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Abstract

People with intellectual disability (ID) form one of the most underserved/stigmatised groups in society. Published data have documented stigma towards this population group in different countries, however this phenomenon has received scant attention in South American countries. We conducted a systematic search of published and grey literature in the area of stigma towards persons with ID within the twelve countries of the region. Available though limited information is organised by stakeholder groups, but the quality of the studies is variable. Future research, at population level, is needed in the region to ensure improvements in the quality of life and in the civil participation of people with ID.

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Intellectual disability (ID) is characterised by significant limitations in cognitive functions and in adaptive behaviour in a wide range of daily activities, with an origin before the age of eighteen years-old (Schalock, Luckasson, Tassé, & Verdugo, 2018). ID is a neurodevelopmental disorder, and in the current international classifications, it is categorised under "Intellectual and Developmental Disabilities (IDD)" with other conditions such as Autism Spectrum Disorders (ASD), Attention Hyperactivity Disorder (ADHD), Learning Disabilities, Motor Developmental Disabilities and Communication Disorders (American Psychiatric Association, 2013). Several studies have showed that people with IDD are a group that are commonly the victims of stigma and prejudice (i.e. Hamdani, Ary, & Lunsky, 2017; Mitter, Ali, & Scior, 2018) and, some of these studies, pointed that persons with ID are one of the most underserved/stigmatised groups in society (i.e. Walker & Scior, 2013).

Stigma and prejudice are complex concepts related to individual experiences that emerge as a result of the interaction between marginalised and non-marginalised groups (Stuber, Meyer, & Link, 2008). The seminal works by Allport (1954) and Goffman (1963) defined stigma as a personal attribute that triggers a negative stereotype with undesirable consequences for the daily life of the person. Stigma is a useful concept to characterise the social interactions that emerge from the relationship between people from a group considered typical and another considered atypical, such as people with facial scars, physical disability, mental illness, or intellectual and developmental disabilities. On the other hand, prejudice is understood as a hostile reaction towards a person because they belong to a specific group. The concept of prejudice appears to be more focused on categories such as ethnicity, gender or socio-economical level (Phelan, Link, & Dovidio, 2008). While differently defined, both concepts are related to social barriers, violations of essential rights, and direct acts of discrimination, among other consequences (Arboleda Flórez, 2005; Drew et al., 2011).

Across the world, minority groups are victims of both stigma and prejudice (Knesebeck, Kofahl, & Makowski, 2017), and some of those groups have received more attention in research than others. People with IDD have been identified as one of the least desirable groups in society (Ali, King, Strydom, & Hassiotis, 2015), and several studies demonstrated that people with ID are subject to different forms of stigma including public, courtesy, and self-perceived (Werner, 2015; Scior, Addai-Davis, Kenyon, & Sheridan, 2012; Ali, Hassiotis, Strydom, & King, 2012; Scior, 2011). Public stigma refers to the general public's response towards people with IDD as a result of negative attitudes and prejudice (Scior, 2011; Walker & Scior, 2013; Werner, 2015). Courtesy stigma affects the closest family members, friends, and professionals that work with a person with ID who may develop negative self-evaluations and emotions related with the condition (Ali, Hassiotis, Strydom, & King, 2012; Birenbaum, 1992; Birenbaum, 1970). Self-perceived stigma refers to the extent to which a person with ID is aware of stigma and discrimination from the public or from individuals (O'Byrne & Muldoon, 2017; Ali et al., 2012; Corrigan, Watson, & Barr, 2006).

In parallel with the advances in research, the fight for the rights of people with IDD has been a continuous process during the last 30 years (Wilson & Scior, 2015) and advocates have used a number of frameworks and perspectives to promote rights, e.g. common ideas about humanity and human rights (Coles & Scior, 2012), specific case law, or international declarations to enshrine such rights in law in different countries (American Association on Intellectual and Developmental Disabilities., 2010; Dang, 2010; Fujiura, Park, & Rutkowski-Kmitta, 2005; Meijer, Carpenter, & Scholte, 2004).

However, these actions are insufficient as explicit and implicit negative attitudes towards people with IDD are still prevalent in society (Scior, 2011; Wilson & Scior, 2015). Furthermore, other disparities arise when considering the social and geopolitical position of people with IDD.

Studies of the different forms of stigma towards people with IDD have been conducted mostly in high-income countries. People with IDD who report feeling stigmatised are more likely to have symptoms of anxiety and depression, a lower quality of life, and increased contacts with social services and the police (Ali et al., 2015). Some authors suggest that, in particular, self-perceived stigma could be a precursor for victimisation and loneliness in the presence of mental illness (Gilmore & Cuskelly, 2014; Horsselenberg, van Busschbach, Aleman, & Pijnenborg, 2016).

Little is known about the expression and consequences of stigma in middle or low-income countries. Previous studies conducted in South-Asia (Abraham, Gregory, Wolf, & Pemberton, 2002; Azmi, Hatton, Emerson, & Caine, 1997; Edwardraj, Mumtaj, Prasad, Kuruvilla, & Jacob, 2010) and Africa (Ali et al., 2015; Kock et al., 2012) suggest that cultural characteristics influence the social expression of stigma and prejudice, which are moderated by variables such as religion, personal beliefs about the origin of the condition or previous contact with persons with IDD. However, given the paucity of research in many regions including Latin America, conclusive actions cannot be achieved due to lack of engagement with the topic at population level (Ali et al., 2015; Ali et al., 2016; Hatzenbuehler, Phelan, & Link, 2013).

New studies are needed to clarify the cultural impact of the expression of stigma towards people with IDD and more countries should promote such research to gain a wider, global comprehension of the problems and the formulation of policies to improve the lives and acceptance of people with IDD over the life course.

South America is a region extending from the Caribbean in the north to the Antarctic region in the south and formed by twelve countries (Colombia, Ecuador, Venezuela, Guyana, Suriname, Peru, Brazil, Chile, Argentina, Uruguay, Paraguay, and Bolivia). It has a total population of approximately 600 million with significant cultural differences between countries. Most of the countries are lower-middle or upper-middle income, except for Argentina, Chile and Uruguay classified as high-income economies (World Bank, 2018). Some countries in the region though they have an established economy in terms of the gross national product and other macro-economic variables (as Chile and Brazil, for example), yet they are still considered developing countries because of the low standards of living and human development index (Frey & Temple, 2008). In addition, social inequality, characterised by problems with capital distribution, access to social services, education, health, and opportunities, is a major challenge experienced by all South American countries. As a consequence, socio-economic status is a pivotal variable for social research in the region (Central Intelligence Agency, 2017; Gapminder, 2017). Specific information about the geopolitical status for each of the South American countries, as well as the estimated population of people with disability, is presented in Table 1 to provide context to the review.

<<Insert here table 1>>

Several South American countries, have a history of political instability secondary to the military coups during the 20th century i.e. Colombia in 1953, Argentina in 1976, Chile in 1973, Uruguay in 1973, Paraguay in 1989, Brazil in 1964, and Peru in 1992, with well documented human rights violations (Sikkink & Walling, 2007). Political violence and human rights violations have morphed into social violence (Oxhorn & Jouve-Martín, 2017).

The global prevalence of IDD, and specifically for ID, is unknown due to technical and political factors such as problems with surveillance systems, differences in how the condition is defined, or lack of governmental programs oriented towards ascertainment. Current data suggests that in Latin America (Central America, the Caribbean and South American countries), 13.8 million people have IDD (PAHO, 2012). As far as we know, there is no specific prevalence rate of IDD available for the South American region only.

People with IDD are common victims of violence, e.g. they are at high risk of being victims of hate crimes, social rejection, violations of rights, and lack of opportunities (Mikton, Maguire, & Shakespeare, 2014; Sherry, 2010). They are likely to suffer inequalities in social care, health and education (Ali et al., 2013; Hassiotis, Barron, & O'Hara, 2000; Rimmer, 1999); they are at a disadvantage in the judicial process and, in general, they have worse quality of life than people without disability in the same territory (i.e. Ncube, Perry, & Weiss, 2018).

The aim of this paper is to present a narrative review of the expression of stigma and prejudice towards people with ID in South America. In this review, we focus on studies relating to stigma towards people with ID only although some may have comorbid conditions. We hope that this work will help to improve the scientific research on the topic in South America and will be relevant to a wide range of stakeholders including professionals, policy makers and Not-for-Profit organisations working with disability groups.

Method

In this review, we considered evidence available in catalogued journals and the grey literature, including academic theses, organisation reports, government papers, etc. (Haddaway, Collins, Coughlin, & Kirk, 2015).

We used the 27-item checklist recommended by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) to assess studies included in the review (Moher, Liberati, Tetzlaff, Altman, & Group, 2009). The four-phase diagram recommended by PRISMA group and that included identification process, screening, eligibility and definition of included studies, was adapted for the study (Moher et al., 2009).

The protocol recommended by Haddaway et al. (2015) to conduct systematic reviews in Google Scholar was implemented for the grey literature search.

The Mixed Method Appraisal Tool version 2018 (MMAT), (Hong et al., 2008) was used to critically appraise the methodological quality of the included studies.

Information sources

Five databases (Web of Science, EBSCO, Scopus, PubMed and LiLACS) were used for the literature search. In all cases, the date range was fixed from 2008 to 2019. There is no consensus about ideal range of dates for a systematic review (Cooper, Booth, Varley-Campbell, Britten, & Garside, 2018; Liberati et al., 2009), this date range was considered relevant based on the period in which countries in South America ratified the Convention on the Rights of Persons with Disabilities (CRPD). The search was conducted in March 2019, information from the first ten pages of Google was considered at title and text level.

Search strategy

We included search terms which had been used in previous systematic reviews about stigma in the English language and we supplemented those by additional terms that have been used in Spanish and Portuguese reviews. We chose these terms in order to replicate what has been carried out in previous reviews, as well as to integrate new sources of information.

Search terms related to ID, were combined with stigma, prejudice, attitudes and stereotypes, and with the names of all the South American countries. Due to the known relationship between ID and Autism Spectrum Disorder, this term was included in the search. We conducted the search in English, Spanish, and Portuguese as follows:

Neurodevelopmental disorder OR developmental disorder OR learning disorder OR learning disability OR mental retardation OR intellectual disability OR autism OR down syndrome

AND stigma OR prejudice OR stereot* OR attitude

AND Latin America OR South America OR Colombia OR Venezuela OR Guyana OR Suriname OR Ecuador OR Bolivia OR Peru OR Brazil OR Chile OR Argentina OR Uruguay OR Paraguay.

The Spanish and Portuguese terms selected for clinical conditions were the same as those used in English with the corresponding translation. At the level of stigma, the search in Spanish also included “imaginario”, a common term used in Colombia to describe idiosyncratic ideas about something. “Imaginario” corresponds to stereotyped ideas about groups of individuals that may be held due to particular political or social views.

The inclusion criteria for the studies were: (a) an explicit mention of ID in any part of the manuscript; (b) an explicit mention of one of the key components of stigma (attitude, stereotype, prejudice, and discrimination) and; (c) the study was conducted in South America. Exclusion criteria considered: (a) mention of conditions not included in the search terms; (b) focus on stigma towards medical conditions such as HIV/AIDS, Epilepsy, Leprosy or Tuberculosis (frequent topics of interest in the region); (c) lack of relation to stigma; and (d)) studies of immigrant populations that are not native to South America as these groups are likely to hold different cultural values that might influence the expression of stigma.

The final selection of manuscripts was reviewed and validated independently by two of the authors and an expert in statistical analysis with a third author arbitrating any disagreements that could not be resolved by the reviewers.

The MMAT approach was applied by two independent reviewers and in those cases where there was disagreement, a third person arbitrated the decision.

Results

The results are summarised in Figure 1, and in Figure 2 following the PRISMA flowchart (Moher et al., 2009).

<<Insert here figure 1>>

<<Insert here figure 2>>

Seventeen papers were retained in this review and are presented in Table 2. The MMAT algorithm was used to classify the studies according to their methodological approach. Eight studies used a qualitative approach to answer the research questions, seven used a quantitative approach, and two used a mixed methods approach. For two qualitative studies (Cerreta, 2018; Furstenberg, Iriarte, & Navarro, 2012) and one quantitative study (Retazzi, Valdez & Cukier, 2016) the MMAT approach was not feasible. However, these studies were included because the MMAT authors point out that excluding studies with low methodological quality is discouraged.

Eleven percent (11%) of the studies obtained the maximum MMAT score (5 points): one qualitative study (Lopera-Escobar, Bastidas-Acevedo, & Lopera Escobar, 2018) and one of the mixed methods study (de Menil & Cohen, 2009). Thirty-five percent (35%) of the studies obtained a MMAT score of 4 points and the remaining fifty four percent (54%) of the studies scored 3 or fewer points on quality.

In terms of content, twelve studies explored stigma, attitudes or prejudice towards persons with ID (including towards people with Down Syndrome) and five studies explored stigma towards people with ID and ASD (the specific target population for each study is available in Table 2).

The majority of the included studies were conducted in Chile (35.2%) and Colombia (17.6%). The remainder (47.2%) were from Brazil (11.7%), Ecuador (11.7%), Peru (5.8%) and Argentina (5.8%). Cross-cultural data are available in 11.7% of the included studies. No studies from Bolivia, Guyana, Suriname, Paraguay or Uruguay were found in the search process. Table 2 presents the specific country included in each study.

<<Insert here Table 2>>

The narrative synthesis has been organised to present the reported perspective of four stakeholder groups: persons with ID; family and caregivers; mental health professionals; and community members (Table 3). Ten studies were conducted with families and caregivers, three studies considered community members (students and teachers); two with persons with IDD, and one with mental health workers.

<<Insert here Table 3>>

Attitudes and beliefs about ID perceived by persons with this condition

There is only one included study that interviewed participants with ID (Dehays, Hitchins & Vidal, 2012), which was conducted in Chile. Three mothers with ID reported on their experiences of being women and mothers. Both the presence of an intellectual disability and the lack of financial support were identified as the main barriers in their role as mothers, specifically to look after their children, to have an active social participation, and to be recognised as productive members in their families and in society. These women report being criticised in the way they lived and experienced motherhood, and they perceived this as stigmatisation. Furthermore, they report that in some cases their families replace them as decision-makers in the process of raising their own children.

The main goal of the other study (de Menil & Cohen, 2009) was to describe the obstacles for the rational use of psychiatric drugs in a 1000-bed institution for persons with IDD called *La Colonia*, in Argentina. Authors used patients' charts to present descriptive data about the medical situation of the persons who are living in La Colonia and about the institution. They refer to the use of an ethnographic approach to collect qualitative data from fourteen individuals that included administrators, two psychiatrists, two nurses, two nurses' aids, two inpatients with ID, and one pharmacist. However, in the results and discussion sections the text refers mostly to staff, ignoring the views of people with ID. The authors mainly mentioned violations of human rights, and expression of stigma by caregivers and mental health workers; these results will be further discussed in the section about attitudes and beliefs about IDD in that group.

Attitudes and beliefs about ID perceived by families and caregivers

The first quantitative study was the Caregiver Needs Survey completed by 2965 relatives of persons with ASD in Argentina, Brazil, Chile, Uruguay, Venezuela and Dominic Republic General. Information about this survey was presented in a congress abstract (Retazzi, Valdez & Cukier, 2016). We searched for the original work and part of the results are available in "La Nación", an Argentinian national newspaper. According to the survey, families of persons with ASD in Argentina perceived stigma towards their relatives as a consequence of the diagnosis and reported higher levels of stigma when ID was present in co-occurrence with behavioural problems. Fifty-five percent of caregivers reported that they thought their sons and daughters were stigmatised, 50% reported the need to work fewer hours to take care of their relatives and

42% experienced financial difficulties as an indirect consequence of the diagnosis because they have to pay for special services. We were unable to find data from the other countries included in this survey.

The second quantitative study included data from research which described implicit attitudes towards persons with DS. In this study, authors compared implicit attitudes towards DS expressed in relatives of persons with DS and the implicit attitudes towards the condition presented by college students in Colombia (Bernal, 2016). The data were collected with the Relational Responding Task (De Houwer et al., 2015) and the Escala de Pecepción Social Hacia Las Personas Con Síndrome de Down (Scale About Perceptions Towards People With Down Syndrome, EPSD-1) (Molina Saorín, Nunes Corredeira & Vallejo Ruíz, 2012). In this study, a group of twenty relatives was compared with a group of twenty-nine college students. Based on the hypothesis that previous contact is associated with more positive attitudes, the authors expected lower negative attitudes and perceptions towards people with DS in relatives. Results showed no differences among groups (college students vs relatives) in relation to negative stereotypes or attitudes towards persons with DS. A possible explanation of the findings maybe the small sample size.

The third quantitative study was conducted in Chile and explored the relationship between the severity of symptoms in children with ASD and other family characteristics, including stigma (Hartmann et al., 2018). With a study-specific questionnaire, the authors found a negative correlation between social stigma and overall ASD severity score in general functions, language impairment, difficulties for social interaction and stress.

Two Ecuadorian studies included parents of children with DS, exploring the feelings of families towards DS (Huiracocha et al., 2013) and the impact of diagnosis (Huiracocha et al., 2017). Both studies included the same number of participants (seven mothers and one father) and found that the parents were aware of stigma towards their child in Ecuador. The authors suggest that stigma influences the parents' perception about the capability of their children and the importance of support in light of participants reporting lack of social support, widespread stigmatization, and institutionalised stigma mainly expressed among physicians.

In Chile, one study explored the life experiences of young people with ID and ASD in Temuco, a small city in the south of the country, based on two mothers' perceptions of their young son's and daughter's lives (Cerreta, 2018). A second study (von Furstenberg, Iriarte & Navarro, 2012) identified social factors that prevent the inclusion of people with ID in regular jobs in Santiago (capital of Chile) based on the opinions of the mothers. Both studies concluded that it is possible to identify stigma towards persons with IDD in Chile. The study goes beyond this affirmation and suggests: (a) that Chilean society has difficulties in including persons with ID due to existing social structures and negative attitudes towards this condition; (b) the most common parental attitudes are lack of affection and warmth towards their sons and daughters, which may be a form of active discrimination; (c) the highly segregated educational system of the country (Arango, Aparicio, & Tenorio, 2018) and the scarce governmental resources available to support people with ID, are major barriers to inclusion.

One Brazilian study investigated the experiences of mothers of young people with ID and ASD. They explored the mothers' initial reactions to the diagnosis of autism; the difficulties that children encountered during adolescence and the mothers' expectations about the child's future (Segeren & de Campos Francozo, 2014). The mothers stated that they had to change their routines by avoiding public places due to their child's behavioural problems, which were perceived negatively by the public, resulting in social stigmatisation and exclusion.

In Colombia, Lopera-Escobar & Bastidas-Acevedo (2018) describe the experiences of mothers of children with DS about the medical attention offered to their children. Participants complained that in the health system in Colombia, the identity of their child is based on the condition (with common expressions as: "*the Mongolic children…*"). They also talked about the difficulties in accessing health services for the child's condition, with misinformation and stigmatising attitudes from physicians and other health workers. For example, one of the participants reported that "*With the neurologists I had a very bad experience. I needed the authorization for therapies, but he denied it because, according with him, this kind of child doesn't need that*". An important finding was the participants' perceived lack of information about rights of persons with DS and the loss of hope and feelings of guilt were prevalent emotions amongst families of children with DS in Colombia.

Also, in Colombia, but with a mixed method approach, Polanco-Valenzuela & Marín-Araya (2017) explored the knowledge, attitudes and practices in terms of decisions in fathers, mothers and caregivers of adolescents with ID, with an emphasis on sexuality. The main finding is that participants were knowledgeable about the rights of persons with ID; however, the implementation and the use of mechanisms to support the expression of sexuality was limited because families and caregivers failed to recognise their children's capacity to make decisions regarding their sexuality. Mothers and father report ambivalence towards their child's emerging sexuality.

Mental health workers attitudes and beliefs about ID

Among the seventeen studies included in the review, one presented information about attitudes and beliefs of mental health workers about ID, carried out in Argentina (de Menil & Cohen, 2009). The authors describe stigma towards persons with IDD, discriminatory actions, and some violations of human rights. The predominance of negative attitudes and stereotypes are considered to have direct consequences on the quality of health services offered to this population. De Manil and Cohen (2009) investigated the over-use of psychiatric drugs in this context. They found that 83% of patients were taking psychiatric medications, although 67% of patients had no psychiatric diagnosis. Patients were mostly prescribed antipsychotics. They also point to mistreatment and inhuman actions such as denying anaesthesia to persons with ID because "(…) *they are like animals*". Mental health workers had a lack of awareness of ID and the lack of availability of non-medical treatments and hospitalisation for social reasons were cited (such as psychoanalytic treatments for psychological symptoms in persons with ID) as the main reasons for the over use of psychiatric medication.

Attitudes and beliefs about ID in community members

Among the quantitative studies, one was carried out in Brazil (Gregoul, Malagodi & Carraro, 2018) with physical education teachers. The Teacher Inclusion Attitudes Questionnaire was used to collect data form 35 Physical Education teachers. Findings suggested the presence of a general positive attitude to inclusion, but a lack of institutional support. Teachers perceived that students with ID were well accepted by their classmates. They also reported gender differences attributing better abilities to male students. There was a positive correlation between the number of years of experience of teaching children with special needs and positive attitudes towards their inclusion.

There were two quantitative studies that were conducted in two types of schools in Chile and explored attitudes (explicit and implicit) towards children with DS (Sirlopú et al., 2008; Sirlopú et al., 2012). In these studies, authors presented overlapping data. One study collected data on implicit and explicit attitudes towards other students with DS from 80 students without disability attending 4 schools in Santiago (2 with an inclusion program and 2 without) (Sirlopú et al., 2012). In the other study (Sirlopu et al., 2008), data were collected with 120 students without ID from four schools (2 with an inclusion program and 2 without). In both of these studies, the authors concluded that the type of school did not have an impact on the prejudice, attitudes and general perceptions of typically developing children towards children with DS. They argued that the attitudes were generally positive. However, an interaction was found between gender and type of school with more prejudice and negative attitudes in males who attended schools without inclusion programs.

Finally, the study conducted with a mixed approach (de Menil & Cohen, 2009) informed about the inclusion of community members in their sample. Accordingly with the authors, they conducted interviews with some community members at La Colonia but results related with this interviews is not presented in the manuscript.

Discussion

Stigma is considered one of the most important concerns of our era, especially in relation to conditions such as HIV, leprosy, and mental illness. However, scant attention has been paid to stigma towards people with ID, even when it affects an estimated of 300 million people globally (Scior et al., 2016). The results of the narrative review are indicative of the limited scientific study of stigma towards people with ID in South American countries and the clear sense that people with ID living in those countries report experience of stigmatising attitudes.

The published studies identified for this narrative review are mainly qualitative. None of the studies included a large sample. Families and caregivers are the most frequent stakeholder group studied. The most important finding is the lack of studies including participants with ID and their personal experiences of stigma and discrimination. This suggests that there is low participation of persons with ID in research, which is reflective of the low social and civil participation of persons with ID in the region.

Whilst stigma towards persons with ID appears to be common in Latin America, however, there is no information about the mediating influence of socio-demographic variables such as age and educational level. There is a lack of available information about cultural differences and specific idiosyncratic characteristics between countries.

Specific public policy about ID in the region is scarce and this seems to be a consequence of social and institutionalised stigma towards this groups. A closer inspection of legislative statements regarding people with ID shows that some of the countries have formulated specific statements declaring that an adult with ID does not have legal capacity (referred as the capacity of a person to exert rights and duties according to each national legislation), and that specific indications are available about school inclusion. The available policies have not been updated since they were written, and they still use pejorative terminology, failing to incorporate a rights-based approach to laws affecting people with ID (Silva, 2017). The reports presented by the United Nations about the process to incorporate changes in the legislation according with the CRPD suggested the need to take more clear actions in favour to persons with disability in the region (i.e. United Nations, 2016).

News and social media in general are one of the most important sources of documenting rights violations and stigma towards people with ID in South America. A recent example in the Chilean context is about the current scandal in the “looked-after children” program, where videos were disseminated via social media showing physical maltreatment of children from paid caregivers. These types of headlines are frequent, but due to the scarcity of research in the area as well as the lack of general and political interest, there is little action taken by governments to deal with this situation.

As far as we know, this is the first systematic examination of stigma towards persons with ID in the South American context. We have interrogated literature in English, Spanish and Portuguese languages to ensure that all relevant papers have been identified. We supplemented the databases search with a specific protocol to identify appropriate published data among grey material. We think this mixed approach in the search process enriched the final results. However, a degree of bias in the selections of manuscripts may have been introduced in the review process during study selection. We implemented different approaches to control for this, i.e. blind reviews and a systematic process to select documents but this bias could be still present.

In relation to the quality of research, based on the MMAT appraisal system, there is an urgent need to improve the quality of research in this field in the region.

Future research in the area of stigma towards persons with ID in South America must be conducted. A total comprehension of this phenomena, as well scientific data, will be very useful to enable researchers to design and evaluate the impact of different initiatives oriented to change the cultural attitudes towards people with ID. An increase of intellectual production in Spanish, available to general public in the South American countries is needed to increase comprehension and compromise with persons with ID.

The lack of public policies and national planning in favour of social inclusion and protection of the rights of people with ID across the South American countries should be a matter of attention for international agencies and non-profit organizations. As some authors have already suggested, there is an urgent need for political coordination to promote better conditions for persons with ID in the region. People with ID are one of least considered groups, they are victims of all forms of violence (Fogden, Thomas, Daffern, & Ogloff, 2016; Hughes et al., 2012), and specific studies are needed to describe, understand, and combat all possible forms of stigma in South America.

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Table 1

Contextual information for each country in South America

Country	Gross domestic product (GDP)[1]	Total population[2]	Life expectancy[3]	Population extreme poverty[4]	Index Human Development[5]	Estimated population with disability[6]
Colombia	282.5	48.6	74.3	7.0%	0.72	6.3%
Venezuela[7]	371.1	28.3	75.8	18.5%	0.76	5.38%
Guyana	3.4	0.7	66.6	No data available	0.63	6.4%
Surinam	3.6	0.5	74.8	No data available	0.72	12.5%
Ecuador	97.8	16.4	79.9	11.7%	0.73	2.6%
Peru	192.1	31.7	74.9	19.5%	0.74	5.2%
Bolivia	33.8	10.8	69.1	23.2%	0.67	0.7%
Chile	247	17.9	80.5	<2%	0.84	20%
Uruguay	52.4	3.4	77.4	<2%	0.79	15.8%
Paraguay	24.4	6.7	77.2	13.6%	0.69	10%
Argentina	545.9	43.8	76.5	<5%	0.82	12.9%
Brazil	1796	207.7	75.8	7.5%	0.75	11.5%

[1] Expressed in USD millions based on The World Bank Data

[2] Expressed in millions, data from the last national census available

[3] Expressed in years

[4] Data available in the International Monetary Fund (2011), based on people living with less than 1 USD per day.

[5] The Human Development Index (HDI) is a composite statistic (composite index) of life expectancy, education, and per capita income indicators, which are used to rank countries into four tiers of human development. It was designed for the United Nations Development Program (UNDP). Values closed to 1 indicated better results. Data available in UNDP (2016).

[6] Percentage of general population with disability reported by each governmental division in charge of disability in South America.

[7] General data about Venezuela needs future revisions due to the current political situation in the country.

Table 2

Specific information about studies included in this narrative review

Author	Aim	Participants	Instruments	Data analysis	Main findings
Qualitative studies					
Brazil					
Segeren & de Campos Francozo (2014)	To investigate the experiences of mothers of young people with autism to identify initial reactions to the diagnosis, daily routines and social difficulties faced by them	11 mothers of adolescents with ASD	Semi structured interviews	Content analysis techniques	-Diagnosis was given comprehensively with emphasis in the expected difficulties of child development -Changes in mothers routines were necessary to care the child -Those changes included social adaptations secondary to stigma expressed towards children with ASD
Colombia					
Lopera	To describe the experiences of mothers of children with Down Syndrome about the medical attention offered to their daughters and sons.	17 mothers of children with DS	Semi structured interviews	Content analysis techniques	-An identity based on the condition ("the mongolic children…") - Denied of health services for these children based on their condition with misinformation and stigma attitudes from physicians and other professionals from the health system. -Misinformation about the rights of persons with ID in all the actors (physicians, professionals and families) -The loss of hope and guilty as predominant emotions in mothers as a consequence of stigma and prejudice expressed to their children –

Chile					
Dehays, Hichins, & Vidal (2012)	To analyse the meanings that women with Intellectual Disability (ID) give to the experiences of being a woman and mother	Three females with Intellectual Disability	Semi structured interviews	Grounded theory	- For participants, the meanings about be woman and mother are based on specific actions, this is interpreted as a consequence of low IQ by authors. -Family supports are perceived as a basic conditions to have a good role as a mother - The intellectual disability and lack of financial support are identified as barriers.
Cerreta (2018)	To describe the life experiences of young people with moderate to severe autism who attend specialized schools in the city of Temuco (Chile)	Two mothers and four teachers	A semi-structured interview	Grounded theory	-Mothers and teachers informed about stigma towards people with ASD expressed in public space -The authors suggested that it is possible to identify stigma towards people with ASD expressed in their families -Chilean society has problems to include persons with ID in work places due to social structure and negative attitudes towards this condition
von Furstenberg, Iriarte & Navarro (2012)	To identify the social factors that prevent the inclusion of persons with ID in regular works in Chile, accordingly with the mother's point of view	62 mothers and 2 fathers of young persons with ID	Questionnaire and semi structured interviews (with 7 mothers)	Content analysis techniques	-The most common attitudes attributed by parents are coldness and hardness. They identify active discrimination against their sons and daughters. - They kind of works available for persons with ID are based on charity or good will but they are not based on their relatives' skills. -Parents remember the difficulties to find a school for the education of their sons and daughters because "(...) in Chile the schools are not prepared to receive our children". There is any official program at Universities for persons with ID in the country. -Institutional stigma is identified by parents. They express that any governmental division helped them in the process of labor inclusion for their relatives.

Ecuador					
Huiracocha et al. (2013)	To identify the feelings of families of children with Down Syndrome	8 parents of children with DS	Focus group, interviews, group discussion	Descriptive coding	-The study identify stigma towards people with DS -This stigma influences the family perception and support offered to their children with DS -Specific competences should be trained in health teams -
Huiracocha et al. (2017)	This study examined the impact of a diagnosis of DS on Ecuadorian families	8 parents of children with DS	Focus group, interviews, group discussion	Descriptive coding	- Professionals rarely communicate a DS diagnosis in an appropriate manner. - The lack of social support, and the widespread stigmatization confronting children with DS and their families, hinder development of positive and empowering adjustments that would best serve the child's and the family's interest.
Peru					
O'Shea et al. (2012)	To characterize public perceptions regarding intellectual disability in a peri-urban community of limited resources	12 key informants and 10 community members	A semi-structured interview	Grounded theory	- The themes derived from categories were poverty and its related concerns, lack of attention paid to ID and the role of family -Persons have difficulties to differentiate ID from mental illness -Some participants identified scientific background - Lack of resources was reported as a source of difficulties to educate a child -Attitudes are affected by personal priorities, ideology, and previous interaction with persons with ID
			Quantitative Studies		
Brazil					
Greguol, Malagodi, & Carraro (2018)	To analyze the attitudes of Physical Education teachers towards the inclusion of students with disabilities in regular classes	35 physical education teachers	Teacher Inclusion Attitudes Questionnaire (TIAQ)	Descriptive data and mean comparisons	- General positive attitude to inclusion without institutional support. Low scores in skills and support items. - Skills factor is related with the severity of the condition - Students with disability are well accepted by their classmates from teacher point of view

					- A gender effect on Skills perception, better abilities perceived by men. - Positive correlation among time of experience and positive attitude towards inclusion
Colombia					
Bernal (2016)	- To observe and describe implicit attitudes towards persons with DS in relatives and college students	49 participants, 20 relatives y 29 college students	Relational responding task (De Houwer et al., 2015), EPSD-1 (Molina Saorín, Nunes Corredeira, & Vallejo Ruiz, 2012).	Descriptive and inferential analysis	-No differences among groups -Without identification of negative stereotypes or attitudes - The sample size is criticized
Chile					
Hartmann et al. (2018)	To explore relationships between severity of ASD traits, community supports, and other family variables as reported by caregivers.	50 caregivers of individuals with ASD	Study-specific questionnaire	Correlations	- A negative correlation among social stigma and child's overall ASD score, impairment in language and communication, difficulties in social interaction and stress
Sirlopú et al. (2008)	To assess if students at schools with inclusion programs will hold more positive stereotypes and attitudes toward people with Down syndrome than will students at schools without inclusion programs.	120 Chilean students, between 11 to 15 years	Questionnaire	Factor analysis mean comparisons	- No effects of school system on any of the stereotype measures. - Relative low level of prejudice among students -Positive attitudes toward people with DS, high levels of linking and low levels of patronizing, avoidance and rejection - Pleasure and pity scores exceed aversion scores - Major tendency to negative attitudes, prejudice and aversion among men in non-inclusive schools

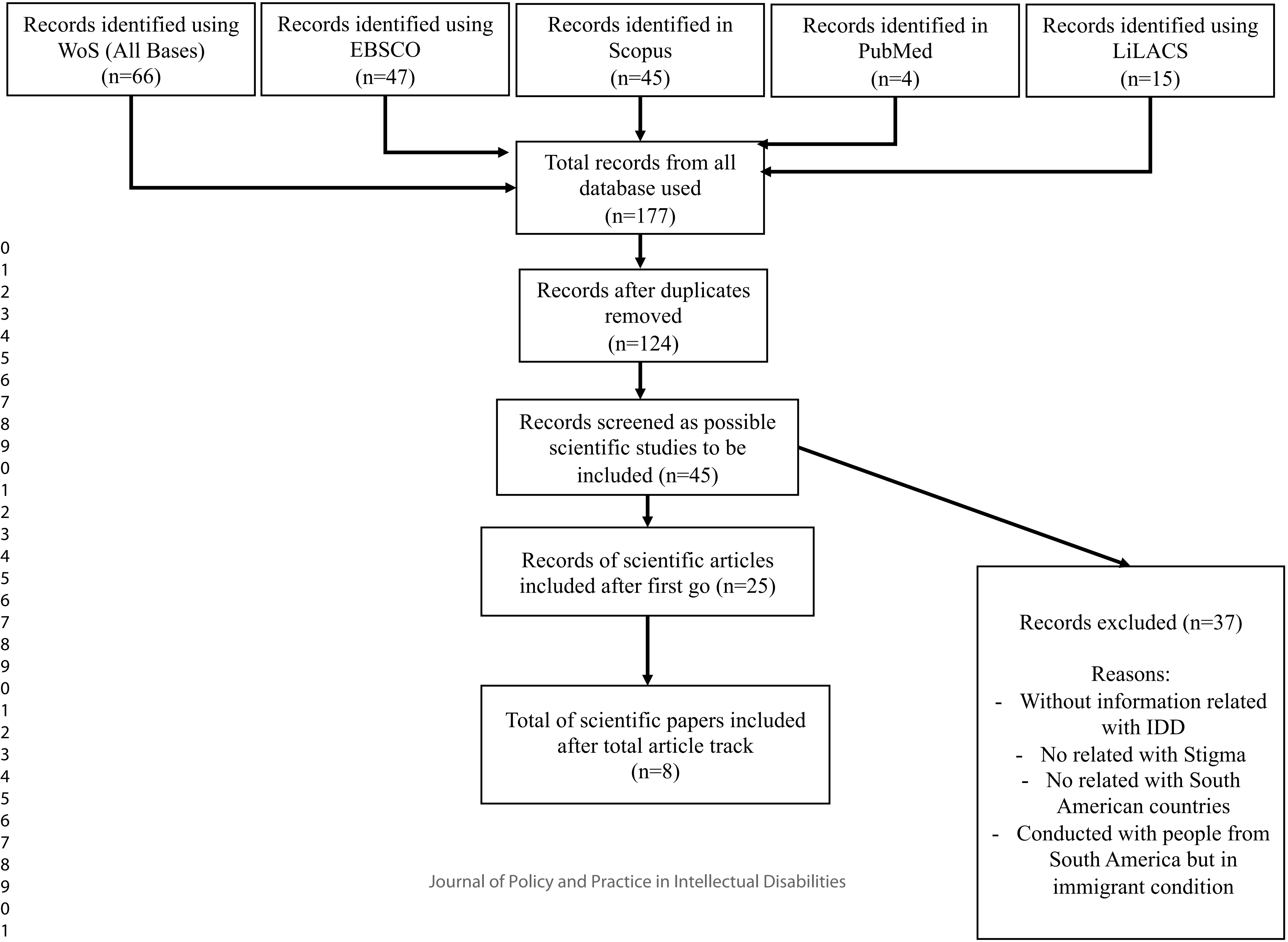
Sirlopú et al. (2012)	To evaluate both types of attitudes towards People with Down syndrome (PWDS)	80 Chilean students, between 11 to 15 years	Implicit Association Test (IAT)	Descriptive data and mean comparisons	- No differences were found in implicit bias towards PWDS among the two groups of students - Low rates of prejudice were identified in this study - Difference on “contact anxiety” and “amount of contact” in favor to children from schools with inclusion
Cross-cultural					
Luengo (2018)	To explore the language used in media from Venezuela and Argentina to talk about autism	1480 articles published in 480 national papers		Media framing theory	-Significant differences between the countries’ coverage of autism in their description of issues, discourse types, sources, images, roles and stigmatizing cues -A scientific discourse type is more common in Venezuelan articles than in Argentina which focuses on human-interest stories. -Individuals with autism are quoted in less than 5% of stories from each country -Results explain why both countries perpetuate stigmatizing cues regarding labeling, psychological symptoms, social skills and physical appearance.
Retazzi, Valdez & Cukier (2016)	To analyse the results obtained with a multi-national survey applied in five countries in South America (Argentina, Brazil, Chile, Venezuela, Uruguay) to families of children with Autism Spectrum Disorder	2965 caregivers of children with ASD	Study-specific questionnaire	Descriptive analysis	-55% of the caregivers in Argentina informed stigma towards them and their sons and daughters with ASD. 50% had to cut hours in their work. 42% of the families informed financial difficulties - There is not available information about the other countries
			Mixed methods		
Argentina					
De Menil & Cohen (2009)	To describe the obstacles to the rational	98 patients’ charts, 5 hospital	Study-specific questionnaire	Descriptive analysis and	-Two-thirds (67%) of individuals taking psychiatric medication, did not have a psychiatric diagnosis

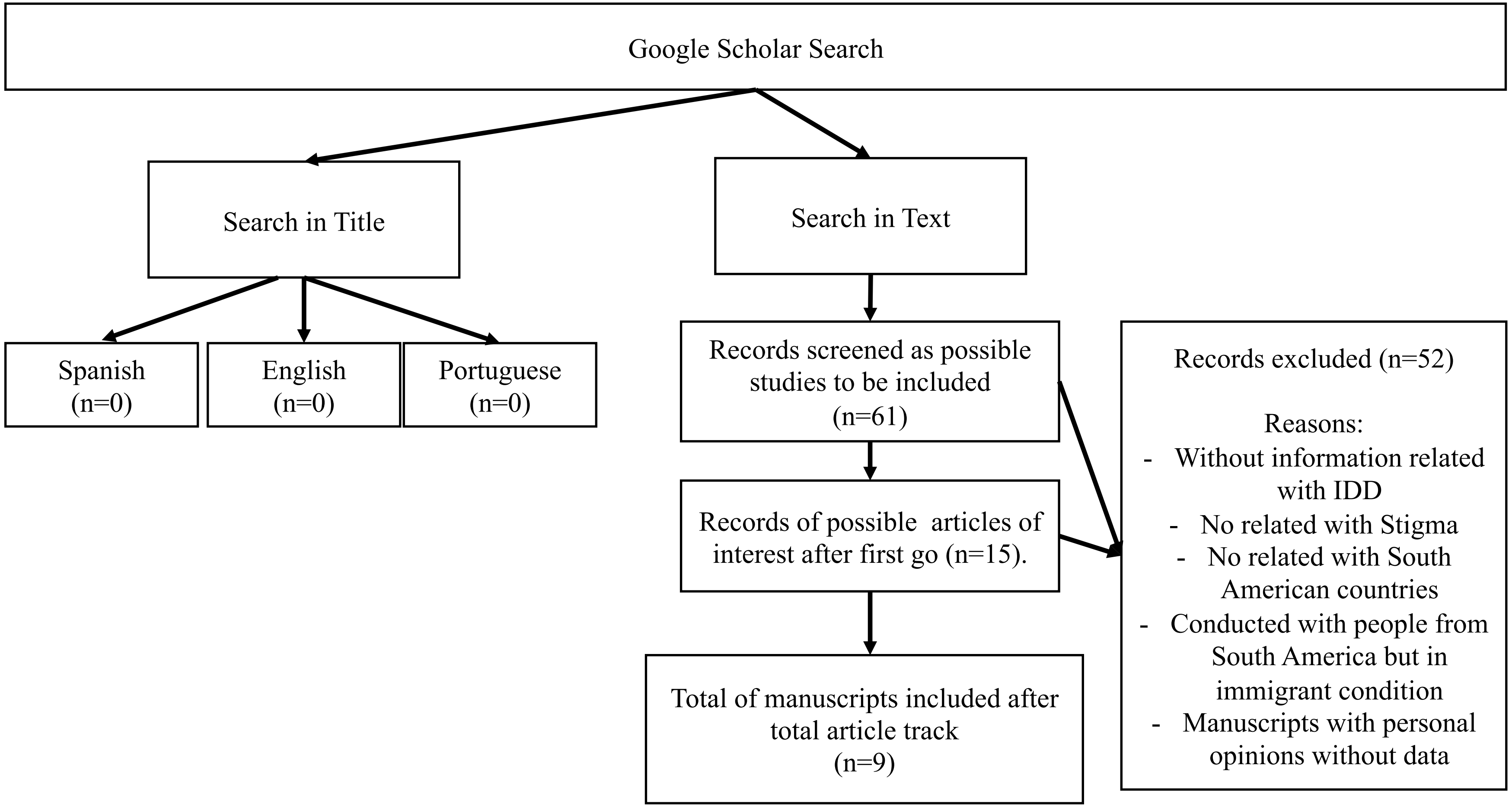
	use of psychiatric drugs in a 1000-bed institution for people with ID.	administrators, 2 psychiatrists, 2 nurses, 2 nurses aids, 2 patients and 1 pharmacist.		ethnographic analysis content	-Antipsychotics are more commonly prescribe than any other drugs -Absence of specific training to work with persons with ID, in all the professional in the health system with emphasis in psychiatrists and psychologists (mainly educated in the psychoanalytic orientation) -In absence of training, the staff developed their own theories and ideas about ID including some like: "some patients didn't require anesthesia during procedures, just like animals" The study identified structural impediments and barriers for the expression of rights of persons with ID. Violence is visible in staff and patients.
Colombia					
Polanco-Valenzuela & Marín-Araya (2017)	To explore knowledge, attitudes and practices in fathers, mothers and caregivers of adolescents with ID	32 families of adolescents with ID	Study-specific questionnaire and semi-structure interview	Descriptive and content analysis	-The interviewers express knowledge about the rights of persons with disability. However, implementation and mechanisms to support the expression of these rights is fragile. Mothers and fathers don't recognize their daughter's and son's abilities to take decisions about their sexuality. Attitudes are ambivalent.

Table 3

Included studies organised by stakeholder's groups and methodological approach

	Quantitative approach	Qualitative approach	Mixed approach
Persons with Intellectual and Developmental Disabilities		Dehays, Hichins, & Vidal (2012)	de Menil & Cohen, (2009)
Families and caregivers	Bernal (2016)	Lopera-Escobar & Bastidas-Acevedo (2018)	Polanco-Valenzuela & Martín-Ayala (2017)
	Hartmann et al. (2018)		
		Cerreta (2018)	
	Ratazzi, Valdez, & Cukier (2016)	Furstenberg, Iriarte, & Navarro (2012)	
		Huiracocha et al. (2013)	
		Huiracocha et al. (2017)	
		O'Shea, Maziel Girón, Cabrera, Lescano, & Taren (2012)	
Mental health workers			De Menil & Cohen (2009)
Community members	Gregoul, Malagodi, & Carraro (2018)		
	Sirlopú et al. (2008)		
	Sirlopú et al. (2012)		


Records identified using WoS (All Bases) (n=66)
Records identified using EBSCO (n=47)
Records identified in Scopus (n=45)
Records identified in PubMed (n=4)
Records identified using LiLACS (n=15)
Total records from all database used (n=177)
Records after duplicates removed (n=124)
Records screened as possible scientific studies to be included (n=45)
Records of scientific articles included after first go (n=25)
Total of scientific papers included after total article track (n=8)
Records excluded (n=37)
Reasons:
- Without information related with IDD
- No related with Stigma
- No related with South American countries
- Conducted with people from South America but in immigrant condition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English (n=0)
Portuguese (n=0)
Records screened as possible studies to be included (n=61)
Records of possible articles of interest after first go (n=15).
Total of manuscripts included after total article track (n=9)
Records excluded (n=52)
Reasons:
- Without information related with IDD
- No related with Stigma
- No related with South American countries
- Conducted with people from South America but in immigrant condition
- Manuscripts with personal opinions without data

STIGMA TOWARDS PERSONS WITH INTELLECTUAL DISABILITY IN SOUTH-AMERICA: A NARRATIVE REVIEW

Reviewer 1	
Reviewer comments	Author's revision
Stigma theory would suggest that one of the forms of stigma that people with ID are subject to is self-stigma. While I agree with the authors that 'self-perceived stigma' is an issue, it is not just the perception of being stigmatised but the risk of internalising others' negative perceptions that places people with ID at risk of poor self-esteem and other negative outcomes. Recent review by Logeswaran et al. (doi.org/10.1111/jar.12566) would make a useful addition to the introduction, particularly paragraph 2, p.5	Thank you for recommending this interesting paper. We included it in the background section. Pp5-p2
Caution regarding where previous studies were carried out - Azmi et al. to my knowledge was a study of South Asian people in the UK, not Asian countries.	Yer, our mistake. The incorrect reference was deleted. Pp5 - p4
The following sentence is confusing as it suggests that countries such as Chile are considered 'developing' - Chile, as noted by the authors, is classified as a high income country by the world bank and any suggestion that it is a 'developing country' is misleading.	The paragraphs' order was changed, Pp6
Minor point but on p.6 I'd place the countries of South America in alphabetical order.	Done. Pp6 - p1
p.3- studies have shown	Done. Pp3 - p1
p.3- some of these studies noted that... (not pointed)	Done. Pp3 - p1
p.6 - this sentence needs some corrections, to this "Some countries in the region though have an established economy in terms of the gross national product and other macro economic variables (Chile and Brazil, for example).	Done. Pp6 - p2
Commas are misplaced in many places and should not be used where they interrupt the basic sentence structure, e.g. "Several South American countries have a history..." should not have a comma.	Done.
p.10, last paragraph - no need to present % both in words and numbers	The numbers were eliminated.
p.19: in South American countries, not 'in the South American countries'	Done.
In line with usual convention, I suggest writing numbers up to ten in words but as numbers from 11 upwards.	Done.
Reviewer 2	
I think the article could benefit from clarification at some points and perhaps reorganisation of some of the material. I would particularly consider moving the paragraphs on P18 beginning 'specific public policy' and 'news and social media' to the introduction. These feel important in setting the scene for the study, and at the moment introducing this amount of new material in the discussion feels a little confusing.	The order was reformulated. Some material from the discussion was moved to the introduction.

I would also consider expanding in these paragraphs on the importance of the UN CRPD to say why it is relevant.	A statement was included, Pp10 -p1
I would also consider adding to Table 1 the year in which each country ratified the Convention.	Done. Pp 32. An explanatory note about ratification for Suriname and Venezuela was included
In the methods you say that you used the date range based on CRPD ratification but none of these dates are provided.	Specific data about ratification process was incorporated in table 1
I would also consider adding some information to the introduction about what other review studies have found about stigma in other regions. You say that you drew search terms from previous reviews, but these are not mentioned explicitly in the introduction.	A direct reference to the previous reviews considered was added, Pp12-p2
You have also said that most of the work looking at stigma is conducted in high income countries (with some in South-Asia and Africa), but have not described what these have found (you have described some of the effects on people with IDD, but not the nature of stigma or any estimates of prevalence). At the moment whilst your paper presents a very interesting insight to South America, I think it may be hard for a reader to understand how this compares to other areas or other studies' findings.	A description was added, Pp7-p2
I am unsure what 'desirable' means in this context – is this in terms of relationships, attractiveness, social contact? Perhaps consider rephrasing.	The term was replaced Pp4 -P1
Are you referring to people with IDD specifically in South America or globally?	Globally. This is now clarified Pp7 - p4
I would specify Google Scholar here rather than Google.	Done. Pp10 - P1
It sounds as though you included papers in English, Spanish and Portugese (although this is not explicitly stated). I think it would be helpful to state whether the authors are native speakers of these languages or how translation was otherwise achieved. Could each author read all languages or did some authors review one language and some others?	Done. Pp10 - P3
Where you discuss the MMAT scores I think it would be helpful to list the actual number of studies in addition to the percentage. I would also consider adding the MMAT score against each study in your summary table.	The number of studies was included Pp.12 -P2. MMAT score was matched with each study in Table 2. Pp 34
Do the authors include a power calculation?	The sentence was changed and more information about the conclusions presented by the authors was incorporated Pp15 - P1
It may be helpful to include a note here about the sense the authors make of this/conclusions drawn from the study about this correlation.	Information was revised Pp15 - P2
I would consider rewording the paragraph beginning 'finally, the study...'. The grammar is a little confusing here.	The grammar was reviewed Pp19-P2

I agree that an important finding is the lack of inclusion of the views of people with ID. I think it might be helpful though to give a sense of how this compares to the global picture of ID research and whether other reviews have identified the same problem in different regions or whether some regions are achieving greater rates of participation. At the moment this paragraph seems to suggest this is indicative of how people with IDD are viewed specifically in South America, but my sense is that this is a global issue.	We offer some thoughts about the global situation Pp19-P4
You say that there is a need for increased production in Spanish, as far as I could see though you have not said how many papers were in Spanish/Portugese/English. It might be worth stating this, particularly as it sounds as though one of the conclusions you have drawn is that a limited production in Spanish will mean the research is not being accessed by the people living in this region.	The information was incorporated as part of the results to contextualise the discussion Pp11 -P5
You state 'some authors have already suggested' - include some references for these authors?	References were incorporated Pp21 - P1
I like the clarity of this table and the information included. There are some phrasing and grammar edits needed in the text however. Lopera's paper requires a publication year	We checked and corrected grammar. Lopera's reference was corrected
You say here that a study was excluded because it was personal opinion. It may be helpful to explicitly state in your methods section that you were only including empirical papers.	Done. Pp10-p1

Abstract

Background: People with intellectual disability (ID) form one of the most underserved/stigmatised groups in society. Published data have documented stigma towards this population group in different countries. However, this phenomenon has received scant attention in South American countries. Specific Aim: To conduct a systematic search of published and grey literature in the area of stigma towards persons with ID within the twelve countries of the region to explore expression of stigma towards people with ID in the Region. Method: Systematic research of published data and grey literature, based on previous published protocol, was run in this work. Research strategy included terms related to intellectual disabilities, were combined with stigma, prejudice, attitudes and stereotypes, and with the names of all the South American countries. Due to the known relationship between ID and Autism Spectrum Disorder, this term was included in the search. The search was conducted in English, Spanish, and Portuguese. A narrative approach to results is presented. Findings: Available through limited information is organised by stakeholder groups, including persons with ID, families, caregivers and mental health workers. The quality of the studies was analysed based on the Mixed Method Appraisal Tool version 2018 (MMAT), results are variable. Discussion: The results of the narrative review are indicative of the limited scientific study of stigma towards people with ID in South American countries and the clear sense that people with ID living in those countries report experience of stigmatising attitudes. Future research, at population level, is needed in the region to ensure improvements in the quality of life and in the civil participation of people with ID.

Key words: stigma, prejudice, stereotype, intellectual disability, South America

Intellectual disability (ID) is characterised by significant limitations in cognitive functions and in adaptive behaviour in a wide range of daily activities, originating before eighteen years of age (Schalock, Luckasson, Tassé, & Verdugo, 2018). ID is a neurodevelopmental disorder, and in the current international classifications, it is categorised under "Intellectual and Developmental Disabilities (IDD)" with other conditions such as Autism Spectrum Disorders (ASD), Attention Hyperactivity Disorder (ADHD), Learning Disabilities, Motor Developmental Disabilities and Communication Disorders (American Psychiatric Association, 2013). Several studies have shown that people with IDD are a group that are commonly the victims of stigma and prejudice (i.e. Hamdani, Ary, & Lunsky, 2017; Mitter, Ali, & Scior, 2018) and, some of these studies noted that persons with ID are one of the most underserved/stigmatised groups in society (i.e. Walker & Scior, 2013).

Stigma and prejudice are complex concepts related to individual experiences that emerge as a result of the interaction between marginalised and non-marginalised groups (Stuber, Meyer, & Link, 2008). The seminal works by Allport (1954) and Goffman (1963) defined stigma as a personal attribute that triggers a negative stereotype with undesirable consequences for the daily life of the person. Stigma is a useful concept to characterise the social interactions that emerge from the relationship between people from a group considered typical and another considered atypical, such as people with facial scars, physical disability, mental illness, or intellectual and developmental disabilities. On the other hand, prejudice is understood as a hostile reaction towards a person because they belong to a specific group. The concept of prejudice appears to be more focused on categories such as ethnicity, gender or socio-economical level (Phelan, Link, & Dovidio, 2008). While differently defined, both concepts are related to social barriers, violations of essential rights, and direct acts of discrimination, among other consequences (Arboleda Flórez, 2005; Drew et al., 2011).

Across the world, minority groups are victims of both stigma and prejudice (Knesebeck, Kofahl, & Makowski, 2017), and some of those groups have received more attention in research than others. People with IDD have been identified as one of the most segregated groups in society (Ali, King, Strydom, & Hassiotis, 2015), and several studies demonstrated that people with ID are subject to different forms of stigma including public, courtesy, and self-perceived (Werner, 2015; Scior, Addai-Davis, Kenyon, & Sheridan, 2012; Ali, Hassiotis, Strydom, & King, 2012; Scior, 2011). Public stigma refers to the general public's response towards people with IDD as a result of negative attitudes and prejudice (Scior, 2011; Walker & Scior, 2013; Werner, 2015). Courtesy stigma affects the closest family members, friends, and professionals that work with a person with ID who may develop negative self-evaluations and emotions related with the condition (Ali, Hassiotis, Strydom, & King, 2012; Birenbaum, 1992; Birenbaum, 1970). Self-perceived stigma refers to the extent to which a person with ID is aware of stigma and discrimination from the public or from individuals (O'Byrne & Muldoon, 2017; Ali et al., 2012; Corrigan, Watson, & Barr, 2006).

In parallel with the advances in research, the fight for the rights of people with IDD has been a continuous process during the last 30 years (Wilson & Scior, 2015) and advocates have used a number of frameworks and perspectives to promote rights, e.g. common ideas about humanity and human rights (Coles & Scior, 2012), specific case law, or international declarations to enshrine such rights in law in different countries (Dang, 2010; Fujiura, Park, & Rutkowski-Kmitta, 2005; Meijer, Carpenter, & Scholte, 2004; Schalock, Borthwick-Duffy, Bradley, Buntinx, Coulter, Craig, E.,…& Yeager, 2010).

However, these actions are insufficient as explicit and implicit negative attitudes towards people with IDD are still prevalent in society (Scior, 2011; Wilson & Scior, 2015). Furthermore, other disparities arise when considering the social and geopolitical position of people with IDD.

Studies of the different forms of stigma towards people with IDD have been conducted mostly in high-income countries. Published data suggests that people with intellectual disabilities consistently emerge as the group with the highest stigma, and the stigma expression is higher towards this group than to other disability groups (Werner, 2015). In these countries, variables such as age, educational attainment and prior contact predict attitudes towards persons with ID. However, there are inconsistent findings in relation to gender (Scior, 2011). Previous studies conducted in high-income countries also report that people with ID who participate in community activities are subject to hostility (i.e. Cummins & Lau, 2003). More recently, researchers have focused attention on people with ID being victims of hate crime, alongside bullying, abuse and harassment (Walker & Scior, 2013).

In the area of self-perceive stigma, people with IDD who report feeling stigmatised are more likely to have symptoms of anxiety and depression, a lower quality of life, and increased contacts with social services and the police (Ali et al., 2015). Self stigma is receiving special attention from researchers. In a recent review (Logeswaran, Hollett, Zala, Richardson, & Scior, 2019), authors explored how people with ID view their ascribed label; to what extent they ascribe it to themselves; and whether they recognize it as devalued in society. The review included 16 manuscripts, most of them related to studies conducted in Western countries, one from Afica, and one from Vietnam. People with ID experience negative feelings about the label, and report shame, discomfort, anger, powerlessness and frustration towards the label. However, in some cases it was also possible to report positive views of the label, a core element of the self-advocacy movement leading to collective actions as a way to combat stigma. Negative feelings may result from the negative treatment and interactions they have experienced. Some authors suggest that, in particular, self-perceived stigma could be a precursor for victimisation and loneliness in the presence of mental illness (Gilmore & Cuskelly, 2014; Horsselenberg, van Busschbach, Aleman, & Pijnenborg, 2016).

Little is known about the expression and consequences of stigma in middle or low-income countries. Previous studies conducted in South-Asia (Abraham, Gregory, Wolf, & Pemberton, 2002; Edwardraj, Mumtaj, Prasad, Kuruvilla, & Jacob, 2010) and Africa (Ali et al., 2015; Kock et al., 2012) suggest that cultural characteristics influence the social expression of stigma and prejudice, which are moderated by variables such as religion, personal beliefs about the origin of the condition or previous contact with persons with IDD. However, given the paucity of research in many regions including Latin America, conclusive actions cannot be achieved due to lack of engagement with the topic at population level (Ali et al., 2015; Ali et al., 2016; Hatzenbuehler, Phelan, & Link, 2013).

New studies are needed to clarify the cultural impact of the expression of stigma towards people with IDD and more countries should promote such research to gain a wider, global comprehension of the problems and the formulation of policies to improve the lives and acceptance of people with IDD over the life course.

South America is a region extending from the Caribbean in the north to the Antarctic region in the south and formed by twelve countries (Argentina, Bolivia, Brazil, Chile, Colombia, Ecuador, Guyana, Paraguay, Peru, Suriname, Uruguay, and Venezuela). It has a total population of approximately 600 million with significant cultural differences between countries. Most of the countries are lower-middle or upper-middle income, except for Argentina, Chile and Uruguay classified as high-income economies (World Bank, 2018).

Social inequality, characterised by problems with capital distribution, access to social services, education, health, and opportunities, is a major challenge experienced by all South American countries. As a consequence, socio-economic status is a pivotal variable for social research in the region (Central Intelligence Agency, 2017; Gapminder, 2017). Specific information about the geopolitical status for each of the South American countries, as well as the estimated population of people with disability, is presented in Table 1 to provide context to the review.

Chile is considered a developed country due to macro-economic indicators and its gross national product (World Bank, 2018). However, some authors have argued that because of the low standards of living and human development index (Frey & Temple, 2008; Gapminder, 2017), countries such as Chile should be considered as developing countries.

<<Insert here table 1>>

Several South American countries have a history of political instability secondary to the military coups during the 20th century i.e. Colombia in 1953, Argentina in 1976, Chile in 1973, Uruguay in 1973, Paraguay in 1989, Brazil in 1964, and Peru in 1992, with well documented human rights violations (Sikkink & Walling, 2007). Political violence and human rights violations have morphed into social violence (Oxhorn & Jouve-Martín, 2017).

The global prevalence of IDD, and specifically for ID, is unknown due to technical and political factors such as problems with surveillance systems, differences in how the condition is defined, or lack of governmental programs oriented towards ascertainment. Current data suggests that in Latin America (Central America, the Caribbean and South American countries), 13.8

million people have IDD (PAHO, 2012). As far as we know, there is no specific prevalence rate of IDD available for the South American region only.

People with IDD are common victims of violence at a global level, e.g. they are at high risk of being victims of hate crimes, social rejection, violations of rights, and lack of opportunities (Mikton, Maguire, & Shakespeare, 2014; Sherry, 2010). They are likely to suffer inequalities in social care, health and education (Ali et al., 2013; Hassiotis, Barron, & O'Hara, 2000; Rimmer, 1999); they are at a disadvantage in the judicial process and, in general, they have worse quality of life than people without disability in the same territory (i.e. Ncube, Perry, & Weiss, 2018).

This global situation has particular bearing for South America. Public policy about ID in the region is scarce and this seems to be a consequence of social and institutionalized stigma towards this group. A closer inspection of legislative statements regarding people with ID shows that some of the countries have declarations such that an adult with ID does not have legal capacity (referred as the capacity of a person to exert rights and duties according to each national legislation), and that specific statements about school inclusion. The available policies have not been updated since they were written, and they still use pejorative terminology, failing to incorporate a rights-based approach to laws affecting people with ID (Silva Barroilhet, 2017). The global framework for the rights of people with disabilities is the Convention on the Rights of Persons with Disabilities (CRPD, UN 2006). This convention was created following discussions involving representatives from member states including people with disabilities. Under consideration of the CRPD, these situations represent a clear violation of the international law. Reports published by the United Nations about the implementation of legislation according to the CRPD, recommends the need to take more active measures to support persons with disability in the region (i.e. United Nations, 2016).

News and social media are one of the most important sources of documenting rights, violations and stigma towards people with ID in South America. A recent example in the Chilean context is about the current scandal in the "looked-after children" program, where videos were disseminated via social media showing physical maltreatment of children from paid caregivers. These types of headlines are frequent, but due to the scarcity of research in the area, as well as the lack of general and political interest, almost no action has been taken by the government to deal with this situation.

The aim of this paper is to present a narrative review of the expression of stigma and prejudice towards people with ID in South America. In this review, we focus on studies relating to stigma towards people with ID only, although some may have comorbid conditions. We hope that this work will help to improve research on the topic in South America and will be relevant to a wide range of stakeholders including professionals, policy makers and Not-for-Profit organisations working with disability groups.

Method

In this review, we considered evidence available in catalogued journals and the grey literature, including academic theses, organisation reports, government papers, etc. (Haddaway, Collins, Coughlin, & Kirk, 2015).

We used the 27-item checklist recommended by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) to assess studies included in the review (Moher, Liberati, Tetzlaff, Altman, & Group, 2009). The four-phase diagram recommended by

PRISMA group and that included identification process, screening, eligibility and definition of included studies, was adapted for the study (Moher et al., 2009).

The protocol recommended by Haddaway et al. (2015) to conduct systematic reviews in Google Scholar was implemented for the grey literature search.

The Mixed Method Appraisal Tool version 2018 (MMAT), (Hong et al., 2008) was used to critically appraise the methodological quality of the included studies.

Information sources

Five databases (Web of Science, EBSCO, Scopus, PubMed and LiLACS) were used for the literature search. In all cases, the date range was fixed from 2008 to 2019. There is no consensus about ideal range of dates for a systematic review (Cooper, Booth, Varley-Campbell, Britten, & Garside, 2018; Liberati et al., 2009), this date range was considered relevant based on the period in which countries in South America ratified the Convention on the Rights of Persons with Disabilities (CRPD) (specific information about ratification in South American countries is available in table 1). The search was conducted in March 2019, information from the first ten pages of Google Scholar was considered at title and text level. In this review we only included empirical studies.

Search strategy

We included search terms which had been used in previous systematic reviews (Ali, Hassiotis, Strydom, & King, 2012; Scior, 2011) about stigma in the English language and we supplemented those by additional terms that have been used in Spanish and Portuguese reviews. We chose these terms in order to replicate what has been carried out in previous reviews, as well as to integrate new sources of information.

Search terms related to ID, were combined with stigma, prejudice, attitudes and stereotypes, and with the names of all the South American countries. Due to the known relationship between ID and Autism Spectrum Disorder, this term was included in the search. We conducted the search in English, Spanish, and Portuguese. For each language, a native speaker reviewed all the titles and abstracts, and then an independent review was carried out by a second researcher who was fluent in all three languages. The search was conducted as follows: Neurodevelopmental disorder OR developmental disorder OR learning disorder OR learning disability OR mental retardation OR intellectual disability OR autism OR down syndrome

AND stigma OR prejudice OR stereot* OR attitude

AND Latin America OR South America OR Colombia OR Venezuela OR Guyana OR Suriname OR Ecuador OR Bolivia OR Peru OR Brazil OR Chile OR Argentina OR Uruguay OR Paraguay.

The Spanish and Portuguese terms selected for clinical conditions were the same as those used in English with the corresponding translation. At the level of stigma, the search in Spanish also included “imaginario”, a common term used in Colombia to describe idiosyncratic ideas about something. “Imaginario” corresponds to stereotyped ideas about groups of individuals that may be held due to particular political or social views.

The inclusion criteria for the studies were: (a) an explicit mention of ID in any part of the manuscript; (b) an explicit mention of one of the key components of stigma (attitude, stereotype, prejudice, and discrimination) and; (c) the study was conducted in South America. Exclusion criteria considered: (a) mention of conditions not included in the search terms; (b) focus on stigma towards medical conditions such as HIV/AIDS, Epilepsy, Leprosy or Tuberculosis (frequent topics of interest in the region); (c) lack of relation to stigma; and (d) studies of immigrant populations that are not native to South America as these groups are likely to hold different cultural values that might influence the expression of stigma.

The final selection of manuscripts was reviewed and validated independently by two of the authors and an expert in statistical analysis with a third author arbitrating any disagreements that could not be resolved by the reviewers.

The MMAT approach was applied by two independent reviewers and in those cases where there was disagreement, a third person arbitrated the decision.

Results

The results are summarised in Figure 1, and in Figure 2 following the PRISMA flowchart (Moher et al., 2009).

<<Insert here figure 1>>

<<Insert here figure 2>>

Seventeen papers were retained in this review and are presented in Table 2. Twelve manuscripts were published in Spanish, four in English and one in Portuguese. The MMAT algorithm was used to classify the studies according to their methodological approach. Eight studies used a qualitative approach to answer the research questions, seven used a quantitative approach, and two used a mixed methods approach. For two qualitative studies (Cerreta, 2018; Furstenberg, Iriarte, & Navarro, 2012) and one quantitative study (Retazzi, Valdez & Cukier, 2016) the MMAT approach was not feasible. However, these studies were included because the MMAT authors point out that excluding studies with low methodological quality is discouraged.

Eleven percent (n=2) of the studies obtained the maximum MMAT score (5 points): one qualitative study (Lopera-Escobar & Bastidas-Acevedo, 2018) and one of the mixed methods study (de Menil & Cohen, 2009). Seventeen percent (n=3) of the studies obtained a MMAT score of 4 points and the remaining seventy one percent (n=12) of the studies scored 3 or fewer points on quality.

In terms of content, twelve studies explored stigma, attitudes or prejudice towards persons with ID (including towards people with Down Syndrome) and five studies explored stigma towards people with ID and ASD (the specific target population for each study is available in Table 2).

The majority of the included studies were conducted in Chile (35.2%) and Colombia (17.6%). The remainder (47.2%) were from Brazil (11.7%), Ecuador (11.7%), Peru (5.8%) and Argentina (5.8%). Cross-cultural data are available in 11.7% of the included studies. No studies from Bolivia, Guyana, Suriname, Paraguay or Uruguay were found in the search process. Table 2 presents the specific country included in each study.

<<Insert here Table 2>>

The narrative synthesis has been organised to present the reported perspective of four stakeholder groups: persons with ID; family and caregivers; mental health professionals; and community members (Table 3). Ten studies were conducted with families and caregivers, three studies considered community members (students and teachers); two with persons with IDD, and one with mental health workers.

<<Insert here Table 3>>

Attitudes and beliefs about ID perceived by persons with this condition

There is only one included study that interviewed participants with ID (Dehays, Hitchins & Vidal, 2012), which was conducted in Chile. Three mothers with ID reported on their experiences of being women and mothers. Both the presence of an intellectual disability and the lack of financial support were identified as the main barriers in their role as mothers, specifically to look after their children, to have an active social participation, and to be recognised as productive members in their families and in society. These women report being criticised in the way they lived and experienced motherhood, and they perceived this as stigmatisation. Furthermore, they report that in some cases their families replace them as decision-makers in the process of raising their own children.

The main goal of the other study (de Menil & Cohen, 2009) was to describe the obstacles for the rational use of psychiatric drugs in a 1000-bed institution for persons with IDD called *La Colonia*, in Argentina. Authors used patients' charts to present descriptive data about the medical situation of the persons who are living in La Colonia and about the institution. They refer to the use of an ethnographic approach to collect qualitative data from fourteen individuals that included administrators, two psychiatrists, two nurses, two nurses' aids, two inpatients with ID, and one pharmacist. However, in the results and discussion sections the text refers mostly to staff, ignoring the views of people with ID. The authors mainly mentioned violations of human rights, and expression of stigma by caregivers and mental health workers; these results will be further discussed in the section about attitudes and beliefs about IDD in that group.

Attitudes and beliefs about ID perceived by families and caregivers

The first quantitative study was the Caregiver Needs Survey completed by 2965 relatives of persons with ASD in Argentina, Brazil, Chile, Uruguay, Venezuela and Dominic Republic General. Information about this survey was presented in a congress abstract (Retazzi, Valdez & Cukier, 2016). We searched for the original work and part of the results are available in "La Nación", an Argentinian national newspaper. According to the survey, families of persons with ASD in Argentina perceived stigma towards their relatives as a consequence of the diagnosis and reported higher levels of stigma when ID was present in co-occurrence with behavioural problems. Fifty-five percent of caregivers reported that they thought their sons and daughters were stigmatised, 50% reported the need to work fewer hours to take care of their relatives and 42% experienced financial difficulties as an indirect consequence of the diagnosis because they have to pay for special services. We were unable to find data from the other countries included in this survey.

The second quantitative study included data from research which described implicit attitudes towards persons with DS. In this study, authors compared implicit attitudes towards DS expressed in relatives of persons with DS and the implicit attitudes towards the condition presented by college students in Colombia (Bernal, 2016). The data were collected with the Relational Responding Task (De Houwer et al., 2015) and the Escala de Pecepción Social Hacia Las Personas Con Síndrome de Down (Scale About Perceptions Towards People With Down Syndrome, EPSD-1) (Molina Saorín, Nunes Corredeira & Vallejo Ruíz, 2012). In this study, a group of twenty relatives was compared with a group of twenty-nine college students. Based on the hypothesis that previous contact is associated with more positive attitudes, the authors expected lower negative attitudes and perceptions towards people with DS in relatives. Results showed no differences among groups (college students vs relatives) in relation to negative stereotypes or attitudes towards persons with DS. As a possible explanation of their findings, authors pointed to the sample size (authors compared their sample with the sample included in a previous study conducted in France with 165 participants, Enea-Drapeau, Carlier, & Huguet, 2012) and the high homogeneity of the participants' educational level.

The third quantitative study was conducted in Chile and explored the relationship between the severity of symptoms in children with ASD and other family characteristics, including stigma (Hartmann et al., 2018). With a study-specific questionnaire, the authors found stigma to be positively associated with ASD overall traits, social impairment, language and communication deficits, and family stress but not related to restricted and repetitive behaviours (RRBs). Authors suggested that highly unacceptable behaviour, such as RRBs, may be interpreted as poor parenting and for this reason is less associated with ASD. The results showed that families who perceive more stigma associated with their child's difficulties, are also the families who perceive less support from physicians and other professionals, and experience higher levels of stress.

Two Ecuadorian studies included parents of children with DS, exploring the feelings of families towards DS (Huiracocha et al., 2013) and the impact of diagnosis (Huiracocha et al., 2017). Both studies included the same number of participants (seven mothers and one father) and found that the parents were aware of stigma towards their child in Ecuador. The authors suggest that stigma influences the parents' perception about the capability of their children and the importance of support in light of participants reporting lack of social support, widespread stigmatization, and institutionalised stigma mainly expressed among physicians.

In Chile, one study explored the life experiences of young people with ID and ASD in Temuco, a small city in the south of the country, based on two mothers' perceptions of their young son's and daughter's lives (Cerreta, 2018). A second study (von Furstenberg, Iriarte & Navarro, 2012) identified social factors that prevent the inclusion of people with ID in regular jobs in Santiago (capital of Chile) based on the opinions of the mothers. Both studies concluded that it is possible to identify stigma towards persons with IDD in Chile. The study goes beyond this affirmation and suggests: (a) that Chilean society has difficulties in including persons with ID due to existing social structures and negative attitudes towards this condition; (b) the most common parental attitudes are lack of affection and warmth towards their sons and daughters, which may be a form of active discrimination; (c) the highly segregated educational system of the country (Arango, Aparicio, & Tenorio, 2018) and the scarce governmental resources available to support people with ID, are major barriers to inclusion.

One Brazilian study investigated the experiences of mothers of young people with ID and ASD. They explored the mothers' initial reactions to the diagnosis of autism; the difficulties that children encountered during adolescence and the mothers' expectations about the child's future (Segeren & de Campos Francozo, 2014). The mothers stated that they had to change their routines by avoiding public places due to their child's behavioural problems, which were perceived negatively by the public, resulting in social stigmatisation and exclusion.

In Colombia, Lopera-Escobar & Bastidas-Acevedo (2018) describe the experiences of mothers of children with DS about the medical attention offered to their children. Participants complained that in the health system in Colombia, the identity of their child is based on the condition (with common expressions as: "*the Mongolic children…*"). They also talked about the difficulties in accessing health services for the child's condition, with misinformation and stigmatising attitudes from physicians and other health workers. For example, one of the participants reported that "*With the neurologists I had a very bad experience. I needed the authorization for therapies, but he denied it because, according with him, this kind of child doesn't need that*". An important finding was the participants' perceived lack of information about rights of persons with DS and the loss of hope and feelings of guilt were prevalent emotions amongst families of children with DS in Colombia.

Also, in Colombia, but with a mixed method approach, Polanco-Valenzuela & Marín-Araya (2017) explored the knowledge, attitudes and practices in terms of decisions in fathers, mothers and caregivers of adolescents with ID, with an emphasis on sexuality. The main finding is that participants were knowledgeable about the rights of persons with ID; however, the implementation and the use of mechanisms to support the expression of sexuality was limited because families and caregivers failed to recognise their children's capacity to make decisions regarding their sexuality. Mothers and father report ambivalence towards their child's emerging sexuality.

Mental health workers attitudes and beliefs about ID

Among the seventeen studies included in the review, one presented information about attitudes and beliefs of mental health workers about ID, carried out in Argentina (de Menil & Cohen, 2009). The authors describe stigma towards persons with IDD, discriminatory actions, and some violations of human rights. The predominance of negative attitudes and stereotypes are considered to have direct consequences on the quality of health services offered to this population. de Menil and Cohen (2009) investigated the over-use of psychiatric drugs in this context. They found that 83% of patients were taking psychiatric medications, although 67% of patients had no psychiatric diagnosis. Patients were mostly prescribed antipsychotics. They also point to mistreatment and inhuman actions such as denying anaesthesia to persons with ID because "(…) *they are like animals*". Mental health workers had a lack of awareness of ID and the lack of availability of non-medical treatments and hospitalisation for social reasons were cited (such as psychoanalytic treatments for psychological symptoms in persons with ID) as the main reasons for the over use of psychiatric medication.

Attitudes and beliefs about ID in community members

Among the quantitative studies, one was carried out in Brazil (Gregoul, Malagodi & Carraro, 2018) with physical education teachers. The Teacher Inclusion Attitudes Questionnaire was used to collect data form 35 Physical Education teachers. Findings suggested the presence of a general positive attitude to inclusion, but a lack of institutional support. Teachers perceived that students with ID were well accepted by their classmates. They also reported gender differences attributing better abilities to male students. There was a positive correlation between the number of years of experience of teaching children with special needs and positive attitudes towards their inclusion.

There were two quantitative studies that were conducted in two types of schools in Chile and explored attitudes (explicit and implicit) towards children with DS (Sirlopú et al., 2008; Sirlopú et al., 2012). In these studies, authors presented overlapping data. One study collected data on implicit and explicit attitudes towards other students with DS from 80 students without disability attending 4 schools in Santiago (2 with an inclusion program and 2 without) (Sirlopú et al., 2012). In the other study (Sirlopu et al., 2008), data were collected with 120 students without ID from four schools (2 with an inclusion program and 2 without). In both of these studies, the authors concluded that the type of school did not have an impact on the prejudice, attitudes and general perceptions of typically developing children towards children with DS. They argued that the attitudes were generally positive. However, an interaction was found between gender and type of school with more prejudice and negative attitudes in males who attended schools without inclusion programs.

Finally, de Menil and Cohen (2009) conducted a study with a mixed approach. Authors reported that they included interviews with community members from La Colonia in their sample. However, the findings from these interviews are not presented in the manuscript.

Discussion

Stigma is considered one of the most important concerns of our era, especially in relation to conditions such as HIV, leprosy, and mental illness. However, scant attention has been paid to stigma towards people with ID, even when it affects an estimated of 300 million people globally (Scior et al., 2016). The results of the narrative review are indicative of the limited scientific study of stigma towards people with ID in South American countries and the clear sense that people with ID living in those countries report experience of stigmatising attitudes.

The published studies identified for this narrative review are mainly qualitative. None of the studies included a large sample. Families and caregivers are the most frequent stakeholder group studied. The most important finding is the lack of studies including participants with ID and their personal experiences of stigma and discrimination, this is consistent with research on stigma in other regions, particularly in low income countries where there appears to be very limited research on self-reported experiences of stigma. As in previous studies, where the lack of inclusion and high level of stigma towards people with ID has been reported (i.e. Mitter, Ali & Scior, 2019; Pelleboer-Gunnink, Van Oorsouw, Van Weeghel, & Embregts, 2019; Scior, 2011), our results suggest that there is low participation of persons with ID in research, which is reflective of the low social and civil participation of persons with ID in the region.

Whilst stigma towards persons with ID appears to be common in Latin America, however, there is no information about the mediating influence of socio-demographic variables such as age and educational level. There is a lack of available information about cultural differences and specific idiosyncratic characteristics between countries.

As far as we know, this is the first systematic examination of stigma towards persons with ID in South American context. We have interrogated literature in English, Spanish and Portuguese languages to ensure that all relevant papers have been identified. We supplemented the databases search with a specific protocol to identify appropriate published data among grey material. We think this mixed approach in the search process enriched the final results. However, a degree of bias in the selections of manuscripts may have been introduced in the review process during study selection. We implemented different approaches to control for this, i.e. blind reviews and a systematic process to select documents but this bias could be still present.

In relation to the quality of research, based on the MMAT appraisal system, there is an urgent need to improve the quality of research in this field in the region.

Future research in the area of stigma towards persons with ID in South America must be conducted. A total comprehension of this phenomena, as well scientific data, will be very useful to enable researchers to design and evaluate the impact of different initiatives oriented to change the cultural attitudes towards people with ID. An increase of intellectual production in Spanish, available to general public in the South American countries is needed to increase comprehension and compromise with persons with ID.

The lack of public policies and national planning in favour of social inclusion and protection of the rights of people with ID across the South American countries should be a matter of attention for international agencies and non-profit organizations. As some authors have already suggested, there is an urgent need for political coordination to promote better conditions for persons with ID in the region (Comisión Económica para América Latina y el Caribe (CEPAL), 2012; Espejo Yaksic & Lathrop Gómez, 2019). People with ID are one of least considered groups, they are victims of all forms of violence (Fogden, Thomas, Daffern, & Ogloff, 2016; Hughes et al., 2012), and specific studies are needed to describe, understand, and combat all possible forms of stigma in South America.

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Table 1

Contextual information for each country in South America

	Gross domestic product (GDP)[1]	Total population[2]	Life expectancy[3]	Population extreme poverty[4]	Index Human Development[5]	Estimated population with disability[6]	UN CRPD year ratification
Argentina	545.9	43.8	76.5	<5%	0.82	12.9%	2008
Bolivia	33.8	10.8	69.1	23.2%	0.67	0.7%	2009
Brazil	1796	207.7	75.8	7.5%	0.75	11.5%	2008
Chile	247	17.9	80.5	<2%	0.84	20%	2008
Colombia	282.5	48.6	74.3	7.0%	0.72	6.3%	2011
Ecuador	97.8	16.4	79.9	11.7%	0.73	2.6%	2008
Guyana	3.4	0.7	66.6	No data available	0.63	6.4%	2014
Paraguay	24.4	6.7	77.2	13.6%	0.69	10%	2008

Peru	192.1	31.7	74.9	19.5%	0.74	5.2%	2008
Surinam	3.6	0.5	74.8	No data available	0.72	12.5%	2017*
Uruguay	52.4	3.4	77.4	<2%	0.79	15.8%	2009
Venezuela[7]	371.1	28.3	75.8	18.5%	0.76	5.38%	2013*

[1] Expressed in USD millions based on The World Bank Data
[2] Expressed in millions, data from the last national census available
[3] Expressed in years
[4] Data available in the International Monetary Fund (2011), based on people living with less than 1 USD per day.
[5] The Human Development Index (HDI) is a composite statistic (composite index) of life expectancy, education, and per capita income indicators, which are used to rank countries into four tiers of human development. It was designed for the United Nations Development Program (UNDP). Values closed to 1 indicated better results. Data available in UNDP (2016).
[6] Percentage of general population with disability reported by each governmental division in charge of disability in South America.
[7] General data about Venezuela needs future revisions due to the current political situation in the country.
* These countries ratified the Convention with reservations

Table 2

Specific information about studies included in this narrative review

Author	Aim	Participants	Instruments	Data analysis	Main findings	MMAT score
Qualitative studies						
Brazil						
Segeren & de Campos Francozo (2014)	To investigate the experiences of mothers of young people with autism to identify initial reactions to the diagnosis, daily routines and social difficulties faced by them	11 mothers of adolescents with ASD	Semi structured interviews	Content analysis techniques	-Diagnosis was given comprehensively with emphasis in the expected difficulties of child development -Changes in mothers routines were necessary to care the child -Those changes included social adaptations secondary to stigma expressed towards children with ASD	3
Colombia						
Lopera-Escobar & Bastidas-Acevedo, 2018	To describe the experiences of mothers of children with Down Syndrome about the medical attention offered to their daughters and sons.	17 mothers of children with DS	Semi structured interviews	Content analysis techniques	-An identity based on the condition ("the mongolic children…") - Denial of health services for these children based on their condition with misinformation and stigma attitudes from physicians and other professionals from the health system. -Misinformation about the rights of persons with ID in all the actors (physicians, professionals and families) -Loss of hope and guilt as predominant emotions in mothers as a consequence of stigma and prejudice expressed to their children	5
Chile						
Dehays, Hichins, & Vidal (2012)	To analyze the meanings that women with Intellectual Disability (ID) give to the experiences of being a	Three females with Intellectual Disability	Semi structured interviews	Grounded theory	- For participants, the meanings about being a woman and mother are based on specific actions, this is interpreted as a consequence of low IQ by authors.	1

	woman and mother				-Family supports is perceived as a basic condition to have a good role as a mother - The intellectual disability and lack of financial support are identified as barriers.	
Cerreta (2018)	To describe the life experiences of young people with moderate to severe autism who attend specialized schools in the city of Temuco (Chile)	Two mothers and four teachers	A semi-structured interview	Grounded theory	-Mothers and teachers informed about stigma towards people with ASD expressed in public space -The authors suggested that it is possible to identify stigma towards people with ASD expressed in their families	N.F
von Furstenberg, Iriarte & Navarro (2012)	To identify the social factors that prevent the inclusion of persons with ID in regular jobs in Chile, according to the mothers point of view	62 mothers and 2 fathers of young persons with ID	Questionnaire and semi structured interviews (with 7 mothers)	Content analysis techniques	-Chilean society has problems to include persons with ID in the workplace due to social structure and negative attitudes towards this condition -The most common attitudes attributed by parents are coldness and hardness. They identify active discrimination against their sons and daughters. - The kind of jobs available for persons with ID are based on charity or goodwill but they are not based on their relative skills. -Parents remember the difficulties to find a school for the education of their sons and daughters because "(...) in Chile the schools are not prepared to receive our children". There is no official program at Universities for persons with ID in the country. -Institutional stigma is identified by parents. They express that no governmental division helped them in the process of job inclusion for their relatives.	N.F
Ecuador						
Huiracocha et al. (2013)	To identify the feelings of families of children with Down Syndrome	8 parents of children with DS	Focus group, interviews, group discussion	Descriptive coding	-The study identified stigma towards people with DS -This stigma influences the family perception and support offered to their children with DS -Specific competences should be trained in health teams	4

Huiracocha et al. (2017)	This study examined the impact of a diagnosis of DS on Ecuadorian families	8 parents of children with DS	Focus group, interviews, group discussion	Descriptive coding	- Professionals rarely communicate a DS diagnosis in an appropriate manner. - The lack of social support, and the widespread stigmatization confronting children with DS and their families, hinder development of positive and empowering adjustments that would best serve the child's and the family's interest.	4
Peru						
O'Shea et al. (2012)	To characterize public perceptions regarding intellectual disability in a peri-urban community of limited resources	12 key informants and 10 community members	A semi-structured interview	Grounded theory	- The themes derived from categories were poverty and its related concerns, lack of attention paid to ID and the role of family -Persons have difficulties to differentiate ID from mental illness -Some participants identified scientific background - Lack of resources was reported as a source of difficulties to educate a child -Attitudes are affected by personal priorities, ideology, and previous interaction with persons with ID	3
			Quantitative Studies			
			Brazil			
Greguol, Malagodi, & Carraro (2018)	To analyze the attitudes of Physical Education teachers towards the inclusion of students with disabilities in regular classes	35 physical education teachers	Teacher Inclusion Attitudes Questionnaire (TIAQ)	Descriptive data and mean comparisons	- General positive attitude to inclusion without institutional support. Low scores in skills and support items - Skills factor is related with the severity of the condition - Students with disability are well accepted by their classmates from the teacher point of view - A gender effect on Skills perception, better abilities perceived by men. - Positive correlation among time of experience and positive attitude towards inclusion	2
Colombia						

Bernal (2016)	To observe and describe implicit attitudes towards persons with DS in relatives and college students	49 participants, 20 relatives y 29 college students	Relational responding task (De Houwer et al., 2015), EPSD-1 (Molina Saorín, Nunes Corredeira, & Vallejo Ruiz, 2012).	Descriptive and inferential analysis	-No differences among groups -There was no identification of negative stereotypes or attitudes - The sample size is criticized	1
Chile						
Hartmann et al. (2018)	To explore relationships between severity of ASD traits, community supports, and other family variables as reported by caregivers.	50 caregivers of individuals with ASD	Study-specific questionnaire	Correlations	- A negative correlation between social stigma and child's overall ASD score, impairment in language and communication, difficulties in social interaction and stress	1
Sirlopú et al. (2008)	To assess if students at schools with inclusion programs will hold more positive stereotypes and attitudes toward people with Down syndrome than will students at schools without inclusion programs.	120 Chilean students, between 11 and 15 years	Questionnaire	Factor analyisis, mean comparisons	- No effects of school system on any of the stereotype measures. - Relative low level of prejudice among students -Positive attitudes toward people with DS, high levels of linking and low levels of patronizing, avoidance and rejection - Pleasure and pity scores exceed aversion scores - Major tendency to negative attitudes, prejudice and aversion among men in non-inclusive schools	3
Sirlopú et al. (2012)	To evaluate both types of attitudes towards People with Down syndrome (PWDS)	80 Chilean students, between 11 to 15 years	Implicit Association Test (IAT)	Descriptive data and mean comparisons	- No differences were found in implicit bias towards PWDS among the two groups of students - Low rates of prejudice were identified in this study - Difference on "contact anxiety" and "amount of contact" in favor to children from schools with inclusion	3

Cross-cultural						
Luengo (2018)	To explore the language used in media from Venezuela and Argentina to talk about autism	1480 articles published in 480 national papers		Media framing theory	-Significant differences between the countries' coverage of autism in their description of issues, discourse types, sources, images, roles and stigmatizing cues -A scientific discourse type is more common in Venezuelan articles than in Argentina which focuses on human-interest stories. -Individuals with autism are quoted in less than 5% of stories from each country -Results explain why both countries perpetuate stigmatizing cues regarding labeling, psychological symptoms, social skills and physical appearance.	3
Retazzi, Valdez & Cukier (2016)	To analyze the results obtained with a multi-national survey applied in five countries in South America (Argentina, Brasil, Chile, Venezuela, Uruguay) to families of children with Autism Spectrum Disorder	2965 caregivers of children with ASD	Study-specific questionnaire	Descriptive analysis	-55% of the caregivers in Argentina informed stigma towards them and their sons and daughters with ASD. 50% had to cut hours in their work. 42% of the families informed finantial difficulties - There is no information available about the other countries	N.F
Mixed methods						
Argentina						
de Menil & Cohen (2009)	To describe the obstacles to the rational use of psychiatric drugs in a 1000-bed institution for people with ID.	98 patients charts, 5 hospital administrators, 2 psychiatrists,	Study-specific questionnaire	Descriptive analysis and ethnographic analysis content	-Two-thirds (67%) of individuals taking psychiatric medication, did not have a psychiatric diagnosis -Antipsychotics are more commonly prescribed than any other drugs	5

		2 nurses, 2 nurses aids, 2 patients and 1 pharmacist.			-Absence of specific training to work with persons with ID, in all the professional in the health system with emphasis in psychiatrists and psychologists (mainly educated in the psychoanalytic orientation) -In absence of training, the staff developed their our theories and ideas about ID including some like: “some patients don't require anesthesia during procedures, just like animals" The study identified structural impediments and barriers for the expression of rights of persons with ID. Violence is visible in staff and patients.	
Colombia						
Polanco-Valenzuela & Marín-Araya (2017)	To explore knowledge, attitudes and practices in fathers, mothers and caregivers of adolescents with ID	32 families of adolescents with ID	Study-specific questionnaire and semi-structure interview	Descriptive and content analysis	-The interviewees express knowledge about the rights of persons with disability. However, implementation and mechanisms to support the expression of these rights is fragile. Mothers and fathers do not recognize their daughters' and sons' abilities to take decisions about their sexuality. Attitudes are ambivalent.	4

Table 3

Included studies organised by stakeholder's groups and methodological approach

	Quantitative approach	Qualitative approach	Mixed approach
Persons with Intellectual and Developmental Disabilities		Dehays, Hichins, & Vidal (2012)	de Menil & Cohen, (2009)
Families and caregivers	Bernal (2016)	Lopera-Escobar & Bastidas-Acevedo (2018)	Polanco-Valenzuela & Martín-Ayala (2017)
	Hartmann et al. (2018)		
		Cerreta (2018)	
	Ratazzi, Valdez, & Cukier (2016)	Furstenberg, Iriarte, & Navarro (2012)	
		Huiracocha et al. (2013)	
		Huiracocha et al. (2017)	
		O'Shea, Maziel Girón, Cabrera, Lescano, & Taren (2012)	
Mental health workers			de Menil & Cohen (2009)
Community members	Gregoul, Malagodi, & Carraro (2018)		
	Sirlopú et al. (2008)		
	Sirlopú et al. (2012)		

STIGMA TOWARDS PERSONS WITH INTELLECTUAL DISABILITY IN SOUTH-AMERICA: A NARRATIVE REVIEW

Reviewer: 2

Comments to the Author	Response
I'm pleased to note that the authors have addressed most of the revisions suggested in the last round. However, the authors have not addressed some aspects highlighted previously:	
While the in-text reference to Azmi et al. was removed, it is still in the References section.	The reference has been removed from the Reference section
Logeswaran et al., 2019 was added to the text but is missing from References.	The reference has been added to the Reference section
Numbers are still not written consistently, e.g.:	All the numbers were corrected in the text
Page 21 – "…4 schools in Santiago (2 with an inclusion program and 2 without"	Done
Page 16 – "…from fourteen individuals that included administrators…"	Done
Page 20: "Among the seventeen studies included…"	Done
Some commas still not correctly used: e.g. Page 18: "The results showed that families who perceive more stigma associated with their child's difficulties, are also…" no comma necessary here.	Done
While I'm loathe to set out more minor revisions, in reading the revised manuscript I noted the following minor points:	
Abstract: Unclear sentence: "Available through limited information is organised by stakeholder groups, including…". I assume you mean to say available, though limited, information…	Done
Page 7: Africa is misspelled.	Done
Page 12: "table 1" should be capitalized, in line with other table references	Done
Page 15: "The remainder (47.2%) were from Brazil (11.7%), Ecuador (11.7%), Peru (5.8%) and Argentina (5.8%)." These percentages do not sum to 47.2%.	Done
Page 15: "Ten studies were conducted with families and caregivers, three studies considered community members (students and teachers); two with persons with IDD, and one with mental health workers." As there were 17 studies in total, one study is missing from this description. Also semi-colon should be a comma.	Done
Page 21: Should be Sirlopú et al., 2008.	Done
Page 23: "…could be still": should be could still be.	Done
Pelleboer-Gunnink et al., 2019 missing from References	The reference has been added to the Reference section
Espejo Yaksic & Lathrop Gomez, 2019 is missing from References.	The reference has been added to the Reference section

Silva Barroilhet, 2017 missing from References.	The reference has been added to the Reference section
In general, be careful in using semi-colons, e.g. 19: “They explored the mother’s initial reactions to the diagnosis of autism; the difficulties that..” Use comma instead.	Checked all the manuscript

Abstract

Background: People with intellectual disability (ID) form one of the most underserved/stigmatised groups in society. Published data have documented stigma towards this population group in different countries. However, this phenomenon has received scant attention in South American countries. Specific Aim: To conduct a systematic search of published and grey literature in the area of stigma towards persons with ID within the 12 countries of the region to explore expression of stigma towards people with ID in the Region. Method: Systematic research of published data and grey literature, based on previous published protocol, was run in this work. Research strategy included terms related to intellectual disabilities, were combined with stigma, prejudice, attitudes and stereotypes, and with the names of all the South American countries. Due to the known relationship between ID and Autism Spectrum Disorder, this term was included in the search. The search was conducted in English, Spanish, and Portuguese. A narrative approach to results is presented. Findings: Available information is organised by stakeholder groups, including persons with ID, families, caregivers and mental health workers. The quality of the studies was analysed based on the Mixed Method Appraisal Tool version 2018 (MMAT), results are variable. Discussion: The results of the narrative review are indicative of the limited scientific study of stigma towards people with ID in South American countries and the clear sense that people with ID living in those countries report experience of stigmatising attitudes. Future research, at population level, is needed in the region to ensure improvements in the quality of life and in the civil participation of people with ID.

Key words: stigma, prejudice, stereotype, intellectual disability, South America

Intellectual disability (ID) is characterised by significant limitations in cognitive functions and in adaptive behaviour in a wide range of daily activities, originating before 18 years of age (Schalock, Luckasson, Tassé, & Verdugo, 2018). ID is a neurodevelopmental disorder, and in the current international classifications, it is categorised under "Intellectual and Developmental Disabilities (IDD)" with other conditions such as Autism Spectrum Disorders (ASD), Attention Hyperactivity Disorder (ADHD), Learning Disabilities, Motor Developmental Disabilities and Communication Disorders (American Psychiatric Association, 2013). Several studies have shown that people with IDD as a group are commonly victims of stigma and prejudice (i.e., Hamdani, Ary, & Lunsky, 2017; Mitter, Ali, & Scior, 2018) and, some of these studies noted that persons with ID are one of the most underserved/stigmatised groups in society (i.e. Walker & Scior, 2013).

Stigma and prejudice are complex concepts related to individual experiences that emerge as a result of the interaction between marginalised and non-marginalised groups (Stuber, Meyer, & Link, 2008). The seminal works by Allport (1954) and Goffman (1963) defined stigma as a personal attribute that triggers a negative stereotype with undesirable consequences for the daily life of the person. Stigma is a useful concept to characterise the social interactions that emerge from the relationship between people from a group considered typical and another considered atypical, such as people with facial scars, physical disability, mental illness, or IDD. On the other hand, prejudice is understood as a hostile reaction towards a person because they belong to a specific group. The concept of prejudice appears to be more focused on categories such as ethnicity, gender or socio-economical level (Phelan, Link, & Dovidio, 2008). While differently defined, both concepts are related to social barriers, violations of essential rights, and direct acts of discrimination, among other consequences (Arboleda Flórez, 2005; Drew et al., 2011).

Across the world, minority groups are victims of both stigma and prejudice (Knesebeck, Kofahl, & Makowski, 2017), and some of those groups have received more attention in research than others. People with IDD have been identified as one of the most segregated groups in society (Ali, King, Strydom, & Hassiotis, 2015), and several studies demonstrated that people with ID are subject to different forms of stigma including public, courtesy, and self-perceived (Ali, Hassiotis, Strydom, & King, 2012; Scior, 2011; Scior, Addai-Davis, Kenyon, & Sheridan, 2012; Werner, 2015). Public stigma refers to the general public's response towards people with IDD as a result of negative attitudes and prejudice (Scior, 2011; Walker & Scior, 2013; Werner, 2015). Courtesy stigma affects the closest family members, friends, and professionals that work with a person with ID who may develop negative self-evaluations and emotions related with the condition (Ali, Hassiotis, Strydom, & King, 2012; Birenbaum, 1992; Birenbaum, 1970). Self-perceived stigma refers to the extent to which a person with ID is aware of stigma and discrimination from the public or from individuals (Ali et al., 2012; Corrigan, Watson, & Barr, 2006; O'Byrne & Muldoon, 2017).

In parallel with the advances in research, the fight for the rights of people with IDD has been a continuous process during the last 30 years (Wilson & Scior, 2015) and advocates have used a number of frameworks and perspectives to promote rights, e.g. common ideas about humanity and human rights (Coles & Scior, 2012), specific case law, or international declarations to enshrine such rights in law in different countries (Dang, 2010; Fujiura, Park, & Rutkowski-Kmitta, 2005; Meijer, Carpenter, & Scholte, 2004; Schalock et al., 2010).

However, these actions are insufficient as explicit and implicit negative attitudes towards people with IDD are still prevalent in society (Scior, 2011; Wilson & Scior, 2015). Furthermore, other disparities arise when considering the social and geopolitical position of people with IDD.

Studies of the different forms of stigma towards people with IDD have been conducted mostly in high-income countries. Published data suggests that people with intellectual disabilities consistently emerge as the group with the highest stigma, and the stigma expression is higher towards this group than to other disability groups (Werner, 2015). In these countries, variables such as age, educational attainment and prior contact predict attitudes towards persons with ID. However, there are inconsistent findings in relation to gender (Scior, 2011). Previous studies conducted in high-income countries also report that people with ID who participate in community activities are subject to hostility (i.e. Cummins & Lau, 2003). More recently, researchers have focused their attention on people with ID being victims of hate crime, alongside bullying, abuse, and harassment (Walker & Scior, 2013).

In the area of self-perceive stigma, people with IDD who report feeling stigmatised are more likely to have symptoms of anxiety and depression, a lower quality of life, and increased contacts with social services and the police (Ali et al., 2015). Self stigma is receiving special attention from researchers. In a recent review (Logeswaran, Hollett, Zala, Richardson, & Scior, 2019), authors explored how people with ID view their ascribed label, to what extent they ascribe it to themselves, and whether they recognize it as devalued in society. The review included 16 manuscripts, most of them related to studies conducted in Western countries, one from Africa, and one from Vietnam. People with ID experience negative feelings about the label, and report shame, discomfort, anger, powerlessness, and frustration towards the label. However, in some cases it was also possible to report positive views of the label, a core element of the self-advocacy movement leading to collective actions as a way to combat stigma. Negative feelings may result from the negative treatment and interactions they have experienced. Some authors suggest that, in particular, self-perceived stigma could be a precursor for victimisation and loneliness in the presence of mental illness (Gilmore & Cuskelly, 2014; Horsselenberg, van Busschbach, Aleman, & Pijnenborg, 2016).

Little is known about the expression and consequences of stigma in middle or low-income countries. Previous studies conducted in South-Asia (Abraham, Gregory, Wolf, & Pemberton, 2002; Edwardraj, Mumtaj, Prasad, Kuruvilla, & Jacob, 2010) and Africa (Ali et al., 2015; Kock et al., 2012) suggest that cultural characteristics influence the social expression of stigma and prejudice, which are moderated by variables such as religion, personal beliefs about the origin of the condition or previous contact with persons with IDD. However, given the paucity of research in many regions including Latin America, conclusive actions cannot be achieved due to lack of engagement with the topic at population level (Ali et al., 2015; Ali et al., 2016; Hatzenbuehler, Phelan, & Link, 2013).

New studies are needed to clarify the cultural impact of the expression of stigma towards people with IDD and more countries should promote such research to gain a wider, global comprehension of the problems and the formulation of policies to improve the lives and acceptance of people with IDD over the life course.

South America is a region extending from the Caribbean in the north to the Antarctic region in the south and formed by 12 countries (Argentina, Bolivia, Brazil, Chile, Colombia, Ecuador, Guyana, Paraguay, Peru, Suriname, Uruguay, and Venezuela). It has a total population of approximately 600 million with significant cultural differences between countries. Most of the countries are lower-middle or upper-middle income, except for Argentina, Chile and Uruguay classified as high-income economies (World Bank, 2018).

Social inequality, characterised by problems with capital distribution, access to social services, education, health, and opportunities, is a major challenge experienced by all South

American countries. As a consequence, socio-economic status is a pivotal variable for social research in the region (Central Intelligence Agency, 2017; Gapminder, 2017). Specific information about the geopolitical status for each of the South American countries, as well as the estimated population of people with disability, is presented in Table 1 to provide context to the review.

Chile is considered a developed country due to macro-economic indicators and its gross national product (World Bank, 2018). However, some authors have argued that because of the low standards of living and human development index (Frey & Temple, 2008; Gapminder, 2017), countries such as Chile should be considered as developing countries.

<<Insert here Table 1>>

Several South American countries have a history of political instability secondary to the military coups during the 20th century (i.e., Colombia in 1953, Argentina in 1976, Chile in 1973, Uruguay in 1973, Paraguay in 1989, Brazil in 1964, and Peru in 1992), with well documented human rights violations (Sikkink & Walling, 2007). Political violence and human rights violations have morphed into social violence (Oxhorn & Jouve-Martín, 2017).

The global prevalence of IDD, and specifically for ID, is unknown due to technical and political factors such as problems with surveillance systems, differences in how the condition is defined, or lack of governmental programs oriented towards ascertainment. Current data suggests that in Latin America (Central America, the Caribbean and South American countries), 13.8 million people have IDD (PAHO, 2012). As far as we know, there is no specific prevalence rate of IDD available for the South American region only.

People with IDD are common victims of violence at a global level, for example, they are at high risk of being victims of hate crimes, social rejection, violations of rights, and lack of opportunities (Mikton, Maguire, & Shakespeare, 2014; Sherry, 2010). They are likely to suffer inequalities in social care, health and education (Ali et al., 2013; Hassiotis, Barron, & O'Hara, 2000; Rimmer, 1999); they are at a disadvantage in the judicial process and, in general, they have worse quality of life than people without disability in the same territory (i.e. Ncube, Perry, & Weiss, 2018).

This global situation has particular bearing for South America. Public policy about ID in the region is scarce and this seems to be a consequence of social and institutionalized stigma towards this group. A closer inspection of legislative statements regarding people with ID shows that some of the countries have declarations such that an adult with ID does not have legal capacity (referred as the capacity of a person to exert rights and duties according to each national legislation), and that specific statements about school inclusion. The available policies have not been updated since they were written, and they still use pejorative terminology, failing to incorporate a rights-based approach to laws affecting people with ID (Silva Barroilhet, 2017). The global framework for the rights of people with disabilities is the Convention on the Rights of Persons with Disabilities (CRPD, UN 2006). This convention was created following discussions involving representatives from member states including people with disabilities. Under consideration of the CRPD, these situations represent a clear violation of the international law. Reports published by the United Nations about the implementation of legislation according to the CRPD, recommends the need to take more active measures to support persons with disability in the region (i.e. United Nations, 2016).

News and social media are one of the most important sources of documenting rights, violations and stigma towards people with ID in South America. A recent example in the Chilean context is about the current scandal in the "looked-after children" program, where videos were disseminated via social media showing physical maltreatment of children from paid caregivers. These types of headlines are frequent, but due to the scarcity of research in the area, as well as the lack of general and political interest, almost no action has been taken by the government to deal with this situation.

The aim of this paper is to present a narrative review of the expression of stigma and prejudice towards people with ID in South America. In this review, we focus on studies relating to stigma towards people with ID only, although some may have comorbid conditions. We hope that this work will help to improve research on the topic in South America and will be relevant to a wide range of stakeholders including professionals, policy makers and Not-for-Profit organisations working with disability groups.

Method

In this review, we considered evidence available in catalogued journals and the grey literature, including academic theses, organisation reports, government papers, etc. (Haddaway, Collins, Coughlin, & Kirk, 2015).

We used the 27-item checklist recommended by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) to assess studies included in the review (Moher, Liberati, Tetzlaff, Altman, & Group, 2009a). The four-phase diagram recommended by PRISMA group and that included identification process, screening, eligibility and definition of included studies, was adapted for the study (Moher et al., 2009a).

The protocol recommended by Haddaway et al. (2015) to conduct systematic reviews in Google Scholar was implemented for the grey literature search.

The Mixed Method Appraisal Tool version 2018 (MMAT; Hong et al., 2008) was used to critically appraise the methodological quality of the included studies.

Information sources

Five databases (Web of Science, EBSCO, Scopus, PubMed and LiLACS) were used for the literature search. In all cases, the date range was fixed from 2008 to 2019. There is no consensus about ideal range of dates for a systematic review (Cooper, Booth, Varley-Campbell, Britten, & Garside, 2018; Liberati et al., 2009), this date range was considered relevant based on the period in which countries in South America ratified the Convention on the Rights of Persons with Disabilities (CRPD; specific information about ratification in South American countries is available in Table 1). The search was conducted in March 2019, information from the first ten pages of Google Scholar was considered at title and text level. In this review we only included empirical studies.

Search strategy

We included search terms which had been used in previous systematic reviews (Ali, Hassiotis, Strydom, & King, 2012; Scior, 2011) about stigma in the English language and we supplemented those by additional terms that have been used in Spanish and Portuguese reviews. We chose these terms in order to replicate what has been carried out in previous reviews, as well as to integrate new sources of information.

Search terms related to ID, were combined with stigma, prejudice, attitudes and stereotypes, and with the names of all the South American countries. Due to the known relationship between ID and Autism Spectrum Disorder, this term was included in the search. We conducted the search in English, Spanish, and Portuguese. For each language, a native speaker reviewed all the titles and abstracts, and then an independent review was carried out by a second researcher who was fluent in all three languages. The search was conducted as follows:

Neurodevelopmental disorder OR developmental disorder OR learning disorder OR learning disability OR mental retardation OR intellectual disability OR autism OR down syndrome

AND stigma OR prejudice OR stereot* OR attitude

AND Latin America OR South America OR Colombia OR Venezuela OR Guyana OR Suriname OR Ecuador OR Bolivia OR Peru OR Brazil OR Chile OR Argentina OR Uruguay OR Paraguay.

The Spanish and Portuguese terms selected for clinical conditions were the same as those used in English with the corresponding translation. At the level of stigma, the search in Spanish also included “imaginario”, a common term used in Colombia to describe idiosyncratic ideas about something. “Imaginario” corresponds to stereotyped ideas about groups of individuals that may be held due to particular political or social views.

The inclusion criteria for the studies were: (a) an explicit mention of ID in any part of the manuscript, (b) an explicit mention of one of the key components of stigma (attitude, stereotype, prejudice, and discrimination), and (c) the study was conducted in South America. Exclusion criteria considered: (a) mention of conditions not included in the search terms, (b) focus on stigma towards medical conditions such as HIV/AIDS, Epilepsy, Leprosy or Tuberculosis (frequent topics of interest in the region), (c) lack of relation to stigma, and (d) studies of immigrant populations that are not native to South America as these groups are likely to hold different cultural values that might influence the expression of stigma.

The final selection of manuscripts was reviewed and validated independently by two of the authors and an expert in statistical analysis with a third author arbitrating any disagreements that could not be resolved by the reviewers.

The MMAT approach was applied by two independent reviewers and in those cases where there was disagreement, a third person arbitrated the decision.

Results

The results are summarised in Figure 1, and in Figure 2 following the PRISMA flowchart (Moher, Liberati, Tetzlaff, Altman, & Group, 2009b).

<<Insert here figure 1>>

<<Insert here figure 2>>

Seventeen papers were retained in this review and are presented in Table 2. Twelve manuscripts were published in Spanish, four in English and one in Portuguese. The MMAT algorithm was used to classify the studies according to their methodological approach. Eight studies used a qualitative approach to answer the research questions, seven used a quantitative approach, and two used a mixed methods approach. For two qualitative studies (Cerreta, 2018; Furstenberg, Iriarte, & Navarro, 2012) and one quantitative study (Retazzi, Valdez & Cukier, 2016) the MMAT approach was not feasible. However, these studies were included because the MMAT authors point out that excluding studies with low methodological quality is discouraged.

Two studies (11.8%) obtained the maximum MMAT score (5 points): one qualitative study (Lopera-Escobar & Bastidas-Acevedo, 2018) and one mixed methods study (de Menil & Cohen, 2009). Three (17.6%) studies obtained a MMAT score of 4 points, and the remaining 12 studies (70.6%) scored 3 or fewer points on quality.

In terms of content, 12 studies explored stigma, attitudes or prejudice towards persons with ID (including towards people with Down Syndrome) and five studies explored stigma towards people with ID and ASD (the specific target population for each study is available in Table 2).

The majority of the included studies were conducted in Chile (35.2%) and Colombia (17.6%). The remainder (35.5%) were from Brazil (11.7%), Ecuador (11.7%), Peru (5.8%) and Argentina (5.8%). Cross-cultural data are available in 11.7% of the included studies. No studies from Bolivia, Guyana, Suriname, Paraguay or Uruguay were found in the search process. Table 2 presents the specific country included in each study.

<<Insert here Table 2>>

The narrative synthesis has been organised to present the reported perspective of four stakeholder groups: persons with ID, family and caregivers, mental health professionals, and community members (Table 3). Eleven studies were conducted with families and caregivers, three studies considered community members (students and teachers), two with persons with IDD, and one with mental health workers.

<<Insert here Table 3>>

Attitudes and beliefs about ID perceived by persons with this condition

There is only one included study that interviewed participants with ID (Dehays, Hitchins & Vidal, 2012), which was conducted in Chile. Three mothers with ID reported on their experiences of being women and mothers. Both the presence of an intellectual disability and the lack of financial support were identified as the main barriers in their role as mothers, specifically to look after their children, to have an active social participation, and to be recognised as productive members in their families and in society. These women report being criticised in the way they lived and experienced motherhood, and they perceived this as stigmatisation. Furthermore, they report that in some cases their families replace them as decision-makers in the process of raising their own children.

The main goal of the other study (de Menil & Cohen, 2009) was to describe the obstacles for the rational use of psychiatric drugs in a 1000-bed institution for persons with IDD called *La Colonia*, in Argentina. Authors used patients' charts to present descriptive data about the medical situation of the persons who are living in La Colonia and about the institution. They refer to the use of an ethnographic approach to collect qualitative data from 14 individuals that included administrators, two psychiatrists, two nurses, two nurses' aids, two inpatients with ID, and one pharmacist. However, in the results and discussion sections the text refers mostly to staff ignoring the views of people with ID. The authors mainly mentioned violations of human rights, and expression of stigma by caregivers and mental health workers. These results will be further discussed in the section about attitudes and beliefs about IDD in that group.

Attitudes and beliefs about ID perceived by families and caregivers

The first quantitative study was the Caregiver Needs Survey completed by 2965 relatives of persons with ASD in Argentina, Brazil, Chile, Uruguay, Venezuela and Dominic Republic. General information about this survey was presented in a congress abstract (Retazzi, Valdez & Cukier, 2016). We searched for the original work and part of the results are available in "La Nación", an Argentinian national newspaper. According to the survey, families of persons with ASD in Argentina perceived stigma towards their relatives as a consequence of the diagnosis and reported higher levels of stigma when ID was present in co-occurrence with behavioural problems. Fifty-five percent of caregivers reported that they thought their sons and daughters were stigmatised, 50% reported the need to work fewer hours to take care of their relatives and 42% experienced financial difficulties as an indirect consequence of the diagnosis because they have to pay for special services. We were unable to find data from the other countries included in this survey.

The second quantitative study included data from research which described implicit attitudes towards persons with DS. In this study, authors compared implicit attitudes towards DS expressed in relatives of persons with DS and the implicit attitudes towards the condition presented by college students in Colombia (Bernal, 2016). The data were collected with the Relational Responding Task (De Houwer et al., 2015) and the Escala de Pecepción Social Hacia Las Personas Con Síndrome de Down (Scale About Perceptions Towards People With Down Syndrome, EPSD-1; Molina Saorín, Nunes Corredeira & Vallejo Ruíz, 2012). In this study, a group of 20 relatives was compared with a group of 29 college students. Based on the hypothesis that previous contact is associated with more positive attitudes, the authors expected lower negative attitudes and perceptions towards people with DS in relatives. Results showed no differences among groups (college students vs relatives) in relation to negative stereotypes or attitudes towards persons with DS. As a possible explanation of their findings, authors pointed to the sample size (authors compared their sample with the sample included in a previous study conducted in France with 165 participants; Enea-Drapeau, Carlier, & Huguet, 2012) and the high homogeneity of the participants' educational level.

The third quantitative study was conducted in Chile and explored the relationship between the severity of symptoms in children with ASD and other family characteristics, including stigma (Hartmann et al., 2018). With a study-specific questionnaire, the authors found stigma to be positively associated with ASD overall traits, social impairment, language and communication deficits, and family stress but not related to restricted and repetitive behaviours (RRBs). Authors suggested that highly unacceptable behaviour, such as RRBs, may be interpreted as poor parenting and for this reason is less associated with ASD. The results showed that families who perceive more stigma associated with their child's difficulties, are also the families who perceive less support from physicians and other professionals, and experience higher levels of stress.

Two Ecuadorian studies included parents of children with DS, exploring the feelings of families towards DS (Huiracocha et al., 2013) and the impact of diagnosis (Huiracocha et al., 2017). Both studies included the same number of participants (seven mothers and one father) and found that the parents were aware of stigma towards their child in Ecuador. The authors suggest that stigma influences the parents' perception about the capability of their children and the importance of support in light of participants reporting lack of social support, widespread stigmatization, and institutionalised stigma mainly expressed among physicians.

In Chile, one study explored the life experiences of young people with ID and ASD in Temuco, a small city in the south of the country, based on two mothers' perceptions of their young son's and daughter's lives (Cerreta, 2018). A second study (von Furstenberg, Iriarte & Navarro, 2012) identified social factors that prevent the inclusion of people with ID in regular jobs in Santiago (capital of Chile) based on the opinions of the mothers. Both studies concluded that it is possible to identify stigma towards persons with IDD in Chile. The study goes beyond this affirmation and suggests: (a) that Chilean society has difficulties in including persons with ID due to existing social structures and negative attitudes towards this condition, (b) the most common parental attitudes are lack of affection and warmth towards their sons and daughters, which may be a form of active discrimination, (c) the highly segregated educational system of the country (Arango, Aparicio, & Tenorio, 2018) and (d) the scarce governmental resources available to support people with ID, are major barriers to inclusion.

One Brazilian study investigated the experiences of mothers of young people with ID and ASD. They explored the mothers' initial reactions to the diagnosis of autism, the difficulties that children encountered during adolescence, and the mothers' expectations about the child's future (Segeren & de Campos Francozo, 2014). The mothers stated that they had to change their routines by avoiding public places due to their child's behavioural problems, which were perceived negatively by the public, resulting in social stigmatisation and exclusion.

In Colombia, Lopera-Escobar and Bastidas-Acevedo (2018) describe the experiences of mothers of children with DS about the medical attention offered to their children. Participants complained that in the health system in Colombia, the identity of their child is based on the condition (with common expressions as: "*the Mongolic children…*"). They also talked about the difficulties in accessing health services for the child's condition, with misinformation and stigmatising attitudes from physicians and other health workers. For example, one of the participants reported that "*With the neurologists I had a very bad experience. I needed the authorization for therapies, but he denied it because, according with him, this kind of child doesn't need that*". An important finding was the participants' perceived lack of information about rights of persons with DS and the loss of hope and feelings of guilt were prevalent emotions amongst families of children with DS in Colombia.

Also, in Colombia, but with a mixed method approach, Polanco-Valenzuela & Marín-Araya (2017) explored the knowledge, attitudes and practices in terms of decisions in fathers, mothers and caregivers of adolescents with ID, with an emphasis on sexuality. The main finding is that participants were knowledgeable about the rights of persons with ID; however, the implementation and the use of mechanisms to support the expression of sexuality was limited because families and caregivers failed to recognise their children's capacity to make decisions regarding their sexuality. Mothers and father report ambivalence towards their child's emerging sexuality.

Mental health workers attitudes and beliefs about ID

Among the 17 studies included in the review, one presented information about attitudes and beliefs of mental health workers about ID, carried out in Argentina (de Menil & Cohen, 2009). The authors describe stigma towards persons with IDD, discriminatory actions, and some violations of human rights. The predominance of negative attitudes and stereotypes are considered to have direct consequences on the quality of health services offered to this population. de Menil and Cohen (2009) investigated the over-use of psychiatric drugs in this context. They found that 83% of patients were taking psychiatric medications, although 67% of patients had no psychiatric diagnosis. Patients were mostly prescribed antipsychotics. They also point to mistreatment and inhuman actions such as denying anaesthesia to persons with ID because "(…) *they are like animals*". Mental health workers had a lack of awareness of ID and the lack of availability of non-medical treatments and hospitalisation for social reasons were cited (such as psychoanalytic treatments for psychological symptoms in persons with ID) as the main reasons for the overuse of psychiatric medication.

Attitudes and beliefs about ID in community members

Among the quantitative studies, one was carried out in Brazil (Gregoul, Malagodi & Carraro, 2018) with physical education teachers. The Teacher Inclusion Attitudes Questionnaire was used to collect data form 35 Physical Education teachers. Findings suggested the presence of a general positive attitude to inclusion, but a lack of institutional support. Teachers perceived that students with ID were well accepted by their classmates. They also reported gender differences attributing better abilities to male students. There was a positive correlation between the number of years of experience of teaching children with special needs and positive attitudes towards their inclusion.

There were two quantitative studies that were conducted in two types of schools in Chile and explored attitudes (explicit and implicit) towards children with DS (Sirlopú et al., 2012; 2008). In these studies, authors presented overlapping data. One study collected data on implicit and explicit attitudes towards other students with DS from 80 students without disability attending four schools in Santiago (two with an inclusion program and two without; Sirlopú et al., 2012). In the other study (Sirlopu et al., 2008), data were collected with 120 students without ID from four schools (two with an inclusion program and two without). In both of these studies, the authors concluded that the type of school did not have an impact on the prejudice, attitudes and general perceptions of typically developing children towards children with DS. They argued that the attitudes were generally positive. However, an interaction was found between gender and type of school with more prejudice and negative attitudes in males who attended schools without inclusion programs.

Finally, de Menil and Cohen (2009) conducted a study with a mixed approach. Authors reported that they included interviews with community members from La Colonia in their sample. However, the findings from these interviews are not presented in the manuscript.

Discussion

Stigma is considered one of the most important concerns of our era, especially in relation to conditions such as HIV, leprosy, and mental illness. However, scant attention has been paid to stigma towards people with ID, even when it affects an estimated of 300 million people globally (Scior et al., 2016). The results of the narrative review are indicative of the limited scientific study of stigma towards people with ID in South American countries and the clear sense that people with ID living in those countries report experience of stigmatising attitudes.

The published studies identified for this narrative review are mainly qualitative. None of the studies included a large sample. Families and caregivers are the most frequent stakeholder group studied. The most important finding is the lack of studies including participants with ID and their personal experiences of stigma and discrimination, this is consistent with research on stigma in other regions, particularly in low income countries where there appears to be very limited research on self-reported experiences of stigma. As in previous studies, where the lack of inclusion and high level of stigma towards people with ID has been reported (i.e. Mitter, Ali & Scior, 2019; Pelleboer-Gunnink, Van Oorsouw, Van Weeghel, & Embregts, 2019; Scior, 2011), our results suggest that there is low participation of persons with ID in research, which is reflective of the low social and civil participation of persons with ID in the region.

Whilst stigma towards persons with ID appears to be common in Latin America, however, there is no information about the mediating influence of socio-demographic variables such as age and educational level. There is a lack of available information about cultural differences and specific idiosyncratic characteristics between countries.

As far as we know, this is the first systematic examination of stigma towards persons with ID in South American context. We have interrogated literature in English, Spanish and Portuguese languages to ensure that all relevant papers have been identified. We supplemented the databases search with a specific protocol to identify appropriate published data among grey material. We think this mixed approach in the search process enriched the final results. However, a degree of bias in the selections of manuscripts may have been introduced in the review process during study selection. We implemented different approaches to control for this, i.e. blind reviews and a systematic process to select documents but this bias could still be present.

In relation to the quality of research, based on the MMAT appraisal system, there is an urgent need to improve the quality of research in this field in the region.

Future research in the area of stigma towards persons with ID in South America must be conducted. A total comprehension of this phenomena, as well scientific data, will be very useful to enable researchers to design and evaluate the impact of different initiatives oriented to change the cultural attitudes towards people with ID. An increase of intellectual production in Spanish, available to general public in the South American countries is needed to increase comprehension and compromise with persons with ID.

The lack of public policies and national planning in favour of social inclusion and protection of the rights of people with ID across the South American countries should be a matter of attention for international agencies and non-profit organizations. As some authors have already suggested, there is an urgent need for political coordination to promote better conditions for persons with ID in the region (Comisión Económica para América Latina y el Caribe (CEPAL), 2012; Espejo Yaksic & Lathrop Gómez, 2019). People with ID are one of least considered groups, they are victims of all forms of violence (Fogden, Thomas, Daffern, & Ogloff, 2016; Hughes et al., 2012), and specific studies are needed to describe, understand, and combat all possible forms of stigma in South America.

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Table 1

Contextual information for each country in South America

	Gross domestic product (GDP)[1]	Total population[2]	Life expectancy[3]	Population extreme poverty[4]	Index Human Development[5]	Estimated population with disability[6]	UN CRPD year ratification
Argentina	545.9	43.8	76.5	<5%	0.82	12.9%	2008
Bolivia	33.8	10.8	69.1	23.2%	0.67	0.7%	2009
Brazil	1796	207.7	75.8	7.5%	0.75	11.5%	2008
Chile	247	17.9	80.5	<2%	0.84	20%	2008
Colombia	282.5	48.6	74.3	7.0%	0.72	6.3%	2011
Ecuador	97.8	16.4	79.9	11.7%	0.73	2.6%	2008
Guyana	3.4	0.7	66.6	No data available	0.63	6.4%	2014
Paraguay	24.4	6.7	77.2	13.6%	0.69	10%	2008
Peru	192.1	31.7	74.9	19.5%	0.74	5.2%	2008
Surinam	3.6	0.5	74.8	No data available	0.72	12.5%	2017*
Uruguay	52.4	3.4	77.4	<2%	0.79	15.8%	2009
Venezuela[7]	371.1	28.3	75.8	18.5%	0.76	5.38%	2013*

[1] Expressed in USD millions based on The World Bank Data

[2] Expressed in millions, data from the last national census available

[3] Expressed in years

[4] Data available in the International Monetary Fund (2011), based on people living with less than 1 USD per day.

[5] The Human Development Index (HDI) is a composite statistic (composite index) of life expectancy, education, and per capita income indicators, which are used to rank countries into four tiers of human development. It was designed for the United Nations Development Program (UNDP). Values closed to 1 indicated better results. Data available in UNDP (2016).

[6] Percentage of general population with disability reported by each governmental division in charge of disability in South America.

[7] General data about Venezuela needs future revisions due to the current political situation in the country.

* These countries ratified the Convention with reservations

Table 2

Specific information about studies included in this narrative review

Author	Aim	Participants	Instruments	Data analysis	Main findings	MMAT score
			Qualitative studies			
Brazil						
Segeren & de Campos Francozo (2014)	To investigate the experiences of mothers of young people with autism to identify initial reactions to the diagnosis, daily routines and social difficulties faced by them	11 mothers of adolescents with ASD	Semi structured interviews	Content analysis techniques	-Diagnosis was given comprehensively with emphasis in the expected difficulties of child development -Changes in mothers routines were necessary to care the child -Those changes included social adaptations secondary to stigma expressed towards children with ASD	3
Colombia						
Lopera-Escobar & Bastidas-Acevedo, 2018	To describe the experiences of mothers of children with Down Syndrome about the medical attention offered to their daughters and sons.	17 mothers of children with DS	Semi structured interviews	Content analysis techniques	-An identity based on the condition ("the mongolic children…") - Denial of health services for these children based on their condition with misinformation and stigma attitudes from physicians and other professionals from the health system. -Misinformation about the rights of persons with ID in all the actors (physicians, professionals and families) -Loss of hope and guilt as predominant emotions in mothers as a consequence of stigma and prejudice expressed to their children	5
Chile						
Dehays, Hichins, & Vidal (2012)	To analyse the meanings that women with Intellectual Disability (ID) give to the experiences of being a	Three females with Intellectual Disability	Semi structured interviews	Grounded theory	- For participants, the meanings about being a woman and mother are based on specific actions, this is interpreted as a consequence of low IQ by authors.	1

	woman and mother				-Family supports is perceived as a basic condition to have a good role as a mother - The intellectual disability and lack of financial support are identified as barriers.	
Cerreta (2018)	To describe the life experiences of young people with moderate to severe autism who attend specialized schools in the city of Temuco (Chile)	Two mothers and four teachers	A semi-structured interview	Grounded theory	-Mothers and teachers informed about stigma towards people with ASD expressed in public space -The authors suggested that it is possible to identify stigma towards people with ASD expressed in their families	N.F
von Furstenberg, Iriarte & Navarro (2012)	To identify the social factors that prevent the inclusion of persons with ID in regular jobs in Chile, according to the mothers point of view	62 mothers and 2 fathers of young persons with ID	Questionnaire and semi structured interviews (with 7 mothers)	Content analysis techniques	-Chilean society has problems to include persons with ID in the workplace due to social structure and negative attitudes towards this condition -The most common attitudes attributed by parents are coldness and hardness. They identify active discrimination against their sons and daughters. - The kind of jobs available for persons with ID are based on charity or goodwill but they are not based on their relative skills. -Parents remember the difficulties to find a school for the education of their sons and daughters because "(...) in Chile the schools are not prepared to receive our children". There is no official program at Universities for persons with ID in the country. -Institutional stigma is identified by parents. They express that no governmental division helped them in the process of job inclusion for their relatives.	N.F
Ecuador						
Huiracocha et al. (2013)	To identify the feelings of families of children with Down Syndrome	8 parents of children with DS	Focus group, interviews, group discussion	Descriptive coding	-The study identified stigma towards people with DS -This stigma influences the family perception and support offered to their children with DS -Specific competences should be trained in health teams	4

Huiracocha et al. (2017)	This study examined the impact of a diagnosis of DS on Ecuadorian families	8 parents of children with DS	Focus group, interviews, group discussion	Descriptive coding	- Professionals rarely communicate a DS diagnosis in an appropriate manner. - The lack of social support, and the widespread stigmatization confronting children with DS and their families, hinder development of positive and empowering adjustments that would best serve the child's and the family's interest.	4
Peru						
O'Shea et al. (2012)	To characterize public perceptions regarding intellectual disability in a peri-urban community of limited resources	12 key informants and 10 community members	A semi-structured interview	Grounded theory	- The themes derived from categories were poverty and its related concerns, lack of attention paid to ID and the role of family -Persons have difficulties to differentiate ID from mental illness -Some participants identified scientific background - Lack of resources was reported as a source of difficulties to educate a child -Attitudes are affected by personal priorities, ideology, and previous interaction with persons with ID	3
			Quantitative Studies			
			Brazil			
Greguol, Malagodi, & Carraro (2018)	To analyze the attitudes of Physical Education teachers towards the inclusion of students with disabilities in regular classes	35 physical education teachers	Teacher Inclusion Attitudes Questionnaire (TIAQ)	Descriptive data and mean comparisons	- General positive attitude to inclusion without institutional support. Low scores in skills and support items - Skills factor is related with the severity of the condition - Students with disability are well accepted by their classmates from the teacher point of view - A gender effect on Skills perception, better abilities perceived by men. - Positive correlation among time of experience and positive attitude towards inclusion	2
Colombia						

Bernal (2016)	To observe and describe implicit attitudes towards persons with DS in relatives and college students	49 participants, 20 relatives y 29 college students	Relational responding task (De Houwer et al., 2015), EPSD-1 (Molina Saorín, Nunes Corredeira, & Vallejo Ruiz, 2012).	Descriptive and inferential analysis	-No differences among groups -There was no identification of negative stereotypes or attitudes - The sample size is criticized	1
Chile						
Hartmann et al. (2018)	To explore relationships between severity of ASD traits, community supports, and other family variables as reported by caregivers.	50 caregivers of individuals with ASD	Study-specific questionnaire	Correlations	- A negative correlation between social stigma and child's overall ASD score, impairment in language and communication, difficulties in social interaction and stress	1
Sirlopú et al. (2008)	To assess if students at schools with inclusion programs will hold more positive stereotypes and attitudes toward people with Down syndrome than will students at schools without inclusion programs.	120 Chilean students, between 11 and 15 years	Questionnaire	Factor analyisis, mean comparisons	- No effects of school system on any of the stereotype measures. - Relative low level of prejudice among students -Positive attitudes toward people with DS, high levels of linking and low levels of patronizing, avoidance and rejection - Pleasure and pity scores exceed aversion scores - Major tendency to negative attitudes, prejudice and aversion among men in non-inclusive schools	3
Sirlopú et al. (2012)	To evaluate both types of attitudes towards People with Down syndrome (PWDS)	80 Chilean students, between 11 to 15 years	Implicit Association Test (IAT)	Descriptive data and mean comparisons	- No differences were found in implicit bias towards PWDS among the two groups of students - Low rates of prejudice were identified in this study - Difference on "contact anxiety" and "amount of contact" in favor to children from schools with inclusion	3

			Cross-cultural			
Luengo (2018)	To explore the language used in media from Venezuela and Argentina to talk about autism	1480 articles published in 480 national papers		Media framing theory	-Significant differences between the countries' coverage of autism in their description of issues, discourse types, sources, images, roles and stigmatizing cues -A scientific discourse type is more common in Venezuelan articles than in Argentina which focuses on human-interest stories. -Individuals with autism are quoted in less than 5% of stories from each country -Results explain why both countries perpetuate stigmatizing cues regarding labeling, psychological symptoms, social skills and physical appearance.	3
Retazzi, Valdez & Cukier (2016)	To analyze the results obtained with a multi-national survey applied in five countries in South America (Argentina, Brasil, Chile, Venezuela, Uruguay) to families of children with Autism Spectrum Disorder	2965 caregivers of children with ASD	Study-specific questionnaire	Descriptive analysis	-55% of the caregivers in Argentina informed stigma towards them and their sons and daughters with ASD. 50% had to cut hours in their work. 42% of the families informed finantial difficulties - There is no information available about the other countries	N.F
			Mixed methods			
			Argentina			
de Menil & Cohen (2009)	To describe the obstacles to the rational use of psychiatric drugs in a 1000-bed institution for people with ID.	98 patients charts, 5 hospital administrators, 2 psychiatrists,	Study-specific questionnaire	Descriptive analysis and ethnographic analysis content	-Two-thirds (67%) of individuals taking psychiatric medication, did not have a psychiatric diagnosis -Antipsychotics are more commonly prescribed than any other drugs	5

		2 nurses, 2 nurses aids, 2 patients and 1 pharmacist.			-Absence of specific training to work with persons with ID, in all the professional in the health system with emphasis in psychiatrists and psychologists (mainly educated in the psychoanalytic orientation) -In absence of training, the staff developed their our theories and ideas about ID including some like: “some patients don't require anesthesia during procedures, just like animals" The study identified structural impediments and barriers for the expression of rights of persons with ID. Violence is visible in staff and patients.	
Colombia						
Polanco-Valenzuela & Marín-Araya (2017)	To explore knowledge, attitudes and practices in fathers, mothers and caregivers of adolescents with ID	32 families of adolescents with ID	Study-specific questionnaire and semi-structure interview	Descriptive and content analysis	-The interviewees express knowledge about the rights of persons with disability. However, implementation and mechanisms to support the expression of these rights is fragile. Mothers and fathers do not recognize their daughters' and sons' abilities to take decisions about their sexuality. Attitudes are ambivalent.	4

Table 3

Included studies organised by stakeholder's groups and methodological approach

	Quantitative approach	Qualitative approach	Mixed approach
Persons with Intellectual and Developmental Disabilities		Dehays, Hichins, & Vidal (2012)	de Menil & Cohen, (2009)
Families and caregivers	Bernal (2016)	Segeren & de Campos Francozo (2014)	Polanco-Valenzuela & Martín-Ayala (2017)
	Hartmann et al. (2018)	Lopera-Escobar & Bastidas-Acevedo (2018)	
		Cerreta (2018)	
	Ratazzi, Valdez, & Cukier (2016)	Furstenberg, Iriarte, & Navarro (2012)	
		Huiracocha et al. (2013)	
		Huiracocha et al. (2017)	
		O'Shea, Maziel Girón, Cabrera, Lescano, & Taren (2012)	
Mental health workers			de Menil & Cohen (2009)
Community members	Gregoul, Malagodi, & Carraro (2018)		
	Sirlopú et al. (2008)		
	Sirlopú et al. (2012)		