective consequences for the parents of children with ASD, and (ii) explore whether these links were moderated by trait mindfulness. To this end, they used a one-year, two-wave longitudinal design to test the association between public and courtesy stigma at T1, and cognitive and affective consequences (anxiety, depression, and stress) at T2. The study found a positive correlation between public stigma and courtesy stigma at T1, as well as caregiver self-stigma, perceived stress and symptoms of depression and anxiety at T2 (correlation coefficients ranging from 0.31 to 0.57). Mindfulness traits at T1 were negatively correlated with self-stigma and process, perceived stress, and depressive and anxiety symptoms at T2 (coefficients ranging from − 0.33 to − 0.43). Hierarchical regression analyses also revealed that the interaction term between public stigma and mindfulness accounted for (i) additional variance in self-stigma content (1%; $p = 0.03$) and process (2%: $p = 0.002$) at T1, and (ii) perceived stress (2%; $p = 0.005$) and symptoms of depression (1%; $9 = 00.2$) and anxiety (1%; $p = 0.01$) at T2. These results imply that high levels of mindfulness in parents negatively affect the effects of public stigma on these dimensions. Furthermore, hierarchical regression analysis also showed that the interaction term between courtesy stigma and mindfulness accounts for (i) additional variance in the content (1%; $p = 0.002$) and process (1%; $p = 0.01$) of self-stigma at T1, (ii) perceived stress (1%; $p = 0.04$) and symptoms of depression (1%; $p = 0.02$) and anxiety (1%; $p = 0.02$) at T2. These results showed that a higher level of mindfulness in parents tended to reduce the impact of courtesy stigma on the content and process of self-stigmatization, perceived stress, and symptoms of depression and anxiety.

Correlation analyses by Chan et al. (2022) showed a positive correlation between initial courtesy stigma and later self-stigma, depressive and anxiety symptoms, and parent–child and inter-parental conflicts. Initial compassionate self-responding was negatively correlated with later self-stigma, depressive and anxiety symptoms, and parent–child and inter-parental conflicts. In contrast, initial uncompassionate self-responding was positively correlated with later of these factors. Parental age was negatively correlated with self-stigma, while having a child with ID of ADHD was positively correlated with self-stigma.

Finally, hierarchical regression analysis revealed that the associations between courtesy stigma and self-stigma, depressive and anxiety symptoms, and parent–child and inter-parental conflicts were weaker in parents with high self-compassion levels.

Hierarchical regression models used in Ng et al. (2020) revealed no relationship between affiliate stigma and the frequency of children's participation or involvement at home and at daycare/preschool. However, affiliate stigma was negatively related to the children's participation and involvement in community activities, but not related to the children's frequency of participation. Concerning children's participation and involvement, parents' affiliate stigma also correlated with two specific activities: getting clean at home and organized physical activities in the community (Spearman's rho correlation coefficients − 0.289, $p < 0.05$, and − 0.453, $p < 0.01$).

In Werner et al. (2019), courtesy stigma was negatively associated with personal enabling factors (financial and psychological resources, knowledge and understanding of the health system, history of help-seeking) and professional enabling factors, while help-seeking stigma was negatively associated with personal enabling factors and help-seeking behaviors. Courtesy stigma was also related to higher levels of psychopathology. It was also negatively related to parents' age and years of education.

Path analysis also showed that help-seeking behavior was negatively related with help-seeking stigma. Courtesy and help-seeking stigma were negatively related to personal support. Courtesy stigma was also negatively related to professional support.

The bootstrapping method showed that lower courtesy stigma was related to higher professional enabling factors and higher personal enabling factors. Lower help-seeking stigma was related to higher personal enabling factors and higher help-seeking behaviors. Finally, help-seeking stigma was found to moderate the relationship between professional enabling factors and intentions to seek help, with a significant slope for low stigma (coefficient = 0.28, $t = 3.59$, $p < 0.001$).

In Chan and Leung (2021), correlation analysis showed a positive correlation between all variables: experiences of public and courtesy stigma, parental vicarious stigma, affiliate stigma, parental affective symptoms (anxiety and depression), and both ASD symptoms (social communication and interaction deficits, and restricted and repetitive behaviors). Correlations ranged in strength from modest to strong.

Path analysis found a direct relation between ASD symptoms and public and courtesy stigma. Public stigma was significantly related to parental vicarious stigma, and courtesy stigma had significant direct effects on affiliate stigma. Finally, bootstrap analysis showed that ASD symptoms had significant indirect effects on parental depressive and anxiety symptoms via experiences of (i) public and parental vicarious stigma, and (ii) courtesy stigma and parental self-stigma. Public stigma, parental vicarious stigma, experiences of courtesy stigma, and affiliate stigma also modulated the indirect effects of restricted and repetitive behaviors on parental depressive and anxiety symptoms.

Only two studies clearly described coping strategies among their participants.

In Tilahun et al. (2016), most caregivers reported that talking to health professionals (86.3%) and family (85.3%) helped them to cope. Many caregivers also used support from friends (76.5%) and prayer (57.8%) as coping mechanisms. Negative coping strategies such as drug use were also described (4.9% chewing Catha edulis, 3.9% drinking alcohol, and 2.9% smoking cigarettes). In terms of help-seeking behaviors, 54.9% of caregivers indicated that they first sought support in traditional places (including religious healing centers), while 45.1% first turned to a biomedical institution (hospital, private clinic, etc.). 26.5% of caregivers reported they had tried both types of resources.

In Feaster and Franzen (2021), caregivers' development of formal and informal networks was presented as a resource against stigma, as these networks allowed families with disabled children to share information on resources and support.

Discussion

Stigma Experienced by Caregivers is Common

In many countries, people with disabilities are stigmatized. Intellectual impairments are more stigmatized than physical ones. The specific experience of stigma by autistic individuals with ID and their caregivers is relatively understudied. The current review of the literature indicates that they commonly experienced stigma, but with the bias that the perspective is from family members rather than autistic people themselves. Our findings also suggest that most caregivers perceive low to moderate levels of stigma (Habayeb et al. (2020). In addition, the findings of Mitter et al. (2018) that caregivers experienced more often familial stigma than affiliated stigma, with more pronounced cognitive dimension (65.9%) is than affective or behavioral (11.4% and 5.7% respectively) suggest that individuals may recognize stigma, but they do not necessarily internalize it, feel negatively about it, or respond to it.

Social and Cultural Settings Play an Important Role in Stigma

The social setting including knowledge or understanding of ASD with ID, plays an important role, as reported by four studies (Feaster & Franzen, 2021; Marsack & Perry, 2018; McGarty et al., 2021) (Han et al., 2022). The lack of understanding of ASD linked to its heterogeneity and the media coverage of high-level forms without intellectual disability is thought to contribute to the misconception that people with ASD are more intelligent or more creative than the average person (Jensen et al., 2016). The positive stereotypes of autism depicted in the media limit the understanding of the experiences of autistic people with ID, especially those who are non-or minimally verbal, and the challenges they face. Additionally, the autistic person highlighted in the media often pertains to urban, and either English or north America with limited consideration for the varying socio-cultural stigmas that may exist. The belief that ASD is due to supernatural causes (Tilahun et al., 2016) also feeds prejudice towards autistic people with ID and/or their caregivers, whose situation is then perceived as a punishment for faults and/or negative karma (Feaster & Franzen, 2021). The negative judgment (Marsack & Perry, 2018; Mitter et al., 2018) or even blame (Feaster & Franzen, 2021; Marsack & Perry, 2018) that some caregivers perceive is a consequence of this combination of misconceptions reinforced by collectivist cultures (Ng et al., 2020) that emphasize a sense of obligation to the group. Social stigma fuels other types of stigma, such as vicarious parental stigma, courtesy stigma (Chan & Leung, 2021), and affiliated stigma (Chan & Leung, 2021; Yip & Chan, 2022). Indeed, when caregivers perceive other people's negative views of themselves and/or their child, they may internalize them and develop negative emotions and stigma-related behaviors themselves (Mitter et al., 2018).

Social Support

This systematic review highlights a protective effect among caregivers of social support from friends, family, and professionals, against stigma, psychological distress (Mak & Kwok, 2010), and help-seeking behaviors (Werner et al., 2019). The negative correlation between support from friends and stigmatization of affiliates described by Mak et al. (2010), could be explained by a lower sense of exclusion among caregivers, as suggested by Recio et al. (2020) who showed that social support was negatively correlated with perceived discrimination. These results were consistent with those of Werner et al. (2019) who found that lower family stigma correlates with higher personal enabling factors (e.g.; knowledge about services and previous experience in seeking help). This in turn relates to increased help-seeking behaviors. Furthermore, professionals enabling factors (e.g.; the professional's attitude, availability of services nearby) are linked to greater help-seeking-behaviors. This finding emphasizes that professionals can boost families' sense of self-efficacy in their own help-seeking process by providing knowledge about services and facilitating a more positive experience. In a cross-sectional survey conducted in low-income countries (Tilahun et al., (2016), most caregivers of children with developmental disorders identified discussions with health professionals and family members as their main coping strategy. Families in China (Feaster et al., 2021) employed social networks and information sharing as stratgeies against stigma. Although differences in the cultural contexts of the studies might explains variations in results, both underscore the importance of providing families with a neutral space that offers scientific information about ASD/ ID and emotional support.

Stigma is Influenced by Caregivers' Cognitions and Autistic Child's Characteristics

The influence of cognitions on the stigmatization process in caregivers is suggested by Mitter et al. (2018), and supported by the model proposed by Mak et al. (2010). Thus, self-stigmatization in caregivers would be influenced by the way they view themselves, and it could moreover improve through self-compassion and mindfulness (Chan et al., 2022; Yip & Chan, 2022). Several studies also suggest that higher parental age of caregivers and better education are associated with lower courtesy (Mitter et al., 2018; Werner et al., 2019) and affiliate stigma (Chan et al., 2022). This could be explained by the fact that older and more educated caregivers usually have more social support and financial resources. These characteristics could also provide protection against mental health problems or psychological vulnerability, and modulate the perception and internalization of stigmatization. Indeed, the greater experience of older parents could help them develop coping strategies, thus making them less vulnerable to stigmatizing attitudes (Sarkar, 2010).

Furthermore, the severity of ASD symptoms (Chan & Leung, 2021) and/or comorbidity with ID (Chan et al., 2022) contributes to the stigmatization process among carers and the people concerned. Unlike people with milder symptomatology or better cognitive faculties facilitating the use of camouflage strategies (Han et al., 2022), people with ASD+ID do not have the opportunity to hide their condition from their peers. In addition, their needs may be difficult to meet for their caregivers, who do not always have the appropriate resources (Marsack & Perry, 2018; McGarty et al., 2021; Tilahun et al., 2016).

Strengths

Our systematic review has several strengths. The method used complies with the AMSTAR criteria, there is no publication bias, and the quality of the included studies is assessed as moderate to high according to the STROBE and COREQ criteria. Our review is also, to the best of our knowledge, the first to focus on the stigma of people with ASD+ID and their caregivers, providing a new perspective on their experience and needs. In addition, the large number of participants in several of the included studies, as well as the inclusion of studies from different countries and cultures, allows for a global analysis of the context. Thus, our results can be used to identify several avenues for (i) providing people with ASD+ID and their caregivers with support against stigmatization and the psychological distress that ensues, and (ii) providing guidelines for further research in this area.

Limitations

Our review has a number of limitations that should be considered when interpreting the results. First, the articles included address highly heterogeneous definitions, often without clear explanations about who is affected by stigma, as well as diverse types and tools for measuring stigma. In addition, none of the included studies specifically target the situation of people with ASD+ID alone, who represent only a sample of their total population. In addition, the included studies provided little information on the experience of stigma among people with ASD+ID themselves, and focused on the experience of stigma among their caregivers. The participants with ASD+ID recruited in the reviewed studies were mainly men, and their caregivers women. Future research should focus on exploring the experience of stigma from the perspective of individuals with ASD and ID, taking into account gender differences. While the cultural diversity of the studies included helped to minimize cultural bias, future samples should aim to include a broader range of culturally and linguistically diverse participants and should also report on ethnicity (Steinbrenner et al., 2022).

Conclusions and Strategies to Mitigate Stigma

The stigma of disability can extend to entire families. Our study underscores the pervasive influence of stigma on the daily lives of families impacted by autism and intellectual disability. Stigma in autism has both social and individual origins, highlighting the critical need for external support and empowerment to manage its impacts (Clarke et al., 2024) particularly in case of profound autism (Çaynak et al., 2022). This support is crucial not only for enhancing community integration and psychological well-being, but also for increasing the likelihood of seeking help. Public education about ASD through awareness campaigns and strengthening specialized support systems are key strategies to protect autistic individuals with ID and their caregivers from exclusion, and to foster effective coping strategies against stigma. In addition to indirect initiatives aimed at public health, specific measures tailored for the mental health of parents of autistic children with intellectual disabilities, could protect from stigma's effects. These measures should cover psychosocial support as well as support from qualified professionals such as peer support or and parent support and skills training, which involves ensuring access to quality services.

Despite a growing interest in this field, data and research are still limited, particularly regarding autistic people with ID. More research is required to deepen our understanding of their experiences and to better pinpoint their needs. Future research should investigate the role of unexplored variables, such as culture, ethnicity and gender, in shaping stigma. Additionally, it is crucial to include perspectives from people with autism and intellectual disabilities, not just those of their families.

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