



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

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

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

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.

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

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

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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

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3 of essential rights, and direct acts of discrimination, among other consequences (Arboleda
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5 Flórez, 2005; Drew et al., 2011).

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8 Across the world, minority groups are victims of both stigma and prejudice (Knesebeck,
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10 Kofahl, & Makowski, 2017), and some of those groups have received more attention in research
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12 than others. People with IDD have been identified as one of the least desirable groups in society
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14 (Ali, King, Strydom, & Hassiotis, 2015), and several studies demonstrated that people with ID
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16 are subject to different forms of stigma including public, courtesy, and self-perceived (Werner,
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18 2015; Scior, Addai-Davis, Kenyon, & Sheridan, 2012; Ali, Hassiotis, Strydom, & King, 2012;
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20 Scior, 2011). Public stigma refers to the general public's response towards people with IDD as a
21
22 result of negative attitudes and prejudice (Scior, 2011; Walker & Scior, 2013; Werner, 2015).

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26 Courtesy stigma affects the closest family members, friends, and professionals that work with a
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28 person with ID who may develop negative self-evaluations and emotions related with the
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30 condition (Ali, Hassiotis, Strydom, & King, 2012; Birenbaum, 1992; Birenbaum, 1970). Self-
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32 perceived stigma refers to the extent to which a person with ID is aware of stigma and
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34 discrimination from the public or from individuals (O'Byrne & Muldoon, 2017; Ali et al., 2012;
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36 Corrigan, Watson, & Barr, 2006).

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

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3 However, these actions are insufficient as explicit and implicit negative attitudes towards
4 people with IDD are still prevalent in society (Scior, 2011; Wilson & Scior, 2015). Furthermore,
5
6 other disparities arise when considering the social and geopolitical position of people with IDD.
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10 Studies of the different forms of stigma towards people with IDD have been conducted
11
12 mostly in high-income countries. People with IDD who report feeling stigmatised are more likely
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14 to have symptoms of anxiety and depression, a lower quality of life, and increased contacts with
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16 social services and the police (Ali et al., 2015). Some authors suggest that, in particular, self-
17
18 perceived stigma could be a precursor for victimisation and loneliness in the presence of mental
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20 illness (Gilmore & Cuskelly, 2014; Horsseelenberg, van Busschbach, Aleman, & Pijnenborg,
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22 2016).
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26 Little is known about the expression and consequences of stigma in middle or low-
27
28 income countries. Previous studies conducted in South-Asia (Abraham, Gregory, Wolf, &
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30 Pemberton, 2002; Azmi, Hatton, Emerson, & Caine, 1997; Edwardraj, Mumtaj, Prasad,
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32 Kuruvilla, & Jacob, 2010) and Africa (Ali et al., 2015; Kock et al., 2012) suggest that cultural
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34 characteristics influence the social expression of stigma and prejudice, which are moderated by
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36 variables such as religion, personal beliefs about the origin of the condition or previous contact
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38 with persons with IDD. However, given the paucity of research in many regions including Latin
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40 America, conclusive actions cannot be achieved due to lack of engagement with the topic at
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42 population level (Ali et al., 2015; Ali et al., 2016; Hatzenbuehler, Phelan, & Link, 2013).
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46 New studies are needed to clarify the cultural impact of the expression of stigma towards
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48 people with IDD and more countries should promote such research to gain a wider, global
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50 comprehension of the problems and the formulation of policies to improve the lives and
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52 acceptance of people with IDD over the life course.
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3 South America is a region extending from the Caribbean in the north to the Antarctic
4 region in the south and formed by twelve countries (Colombia, Ecuador, Venezuela, Guyana,
5 Suriname, Peru, Brazil, Chile, Argentina, Uruguay, Paraguay, and Bolivia). It has a total
6 population of approximately 600 million with significant cultural differences between countries.
7 Most of the countries are lower-middle or upper-middle income, except for Argentina, Chile and
8 Uruguay classified as high-income economies (World Bank, 2018). Some countries in the region
9 though they have an established economy in terms of the gross national product and other macro-
10 economic variables (as Chile and Brazil, for example), yet they are still considered developing
11 countries because of the low standards of living and human development index (Frey & Temple,
12 2008). In addition, social inequality, characterised by problems with capital distribution, access
13 to social services, education, health, and opportunities, is a major challenge experienced by all
14 South American countries. As a consequence, socio-economic status is a pivotal variable for
15 social research in the region (Central Intelligence Agency, 2017; Gapminder, 2017). Specific
16 information about the geopolitical status for each of the South American countries, as well as the
17 estimated population of people with disability, is presented in Table 1 to provide context to the
18 review.
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43 Several South American countries, have a history of political instability secondary to the
44 military coups during the 20th century i.e. Colombia in 1953, Argentina in 1976, Chile in 1973,
45 Uruguay in 1973, Paraguay in 1989, Brazil in 1964, and Peru in 1992, with well documented
46 human rights violations (Sikkink & Walling, 2007). Political violence and human rights
47 violations have morphed into social violence (Oxhorn & Jouve-Martín, 2017).
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3 The global prevalence of IDD, and specifically for ID, is unknown due to technical and
4 political factors such as problems with surveillance systems, differences in how the condition is
5 defined, or lack of governmental programs oriented towards ascertainment. Current data suggests
6 that in Latin America (Central America, the Caribbean and South American countries), 13.8
7 million people have IDD (PAHO, 2012). As far as we know, there is no specific prevalence rate
8 of IDD available for the South American region only.
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12 People with IDD are common victims of violence, e.g. they are at high risk of being
13 victims of hate crimes, social rejection, violations of rights, and lack of opportunities (Mikton,
14 Maguire, & Shakespeare, 2014; Sherry, 2010). They are likely to suffer inequalities in social
15 care, health and education (Ali et al., 2013; Hassiotis, Barron, & O'Hara, 2000; Rimmer, 1999);
16 they are at a disadvantage in the judicial process and, in general, they have worse quality of life
17 than people without disability in the same territory (i.e. Ncube, Perry, & Weiss, 2018).
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21 The aim of this paper is to present a narrative review of the expression of stigma and
22 prejudice towards people with ID in South America. In this review, we focus on studies relating
23 to stigma towards people with ID only although some may have comorbid conditions. We hope
24 that this work will help to improve the scientific research on the topic in South America and will
25 be relevant to a wide range of stakeholders including professionals, policy makers and Not-for-
26 Profit organisations working with disability groups.
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28 **Method**

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31 In this review, we considered evidence available in catalogued journals and the grey
32 literature, including academic theses, organisation reports, government papers, etc. (Haddaway,
33 Collins, Coughlin, & Kirk, 2015).
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3 We used the 27-item checklist recommended by the Preferred Reporting Items for
4 Systematic Reviews and Meta-Analyses (PRISMA) to assess studies included in the review
5 (Moher, Liberati, Tetzlaff, Altman, & Group, 2009). The four-phase diagram recommended by
6 PRISMA group and that included identification process, screening, eligibility and definition of
7 included studies, was adapted for the study (Moher et al., 2009).
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12 The protocol recommended by Haddaway et al. (2015) to conduct systematic reviews in
13 Google Scholar was implemented for the grey literature search.
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17 The Mixed Method Appraisal Tool version 2018 (MMAT), (Hong et al., 2008) was used
18 to critically appraise the methodological quality of the included studies.
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21 22 23 **Information sources**

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26 Five databases (Web of Science, EBSCO, Scopus, PubMed and LiLACS) were used for
27 the literature search. In all cases, the date range was fixed from 2008 to 2019. There is no
28 consensus about ideal range of dates for a systematic review (Cooper, Booth, Varley-Campbell,
29 Britten, & Garside, 2018; Liberati et al., 2009), this date range was considered relevant based on
30 the period in which countries in South America ratified the Convention on the Rights of Persons
31 with Disabilities (CRPD). The search was conducted in March 2019, information from the first
32 ten pages of Google was considered at title and text level.
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41 42 43 **Search strategy**

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45 We included search terms which had been used in previous systematic reviews about
46 stigma in the English language and we supplemented those by additional terms that have been
47 used in Spanish and Portuguese reviews. We chose these terms in order to replicate what has
48 been carried out in previous reviews, as well as to integrate new sources of information.
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3 Search terms related to ID, were combined with stigma, prejudice, attitudes and
4 stereotypes, and with the names of all the South American countries. Due to the known
5 relationship between ID and Autism Spectrum Disorder, this term was included in the search.
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9 We conducted the search in English, Spanish, and Portuguese as follows:
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12 Neurodevelopmental disorder OR developmental disorder OR learning disorder OR learning
13 disability OR mental retardation OR intellectual disability OR autism OR down syndrome
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16 AND stigma OR prejudice OR stereot* OR attitude
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19 AND Latin America OR South America OR Colombia OR Venezuela OR Guyana OR
20 Suriname OR Ecuador OR Bolivia OR Peru OR Brazil OR Chile OR Argentina OR Uruguay OR
21 Paraguay.
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26 The Spanish and Portuguese terms selected for clinical conditions were the same as those
27 used in English with the corresponding translation. At the level of stigma, the search in Spanish
28 also included “imaginario”, a common term used in Colombia to describe idiosyncratic ideas
29 about something. “Imaginario” corresponds to stereotyped ideas about groups of individuals that
30 may be held due to particular political or social views.
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34 The inclusion criteria for the studies were: (a) an explicit mention of ID in any part of the
35 manuscript; (b) an explicit mention of one of the key components of stigma (attitude, stereotype,
36 prejudice, and discrimination) and; (c) the study was conducted in South America. Exclusion
37 criteria considered: (a) mention of conditions not included in the search terms; (b) focus on
38 stigma towards medical conditions such as HIV/AIDS, Epilepsy, Leprosy or Tuberculosis
39 (frequent topics of interest in the region); (c) lack of relation to stigma; and (d)) studies of
40 immigrant populations that are not native to South America as these groups are likely to hold
41 different cultural values that might influence the expression of stigma.
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3 The final selection of manuscripts was reviewed and validated independently by two of
4 the authors and an expert in statistical analysis with a third author arbitrating any disagreements
5 that could not be resolved by the reviewers.
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10 The MMAT approach was applied by two independent reviewers and in those cases
11 where there was disagreement, a third person arbitrated the decision.
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14 **Results**

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17 The results are summarised in Figure 1, and in Figure 2 following the PRISMA
18 flowchart (Moher et al., 2009).
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27 Seventeen papers were retained in this review and are presented in Table 2. The MMAT
28 algorithm was used to classify the studies according to their methodological approach. Eight
29 studies used a qualitative approach to answer the research questions, seven used a quantitative
30 approach, and two used a mixed methods approach. For two qualitative studies (Cerreta, 2018;
31 Furstenberg, Iriarte, & Navarro, 2012) and one quantitative study (Retazzi, Valdez & Cukier,
32 2016) the MMAT approach was not feasible. However, these studies were included because the
33 MMAT authors point out that excluding studies with low methodological quality is discouraged.
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42 Eleven percent (11%) of the studies obtained the maximum MMAT score (5 points): one
43 qualitative study (Lopera-Escobar, Bastidas-Acevedo, & Lopera Escobar, 2018) and one of the
44 mixed methods study (de Menil & Cohen, 2009). Thirty-five percent (35%) of the studies
45 obtained a MMAT score of 4 points and the remaining fifty four percent (54%) of the studies
46 scored 3 or fewer points on quality.
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3 In terms of content, twelve studies explored stigma, attitudes or prejudice towards
4 persons with ID (including towards people with Down Syndrome) and five studies explored
5 stigma towards people with ID and ASD (the specific target population for each study is
6 available in Table 2).
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12 The majority of the included studies were conducted in Chile (35.2%) and Colombia
13 (17.6%). The remainder (47.2%) were from Brazil (11.7%), Ecuador (11.7%), Peru (5.8%) and
14 Argentina (5.8%). Cross-cultural data are available in 11.7% of the included studies. No studies
15 from Bolivia, Guyana, Suriname, Paraguay or Uruguay were found in the search process. Table 2
16 presents the specific country included in each study.
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26 The narrative synthesis has been organised to present the reported perspective of four
27 stakeholder groups: persons with ID; family and caregivers; mental health professionals; and
28 community members (Table 3). Ten studies were conducted with families and caregivers, three
29 studies considered community members (students and teachers); two with persons with IDD, and
30 one with mental health workers.
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40 **Attitudes and beliefs about ID perceived by persons with this condition**

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

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5 Furthermore, they report that in some cases their families replace them as decision-makers in the
6
7 process of raising their own children.
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10 The main goal of the other study (de Menil & Cohen, 2009) was to describe the obstacles for the
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12 rational use of psychiatric drugs in a 1000-bed institution for persons with IDD called *La*
13
14 *Colonia*, in Argentina. Authors used patients' charts to present descriptive data about the medical
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16 situation of the persons who are living in La Colonia and about the institution. They refer to the
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18 use of an ethnographic approach to collect qualitative data from fourteen individuals that
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20 included administrators, two psychiatrists, two nurses, two nurses' aids, two inpatients with ID,
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22 and one pharmacist. However, in the results and discussion sections the text refers mostly to
23
24 staff, ignoring the views of people with ID. The authors mainly mentioned violations of human
25
26 rights, and expression of stigma by caregivers and mental health workers; these results will be
27
28 further discussed in the section about attitudes and beliefs about IDD in that group.
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32 33 **Attitudes and beliefs about ID perceived by families and caregivers**

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35 The first quantitative study was the Caregiver Needs Survey completed by 2965 relatives of
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37 persons with ASD in Argentina, Brazil, Chile, Uruguay, Venezuela and Dominican Republic
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39 General. Information about this survey was presented in a congress abstract (Retazzi, Valdez &
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41 Cukier, 2016). We searched for the original work and part of the results are available in "La
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43 Nación", an Argentinian national newspaper. According to the survey, families of persons with
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45 ASD in Argentina perceived stigma towards their relatives as a consequence of the diagnosis
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47 and reported higher levels of stigma when ID was present in co-occurrence with behavioural
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49 problems. Fifty-five percent of caregivers reported that they thought their sons and daughters
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51 were stigmatised, 50% reported the need to work fewer hours to take care of their relatives and
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3 42% experienced financial difficulties as an indirect consequence of the diagnosis because they
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5 have to pay for special services. We were unable to find data from the other countries included
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7 in this survey.
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10 The second quantitative study included data from research which described implicit attitudes
11 towards persons with DS. In this study, authors compared implicit attitudes towards DS
12 expressed in relatives of persons with DS and the implicit attitudes towards the condition
13 presented by college students in Colombia (Bernal, 2016). The data were collected with the
14 Relational Responding Task (De Houwer et al., 2015) and the Escala de Pecepción Social Hacia
15 Las Personas Con Síndrome de Down (Scale About Perceptions Towards People With Down
16 Syndrome, EPSD-1) (Molina Saorín, Nunes Corredeira & Vallejo Ruíz, 2012). In this study, a
17 group of twenty relatives was compared with a group of twenty-nine college students. Based on
18 the hypothesis that previous contact is associated with more positive attitudes, the authors
19 expected lower negative attitudes and perceptions towards people with DS in relatives. Results
20 showed no differences among groups (college students vs relatives) in relation to negative
21 stereotypes or attitudes towards persons with DS. A possible explanation of the findings maybe
22 the small sample size.
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40 The third quantitative study was conducted in Chile and explored the relationship between
41 the severity of symptoms in children with ASD and other family characteristics, including
42 stigma (Hartmann et al., 2018). With a study-specific questionnaire, the authors found a
43 negative correlation between social stigma and overall ASD severity score in general functions,
44 language impairment, difficulties for social interaction and stress.
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51 Two Ecuadorian studies included parents of children with DS, exploring the feelings of
52 families towards DS (Huiracocha et al., 2013) and the impact of diagnosis (Huiracocha et al.,
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3 2017). Both studies included the same number of participants (seven mothers and one father)
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5 and found that the parents were aware of stigma towards their child in Ecuador. The authors
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7 suggest that stigma influences the parents' perception about the capability of their children and
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9 the importance of support in light of participants reporting lack of social support, widespread
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11 stigmatization, and institutionalised stigma mainly expressed among physicians.
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15 In Chile, one study explored the life experiences of young people with ID and ASD in
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17 Temuco, a small city in the south of the country, based on two mothers' perceptions of their
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19 young son's and daughter's lives (Cerreta, 2018). A second study (von Furstenberg, Iriarte &
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21 Navarro, 2012) identified social factors that prevent the inclusion of people with ID in regular
22
23 jobs in Santiago (capital of Chile) based on the opinions of the mothers. Both studies concluded
24
25 that it is possible to identify stigma towards persons with IDD in Chile. The study goes beyond
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27 this affirmation and suggests: (a) that Chilean society has difficulties in including persons with
28
29 ID due to existing social structures and negative attitudes towards this condition; (b) the most
30
31 common parental attitudes are lack of affection and warmth towards their sons and daughters,
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33 which may be a form of active discrimination; (c) the highly segregated educational system of
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35 the country (Arango, Aparicio, & Tenorio, 2018) and the scarce governmental resources
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37 available to support people with ID, are major barriers to inclusion.
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43 One Brazilian study investigated the experiences of mothers of young people with ID and
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45 ASD. They explored the mothers' initial reactions to the diagnosis of autism; the difficulties that
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47 children encountered during adolescence and the mothers' expectations about the child's future
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49 (Segeren & de Campos Francozo, 2014). The mothers stated that they had to change their
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51 routines by avoiding public places due to their child's behavioural problems, which were
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53 perceived negatively by the public, resulting in social stigmatisation and exclusion.
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3 In Colombia, Lopera-Escobar & Bastidas-Acevedo (2018) describe the experiences of
4 mothers of children with DS about the medical attention offered to their children. Participants
5 complained that in the health system in Colombia, the identity of their child is based on the
6 condition (with common expressions as: “*the Mongolic children...*”). They also talked about the
7 difficulties in accessing health services for the child’s condition, with misinformation and
8 stigmatising attitudes from physicians and other health workers. For example, one of the
9 participants reported that “*With the neurologists I had a very bad experience. I needed the*
10 *authorization for therapies, but he denied it because, according with him, this kind of child*
11 *doesn’t need that*”. An important finding was the participants’ perceived lack of information
12 about rights of persons with DS and the loss of hope and feelings of guilt were prevalent
13 emotions amongst families of children with DS in Colombia.
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28 Also, in Colombia, but with a mixed method approach, Polanco-Valenzuela & Marín-Araya
29 (2017) explored the knowledge, attitudes and practices in terms of decisions in fathers, mothers
30 and caregivers of adolescents with ID, with an emphasis on sexuality. The main finding is that
31 participants were knowledgeable about the rights of persons with ID; however, the
32 implementation and the use of mechanisms to support the expression of sexuality was limited
33 because families and caregivers failed to recognise their children’s capacity to make decisions
34 regarding their sexuality. Mothers and father report ambivalence towards their child’s emerging
35 sexuality.
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47 **Mental health workers attitudes and beliefs about ID**

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

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28 Among the quantitative studies, one was carried out in Brazil (Gregoul, Malagodi &
29 Carraro, 2018) with physical education teachers. The Teacher Inclusion Attitudes Questionnaire
30 was used to collect data from 35 Physical Education teachers. Findings suggested the presence of
31 a general positive attitude to inclusion, but a lack of institutional support. Teachers perceived that
32 students with ID were well accepted by their classmates. They also reported gender differences
33 attributing better abilities to male students. There was a positive correlation between the number
34 of years of experience of teaching children with special needs and positive attitudes towards their
35 inclusion.
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47 There were two quantitative studies that were conducted in two types of schools in Chile
48 and explored attitudes (explicit and implicit) towards children with DS (Sirlopú et al., 2008;
49 Sirlopú et al., 2012). In these studies, authors presented overlapping data. One study collected
50 data on implicit and explicit attitudes towards other students with DS from 80 students without
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3 disability attending 4 schools in Santiago (2 with an inclusion program and 2 without) (Sirlopú et
4 al., 2012). In the other study (Sirlopu et al., 2008), data were collected with 120 students without
5 ID from four schools (2 with an inclusion program and 2 without). In both of these studies, the
6 authors concluded that the type of school did not have an impact on the prejudice, attitudes and
7 general perceptions of typically developing children towards children with DS. They argued that
8 the attitudes were generally positive. However, an interaction was found between gender and
9 type of school with more prejudice and negative attitudes in males who attended schools without
10 inclusion programs.
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21 Finally, the study conducted with a mixed approach (de Menil & Cohen, 2009) informed
22 about the inclusion of community members in their sample. Accordingly with the authors, they
23 conducted interviews with some community members at La Colonia but results related with this
24 interviews is not presented in the manuscript.
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30 **Discussion**

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32 Stigma is considered one of the most important concerns of our era, especially in relation
33 to conditions such as HIV, leprosy, and mental illness. However, scant attention has been paid to
34 stigma towards people with ID, even when it affects an estimated of 300 million people globally
35 (Scior et al., 2016). The results of the narrative review are indicative of the limited scientific
36 study of stigma towards people with ID in South American countries and the clear sense that
37 people with ID living in those countries report experience of stigmatising attitudes.
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46 The published studies identified for this narrative review are mainly qualitative. None of
47 the studies included a large sample. Families and caregivers are the most frequent stakeholder
48 group studied. The most important finding is the lack of studies including participants with ID
49 and their personal experiences of stigma and discrimination. This suggests that there is low
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3 participation of persons with ID in research, which is reflective of the low social and civil
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5 participation of persons with ID in the region.
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8 Whilst stigma towards persons with ID appears to be common in Latin America,
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10 however, there is no information about the mediating influence of socio-demographic variables
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12 such as age and educational level. There is a lack of available information about cultural
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14 differences and specific idiosyncratic characteristics between countries.
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18 Specific public policy about ID in the region is scarce and this seems to be a consequence
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20 of social and institutionalised stigma towards this groups. A closer inspection of legislative
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22 statements regarding people with ID shows that some of the countries have formulated specific
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24 statements declaring that an adult with ID does not have legal capacity (referred as the capacity
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26 of a person to exert rights and duties according to each national legislation), and that specific
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28 indications are available about school inclusion. The available policies have not been updated
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30 since they were written, and they still use pejorative terminology, failing to incorporate a rights-
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32 based approach to laws affecting people with ID (Silva, 2017). The reports presented by the
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34 United Nations about the process to incorporate changes in the legislation according with the
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36 CRPD suggested the need to take more clear actions in favour to persons with disability in the
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38 region (i.e. United Nations, 2016).
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43 News and social media in general are one of the most important sources of documenting
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45 rights violations and stigma towards people with ID in South America. A recent example in the
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47 Chilean context is about the current scandal in the “looked-after children” program, where videos
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49 were disseminated via social media showing physical maltreatment of children from paid
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51 caregivers. These types of headlines are frequent, but due to the scarcity of research in the area
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3 as well as the lack of general and political interest, there is little action taken by governments to
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5 deal with this situation.
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8 As far as we know, this is the first systematic examination of stigma towards persons with ID
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10 in the South American context. We have interrogated literature in English, Spanish and
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12 Portuguese languages to ensure that all relevant papers have been identified. We supplemented
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14 the databases search with a specific protocol to identify appropriate published data among grey
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16 material. We think this mixed approach in the search process enriched the final results. However,
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18 a degree of bias in the selections of manuscripts may have been introduced in the review process
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20 during study selection. We implemented different approaches to control for this, i.e. blind
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22 reviews and a systematic process to select documents but this bias could be still present.
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26 In relation to the quality of research, based on the MMAT appraisal system, there is an
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28 urgent need to improve the quality of research in this field in the region.
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31 Future research in the area of stigma towards persons with ID in South America must be
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33 conducted. A total comprehension of this phenomena, as well scientific data, will be very useful
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35 to enable researchers to design and evaluate the impact of different initiatives oriented to change
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37 the cultural attitudes towards people with ID. An increase of intellectual production in Spanish,
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39 available to general public in the South American countries is needed to increase comprehension
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41 and compromise with persons with ID.
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45 The lack of public policies and national planning in favour of social inclusion and
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47 protection of the rights of people with ID across the South American countries should be a matter
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49 of attention for international agencies and non-profit organizations. As some authors have
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51 already suggested, there is an urgent need for political coordination to promote better conditions
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53 for persons with ID in the region. People with ID are one of least considered groups, they are
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3 victims of all forms of violence (Fogden, Thomas, Daffern, & Ogloff, 2016; Hughes et al.,
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5 2012), and specific studies are needed to describe, understand, and combat all possible forms of
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7 stigma in South America.
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10 **References**

- 11
12 Abraham, C., Gregory, N., Wolf, L., & Pemberton, R. (2002). Self-esteem, stigma and
13
14 community participation amongst people with learning difficulties living in the community.
15
16 *Journal of Community & Applied Social Psychology, 12*(6), 430–443.
17
18 <https://doi.org/10.1002/casp.695>
19
20
21 Bernal, M.J. (2016). *Actitudes implícitas y síndrome de Down 2 Tabla de Contenido*. Retrieved
22
23 from
24
25 [https://repository.javeriana.edu.co/bitstream/handle/10554/21350/BernalGiraldoMariaJose2](https://repository.javeriana.edu.co/bitstream/handle/10554/21350/BernalGiraldoMariaJose2016.pdf?sequence=1&isAllowed=y)
26
27 [016.pdf?sequence=1&isAllowed=y](https://repository.javeriana.edu.co/bitstream/handle/10554/21350/BernalGiraldoMariaJose2016.pdf?sequence=1&isAllowed=y)
28
29
30
31 Ali, A., Kock, E., Molteno, C., Mfiki, N., King, M., & Strydom, A. (2015). Ethnicity and self-
32
33 reported experiences of stigma in adults with intellectual disability in Cape Town, South
34
35 Africa. *Journal of Intellectual Disability Research, 59*(6), 530–540.
36
37 <https://doi.org/10.1111/jir.12158>
38
39
40 Ali, A., Hassiotis, A., Strydom, A., & King, M. (2012). Self stigma in people with intellectual
41
42 disabilities and courtesy stigma in family carers: A systematic review. *Research in*
43
44 *Developmental Disabilities, 33*(6), 2122–2140. <https://doi.org/10.1016/j.ridd.2012.06.013>
45
46
47 Ali, A., King, M., Strydom, A., & Hassiotis, A. (2015). Self-reported stigma and symptoms of
48
49 anxiety and depression in people with intellectual disabilities: Findings from a cross
50
51 sectional study in England. *Journal of Affective Disorders, 187*, 224–231.
52
53 <https://doi.org/10.1016/j.jad.2015.07.046>
54
55
56
57
58
59
60

1
2
3 Ali, A., King, M., Strydom, A., & Hassiotis, A. (2016). Self-reported stigma and its association
4 with socio-demographic factors and physical disability in people with intellectual
5
6 with socio-demographic factors and physical disability in people with intellectual
7
8 disabilities: results from a cross-sectional study in England. *Social Psychiatry and*
9
10 *Psychiatric Epidemiology*, 51(3), 465–474. <https://doi.org/10.1007/s00127-015-1133-z>

11
12 Ali, A., Scior, K., Ratti, V., Strydom, A., King, M., & Hassiotis, A. (2013). Discrimination and
13
14 Other Barriers to Accessing Health Care: Perspectives of Patients with Mild and Moderate
15
16 Intellectual Disability and Their Carers. *PLoS ONE*, 8(8), e70855.
17
18 <https://doi.org/10.1371/journal.pone.0070855>

19
20
21 Allport, G. W. (1954). *The nature of prejudice*. Garden City, NY: Doubleday.

22
23 American Association on Intellectual and Developmental Disabilities. (2010). *Intellectual*
24
25 *disability : definition, classification, and systems of supports*. American Association on
26
27 Intellectual and Developmental Disabilities.
28
29

30
31 American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental*
32
33 *Disorders: DSM-5*. Arlington, VA: American Psychiatric Association.

34
35 Arango, P. S., Aparicio, A., & Tenorio, M. (2018). Developmental trajectories of children with
36
37 Down syndrome by socio-economic status: the case of Latin America. *Journal of*
38
39 *Intellectual Disability Research*, 62(9), 759–774. <https://doi.org/10.1111/jir.12516>

40
41 Arboleda Flórez, J. (2005). Stigma and discrimination: an overview. *World Psychiatry*, 4(Suppl
42
43 1), 8. Retrieved from [http://sfx.hbz-](http://sfx.hbz-nrw.de/sfx_due?sid=google&auinit=J&aulast=Arboleda-Flórez&atitle=Stigma and discrimination%3A an overview&title=The world&volume=4&issue=Suppl 1&date=2005&spage=8&issn=1723-8617)
44
45 [nrw.de/sfx_](http://sfx.hbz-nrw.de/sfx_due?sid=google&auinit=J&aulast=Arboleda-Flórez&atitle=Stigma and discrimination%3A an overview&title=The world&volume=4&issue=Suppl 1&date=2005&spage=8&issn=1723-8617)
46
47 [due?sid=google&auinit=J&aulast=Arboleda-Flórez&atitle=Stigma and](http://sfx.hbz-nrw.de/sfx_due?sid=google&auinit=J&aulast=Arboleda-Flórez&atitle=Stigma and discrimination%3A an overview&title=The world&volume=4&issue=Suppl 1&date=2005&spage=8&issn=1723-8617)
48
49 [discrimination%3A an overview&title=The world&volume=4&issue=Suppl](http://sfx.hbz-nrw.de/sfx_due?sid=google&auinit=J&aulast=Arboleda-Flórez&atitle=Stigma and discrimination%3A an overview&title=The world&volume=4&issue=Suppl 1&date=2005&spage=8&issn=1723-8617)
50
51 [1&date=2005&spage=8&issn=1723-8617](http://sfx.hbz-nrw.de/sfx_due?sid=google&auinit=J&aulast=Arboleda-Flórez&atitle=Stigma and discrimination%3A an overview&title=The world&volume=4&issue=Suppl 1&date=2005&spage=8&issn=1723-8617)

52
53
54 Azmi, S., Hatton, C., Emerson, E., & Caine, A. (1997). Listening to Adolescents and Adults with
55
56
57
58
59
60

1
2
3 Intellectual Disabilities from South Asian Communities. *Journal of Applied Research in*
4 *Intellectual Disabilities*, 10(3), 250–263. <https://doi.org/10.1111/j.1468->
5
6 3148.1997.tb00020.x
7

8
9
10 Birenbaum, A. (1992). Courtesy stigma revisited. *Mental Retardation*, 30(5), 265–268. Retrieved
11
12 from <http://www.ncbi.nlm.nih.gov/pubmed/1435279>
13

14 Birenbaum, A. (1970). On Managing a Courtesy Stigma. *Journal of Health and Social Behavior*,
15
16 11(3), 196. <https://doi.org/10.2307/2948301>
17

18
19 Central Intelligence Agency. (2017). Country comparison: GDP - per capita (ppp). Retrieved
20
21 April 21, 2017, from <https://www.cia.gov/library/publications/the-world->
22
23 [factbook/rankorder/2004rank.html](https://www.cia.gov/library/publications/the-world-factbook/rankorder/2004rank.html)
24

25
26 Cerreta, S. (2018). Vivencias de jóvenes con autismo de la ciudad de Temuco, desde la
27
28 percepción de sus familiares y educadores / Experiences of young people with autism in the
29
30 city of Temuco, from the perception of their relatives and educators. *Independent Study*
31
32 *Project (ISP) Collection*. Retrieved from
33
34 https://digitalcollections.sit.edu/isp_collection/2895
35
36

37
38 Coles, S., & Scior, K. (2012). Public Attitudes towards People with Intellectual Disabilities: A
39
40 Qualitative Comparison of White British & South Asian People. *Journal of Applied*
41
42 *Research in Intellectual Disabilities*, 25(2), 177–188. <https://doi.org/10.1111/j.1468->
43
44 3148.2011.00655.x
45

46
47 Cooper, C., Booth, A., Varley-Campbell, J., Britten, N., & Garside, R. (2018). Defining the
48
49 process to literature searching in systematic reviews: a literature review of guidance and
50
51 supporting studies. *BMC Medical Research Methodology*, 18(1), 85.
52
53 <https://doi.org/10.1186/s12874-018-0545-3>
54
55

- 1
2
3 Corrigan, P. W., Watson, A. C., & Barr, L. (2006). The self-stigma of mental illness:
4
5 implications for self-esteem and self-efficacy. *Journal of Social and Clinical Psychology*,
6
7 25(9), 875–884. Retrieved from
8
9 <https://guilfordjournals.com/doi/pdf/10.1521/jscp.2006.25.8.875>
10
11
12 Dang, M. T. (2010). The History of Legislation and Regulations Related to Children With
13
14 Developmental Disabilities. *The Journal of School Nursing*, 26(4), 252–259.
15
16 <https://doi.org/10.1177/1059840510368162>
17
18
19 de Menil, V., & Cohen, A. (2009). Rational Use and Rationale for Use: Psychiatric Medication
20
21 at an Argentine Institution for Intellectual Disability. *Transcultural Psychiatry*, 46(4), 651–
22
23 671. <https://doi.org/10.1177/1363461509351377>
24
25
26 Dehays P., M., Hichins A., M., & Vidal C., V. (2012). Análisis del significado de las
27
28 ocupaciones atribuidas a ser mujer y madre para mujeres con discapacidad intelectual en la
29
30 ciudad de Punta Arenas. *Revista Chilena de Terapia Ocupacional*, 12(2), 1–13.
31
32 <https://doi.org/10.5354/0719-5346.2012.25301>
33
34
35 Drew, N., Funk, M., Tang, S., Lamichhane, J., Chávez, E., Katontoka, S., ... Saraceno, B.
36
37 (2011). Human rights violations of people with mental and psychosocial disabilities: an
38
39 unresolved global crisis. *The Lancet*, 378(9803), 1664–1675. [https://doi.org/10.1016/S0140-](https://doi.org/10.1016/S0140-6736(11)61458-X)
40
41 [6736\(11\)61458-X](https://doi.org/10.1016/S0140-6736(11)61458-X)
42
43
44 Edwardraj, S., Mumtaj, K., Prasad, J. H., Kuruvilla, A., & Jacob, K. S. (2010). Perceptions about
45
46 intellectual disability: a qualitative study from Vellore, South India. *Journal of Intellectual*
47
48 *Disability Research*, 54(8), 736–748. <https://doi.org/10.1111/j.1365-2788.2010.01301.x>
49
50
51 Fogden, B. C., Thomas, S. D. M., Daffern, M., & Ogloff, J. R. P. (2016). Crime and
52
53 victimisation in people with intellectual disability: a case linkage study. *BMC Psychiatry*,
54
55
56
57
58
59
60

- 1
2
3 16(1), 170. <https://doi.org/10.1186/s12888-016-0869-7>
4
5 Frey, G. C., & Temple, V. A. (2008). Health promotion for Latin Americans with intellectual
6
7 disabilities. *Salud Publica Mexicana*, 50, Suppl 2:s167-77.
8
9
10 Fujiura, G. T., Park, H. J., & Rutkowski-Kmitta, V. (2005). Disability Statistics in the
11
12 Developing World: A Reflection on the Meanings in our Numbers. *Journal of Applied*
13
14 *Research in Intellectual Disabilities*, 18(4), 295–304. <https://doi.org/10.1111/j.1468->
15
16 [3148.2005.00268.x](https://doi.org/10.1111/j.1468-3148.2005.00268.x)
17
18
19 Furstenberg, M. T. von, Iriarte, F., & Navarro, D. (2012). Búsqueda e inclusión laboral de
20
21 personas con discapacidad cognitiva en Chile: una mirada desde sus madres. *Revista*
22
23 *Chilena de Terapia Ocupacional*, 12(1), ág. 17-31.
24
25
26 Gapminder. (2017). GINI coefficient.
27
28 Gilmore, L., & Cuskelly, M. (2014). Vulnerability to Loneliness in People with Intellectual
29
30 Disability: An Explanatory Model. *Journal of Policy and Practice in Intellectual*
31
32 *Disabilities*, 11(3), 192–199. <https://doi.org/10.1111/jppi.12089>
33
34
35 Goffman, E. (1963). *Stigma: notes on the management of spoiled identity*. New York, NY:
36
37 Simon and Schuster.
38
39
40 Gregoul, M., Malagodi, B. M., & Carraro, A. (2018). Inclusão de Alunos com Deficiência nas
41
42 Aulas de Educação Física: Atitudes de Professores nas Escolas Regulares1. *Revista*
43
44 *Brasileira de Educação Especial*, 24(1), 33–44. <https://doi.org/10.1590/s1413->
45
46 [65382418000100004](https://doi.org/10.1590/s1413-65382418000100004)
47
48
49 Haddaway, N. R., Collins, A. M., Coughlin, D., & Kirk, S. (2015). The Role of Google Scholar
50
51 in Evidence Reviews and Its Applicability to Grey Literature Searching. *PLOS ONE*, 10(9),
52
53 e0138237. <https://doi.org/10.1371/journal.pone.0138237>
54
55
56
57
58
59
60

- 1
2
3 Hamdani, Y., Ary, A., & Lunsy, Y. (2017). Critical Analysis of a Population Mental Health
4 Strategy: Effects on Stigma for People With Intellectual and Developmental Disabilities.
5
6 *Journal of Mental Health Research in Intellectual Disabilities*, 10(2), 144–161.
7
8 <https://doi.org/10.1080/19315864.2017.1281362>
9
10
11
12 Hartmann, K., Kozikowski, C. T., Urbano, M. R., Williams, T. V., Ba, C. L.-T., & Peterkin, A.
13
14 (2018). Autism spectrum disorder in Latin American families: Experiences in Chile.
15
16 *Families, Systems, & Health*, 36(2), 169–174. <https://doi.org/10.1037/fsh0000340>
17
18
19 Hassiotis, A., Barron, P., & O'Hara, J. (2000). Mental health services for people with learning
20
21 disabilities. A complete overhaul is needed with strong links to mainstream services. *BMJ*
22
23 *(Clinical Research Ed.)*, 321(7261), 583–584. <https://doi.org/10.1136/BMJ.321.7261.583>
24
25
26 Hatzenbuehler, M. L., Phelan, J. C., & Link, B. G. (2013). Stigma as a fundamental cause of
27
28 population health inequalities. *American Journal of Public Health*, 103(5), 813–821.
29
30 <https://doi.org/10.2105/AJPH.2012.301069>
31
32
33 Horselenberg, E. M. A., van Busschbach, J. T., Aleman, A., & Pijnenborg, G. H. M. (2016).
34
35 Self-Stigma and Its Relationship with Victimization, Psychotic Symptoms and Self-Esteem
36
37 among People with Schizophrenia Spectrum Disorders. *Plos One*, 11(10), e0149763.
38
39 <https://doi.org/10.1371/journal.pone.0149763>
40
41
42 Hughes, K., Bellis, M. A., Jones, L., Wood, S., Bates, G., Eckley, L., ... Officer, A. (2012).
43
44 Prevalence and risk of violence against adults with disabilities: a systematic review and
45
46 meta-analysis of observational studies. *The Lancet*, 379(9826), 1621–1629.
47
48 [https://doi.org/10.1016/S0140-6736\(11\)61851-5](https://doi.org/10.1016/S0140-6736(11)61851-5)
49
50
51 Huiracocha, L., Almeida, C., Huiracocha, K., Arteaga, A., Arteaga, J., Barahona, P., & Quezada,
52
53 J. (2013). Explorando los sentimientos de los padres, la familia y la sociedad a las personas
54
55
56
57
58
59
60

- 1
2
3 con Síndrome de Down: Estudio observacional. *Maskana*, 4(2), 47–57.
4
5 <https://doi.org/10.18537/mskn.04.02.04>
6
7
8 Huiracocha, L., Almeida, C., Huiracocha, K., Arteaga, J., Arteaga, A., & Blume, S. (2017).
9
10 Parenting children with Down syndrome: Societal influences. *Journal of Child Health*
11
12 *Care : For Professionals Working with Children in the Hospital and Community*, 21(4),
13
14 488–497. <https://doi.org/10.1177/1367493517727131>
15
16
17 Knesebeck, O. von dem, Kofahl, C., & Makowski, A. C. (2017). Differences in depression
18
19 stigma towards ethnic and socio-economic groups in Germany - Exploring the hypothesis of
20
21 double stigma. *Journal of Affective Disorders*, 208, 82–86.
22
23 <https://doi.org/10.1016/j.jad.2016.08.071>
24
25
26 Kock, E., Molteno, C., Mfiki, N., Kidd, M., Ali, A., King, M., & Strydom, A. (2012). Cross-
27
28 Cultural Validation of a Measure of Felt Stigma in People with Intellectual Disabilities.
29
30 *Journal of Applied Research in Intellectual Disabilities*, 25(1), 11–19.
31
32 <https://doi.org/10.1111/j.1468-3148.2011.00644.x>
33
34
35 Liberati, A., Altman, D. G., Tetzlaff, J., Mulrow, C., Gøtzsche, P. C., Ioannidis, J. P. A., ...
36
37 Moher, D. (2009). The PRISMA Statement for Reporting Systematic Reviews and Meta-
38
39 Analyses of Studies That Evaluate Health Care Interventions: Explanation and Elaboration.
40
41 *PLoS Medicine*, 6(7), e1000100. <https://doi.org/10.1371/journal.pmed.1000100>
42
43
44 Lopera-Escobar, A., Bastidas-Acevedo, M., & Lopera Escobar, A. (2018). Experiencias en la
45
46 atención médica de madres de niños y niñas con síndrome de Down. Estudio cualitativo con
47
48 técnicas etnográficas *Acta de Pediatría Mexicana*, 39(2), 109-120.
49
50
51 Meijer, M. M., Carpenter, S., & Scholte, F. A. (2004). European Manifesto on Basic Standards
52
53 of Health Care For People with Intellectual Disabilities. *Journal of Policy and Practice in*
54
55
56
57
58
59
60

- 1
2
3 *Intellectual Disabilities*, 1(1), 10–15. <https://doi.org/10.1111/j.1741-1130.2004.04002.x>
4
5 Mikton, C., Maguire, H., & Shakespeare, T. (2014). A Systematic Review of the Effectiveness of
6 Interventions to Prevent and Respond to Violence Against Persons With Disabilities.
7
8 *Journal of Interpersonal Violence*, 29(17), 3207–3226.
9
10 <https://doi.org/10.1177/0886260514534530>
11
12
13
14 Mitter, N., Ali, A., & Scior, K. (2018). Stigma experienced by family members of people with
15 intellectual and developmental disabilities: multidimensional construct. *BJPsycho Open*,
16
17 4(5), 332–338. <https://doi.org/10.1192/bjo.2018.39>
18
19
20
21 Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & Group, T. P. (2009). Preferred Reporting
22 Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS*
23
24 *Medicine*, 6(7), e1000097. <https://doi.org/10.1371/journal.pmed.1000097>
25
26
27
28 Ncube, B. L., Perry, A., & Weiss, J. A. (2018). The quality of life of children with severe
29 developmental disabilities. *Journal of Intellectual Disability Research*, 62(3), 237–244.
30
31 <https://doi.org/10.1111/jir.12460>
32
33
34
35 Nha HONG, Q., Pluye, P., Fàbregues, S., Bartlett, G., Boardman, F., Cargo, M., ... Vedel, I.
36 (n.d.). *MIXED METHODS APPRAISAL TOOL (MMAT) VERSION 2018 User guide*.
37 Retrieved from <http://mixedmethodsappraisaltoolpublic.pbworks.com/>
38
39
40
41
42 O’Byrne, C., & Muldoon, O. (2017). Stigma, self-perception and social comparisons in young
43 people with an intellectual disability. *Irish Educational Studies*, 36(3), 307–322.
44
45 <https://doi.org/10.1080/03323315.2017.1327363>
46
47
48
49 O’Shea, M. S., Maziel Girón, J., Cabrera, L., Lescano, A. G., & Taren, D. L. (2012). Public
50 perceptions of intellectual disability in a shantytown community in Lima, Peru.
51
52 *International Health*, 4, 253–259. <https://doi.org/10.1016/j.inhe.2012.07.001>
53
54
55
56
57
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59
60

- 1
2
3 Organization, P. A. H. (2012). *Health in the Americas*. Washington, DC: WHO.
- 4
5 Oxhorn, P., & Jouve-Martín, J. R. (2017). Inequality and Inclusion in Latin America. *Latin*
6
7 *American Research Review*, 52(2), 203–207. <https://doi.org/10.25222/larr.62>
- 8
9
10 Phelan, J. C., Link, B. G., & Dovidio, J. F. (2008). Stigma and prejudice: One animal or two?
11
12 *Social Science & Medicine*, 67(3), 358–367.
13
14 <https://doi.org/10.1016/J.SOCSCIMED.2008.03.022>
- 15
16
17 Polanco Valenzuela, M., Luis, J., & Ayala, M. (2017). Conocimientos, actitudes y prácticas de
18
19 familias de adolescentes con discapacidad cognitiva en sexualidad y afectividad*
20
21 Knowledge, attitudes and practices of families of teenagers with cognitive disabilities in
22
23 sexuality and affectivity, 13(2), 187–199. <https://doi.org/10.15332/s1794->
24
25 9998.2017.0002.04
- 26
27
28 Rimmer, J. H. (1999). Health Promotion for People With Disabilities: The Emerging Paradigm
29
30 Shift From Disability Prevention to Prevention of Secondary Conditions. *Physical Therapy*,
31
32 79(5), 495–502. <https://doi.org/10.1093/ptj/79.5.495>
- 33
34
35 Schalock, R. L., Luckasson, R., Tassé, M. J., & Verdugo, M. A. (2018). A Holistic Theoretical
36
37 Approach to Intellectual Disability: Going Beyond the Four Current Perspectives.
38
39 *Intellectual and Developmental Disabilities*, 56(2), 79–89. <https://doi.org/10.1352/1934->
40
41 9556-56.2.79
- 42
43
44 Scior, K., Addai-Davis, J., Kenyon, M., & Sheridan, J. C. (2012). Stigma, public awareness
45
46 about intellectual disability and attitudes to inclusion among different ethnic groups.
47
48 *Journal of Intellectual Disability Research*, no-no. <https://doi.org/10.1111/j.1365->
49
50 2788.2012.01597.x
- 51
52
53
54 Scior, K. (2011). Public awareness, attitudes and beliefs regarding intellectual disability: A
55
56
57
58
59
60

- 1
2
3 systematic review. *Research in Developmental Disabilities*, 32(6), 2164–2182.
- 4
5 Scior, K., Hamid, A., Hastings, R., Werner, S., Belton, C., Laniyan, A., ... Kett, M. (2016).
6
7 Consigned to the margins: a call for global action to challenge intellectual disability stigma.
8
9 *The Lancet Global Health*, 4(5), e294–e295. [https://doi.org/10.1016/S2214-](https://doi.org/10.1016/S2214-109X(16)00060-7)
10
11
12 109X(16)00060-7
- 13
14 Sherry, M. (2010). *Disability Hate Crimes*. Routledge. <https://doi.org/10.4324/9781315577371>
- 15
16 Sikkink, K., & Walling, C. B. (2007). The Impact of Human Rights Trials in Latin America.
17
18 *Journal of Peace Research*, 44(4), 427–445. <https://doi.org/10.1177/0022343307078953>
- 19
20 Sirlopú, D., González, R., Bohner, G., Siebler, F., Millar, A., Ordóñez, G., ... de Tezanos-Pinto,
21
22 P. (2012). Actitudes implícitas y explícitas hacia personas con síndrome de Down: un
23
24 estudio en colegios con y sin programas de integración de Chile. *Revista de Psicología*
25
26 *Social*, 27(2), 199–210.
- 27
28
29 Sirlopú, David, González, R., Bohner, G., Siebler, F., Ordóñez, G., Millar, A., ... de Tezanos-
30
31 Pinto, P. (2008). Promoting Positive Attitudes Toward People With Down Syndrome: The
32
33 Benefit of School Inclusion Programs. *Journal of Applied Social Psychology*, 38(11), 2710–
34
35 2736. <https://doi.org/10.1111/j.1559-1816.2008.00411.x>
- 36
37
38
39 Stuber, J., Meyer, I., & Link, B. (2008). Stigma, prejudice, discrimination and health. *Social*
40
41 *Science & Medicine (1982)*, 67(3), 351–357.
42
43
44 <https://doi.org/10.1016/j.socscimed.2008.03.023>
- 45
46
47 The World Bank. (2018). Lower middle income | Data. Retrieved June 26, 2018, from
48
49 <https://data.worldbank.org/income-level/lower-middle-income>
- 50
51 Walker, J., & Scior, K. (2013). Tackling stigma associated with intellectual disability among the
52
53 general public: A study of two indirect contact interventions. *Research in Developmental*
54
55
56
57
58
59
60

1
2
3 *Disabilities*, 34(7), 2200–2210.
4

5 Werner, S. (2015). Public stigma and the perception of rights: Differences between intellectual
6 and physical disabilities. *Research in Developmental Disabilities*, 38, 262–271.
7

8
9
10 <https://doi.org/10.1016/j.ridd.2014.12.030>
11

12 Wilson, M. C., & Scior, K. (2015). Implicit attitudes towards people with intellectual disabilities:
13 Their rel...: EBSCOhost. *PLoS ONE*, 10(9), ArtID: e0137902.
14
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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	<ul style="list-style-type: none"> -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	<ul style="list-style-type: none"> -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 –

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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	<ul style="list-style-type: none"> - 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	<ul style="list-style-type: none"> -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	<ul style="list-style-type: none"> -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	<ul style="list-style-type: none"> -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 - - Professionals rarely communicate a DS diagnosis in an appropriate manner.
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	<ul style="list-style-type: none"> - 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	<ul style="list-style-type: none"> - 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	<ul style="list-style-type: none"> - 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

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					- A gender effect on Skills perception, better abilities perceived by men.
					- Positive correlation among time of experience and positive attitude towards inclusion
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Colombia					
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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), EPSP-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
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Chile					
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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

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4						- No differences were found in implicit bias towards PWDS among the two groups of students
5		To evaluate both types	80 Chilean	Implicit	Descriptive data	
6	Sirlopú et al.	of attitudes towards	students, between	Association	and mean	- Low rates of prejudice were identified in this study
7	(2012)	People with Down	11 to 15 years	Test (IAT)	comparisons	- Difference on “contact anxiety” and “amount of contact” in favor to children from schools with inclusion
8		syndrome (PWDS)				
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11	Cross-cultural					
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13						-Significant differences between the countries’ coverage of autism in their description of issues, discourse types, sources, images, roles and stigmatizing cues
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17		To explore the language	1480 articles		Media framing	-A scientific discourse type is more common in Venezuelan articles than in Argentina which focuses on human-interest stories.
18	Luengo (2018)	used in media from	published in 480		theory	
19		Venezuela and	national papers			-Individuals with autism are quoted in less than 5% of stories from each country
20		Argentina to talk about				
21		autism				
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25						-Results explain why both countries perpetuate stigmatizing cues regarding labeling, psychological symptoms, social skills and physical appearance.
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27		To analyse the results	2965 caregivers of	Study-specific	Descriptive	-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
28	Retazzi, Valdez &	obtained with a multi-	children with	questionnaire	analysis	
29	Cukier (2016)	national survey applied	ASD			
30		in five countries in				
31		South America				
32		(Argentina, Brazil,				
33		Chile,				
34		Venezuela, Uruguay) to				
35		families of children				- There is not available information about the other countries
36		with Autism Spectrum				
37		Disorder				
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39	Mixed methods					
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41	Argentina					
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45	De Menil &	To describe the	98 patients’	Study-specific	Descriptive	-Two-thirds (67%) of individuals taking psychiatric medication, did not have a psychiatric diagnosis
46	Cohen (2009)	obstacles to the rational	charts, 5 hospital	questionnaire	analysis and	
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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	<p>-Antipsychotics are more commonly prescribe than any other drugs</p> <p>-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)</p> <p>-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"</p> <p>The study identified structural impediments and barriers for the expression of rights of persons with ID. Violence is visible in staff and patients.</p>
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Colombia

Polanco-Valenzuela & Marin-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	<p>-The interviewers express knowledge about the rights of persons with disability. However, implementation and mechanisms to support the expression of these rights is fragile.</p> <p>Mothers and fathers don't recognize their daughter's and son's abilities to take decisions about their sexuality. Attitudes are ambivalent.</p>
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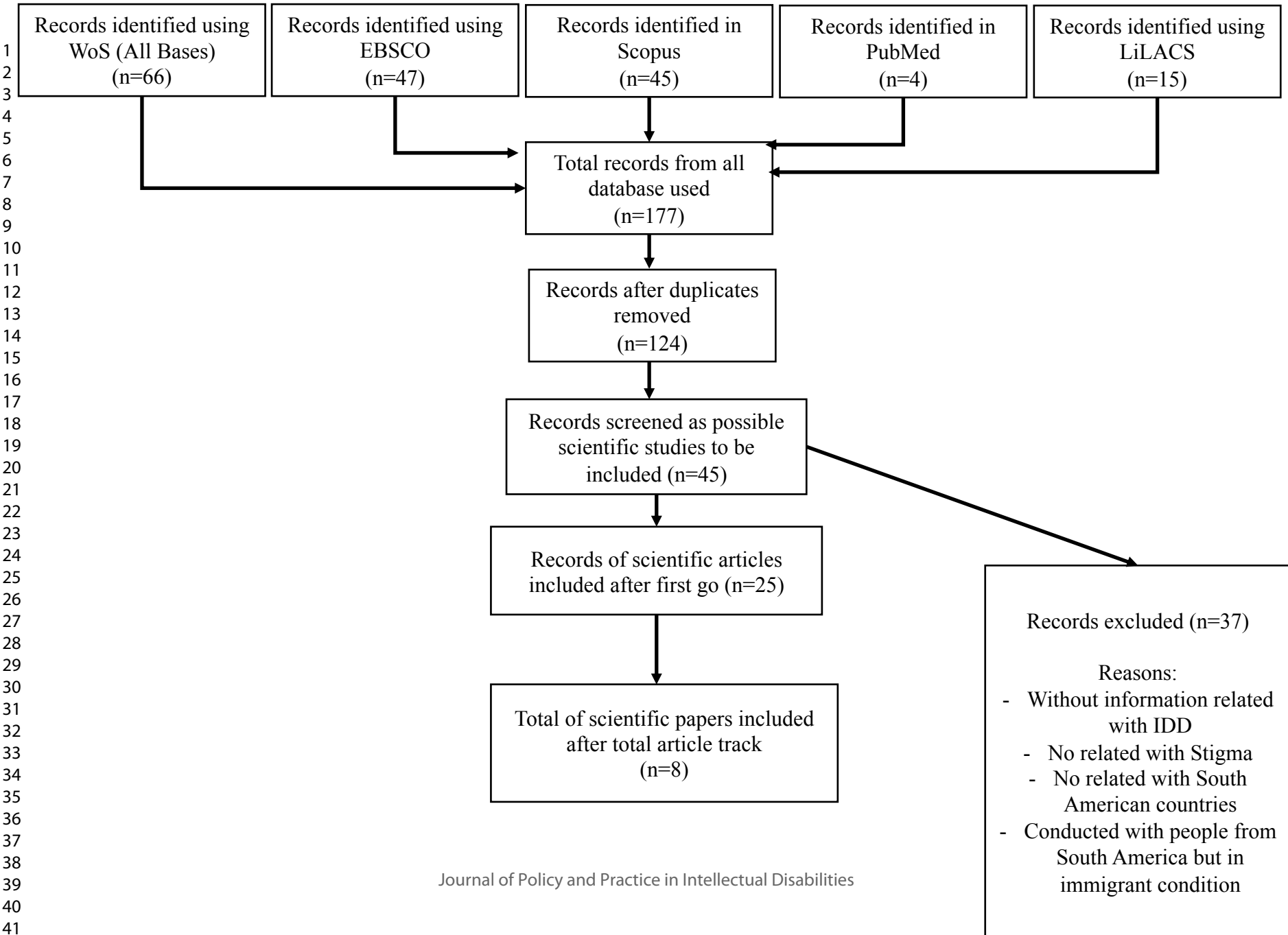
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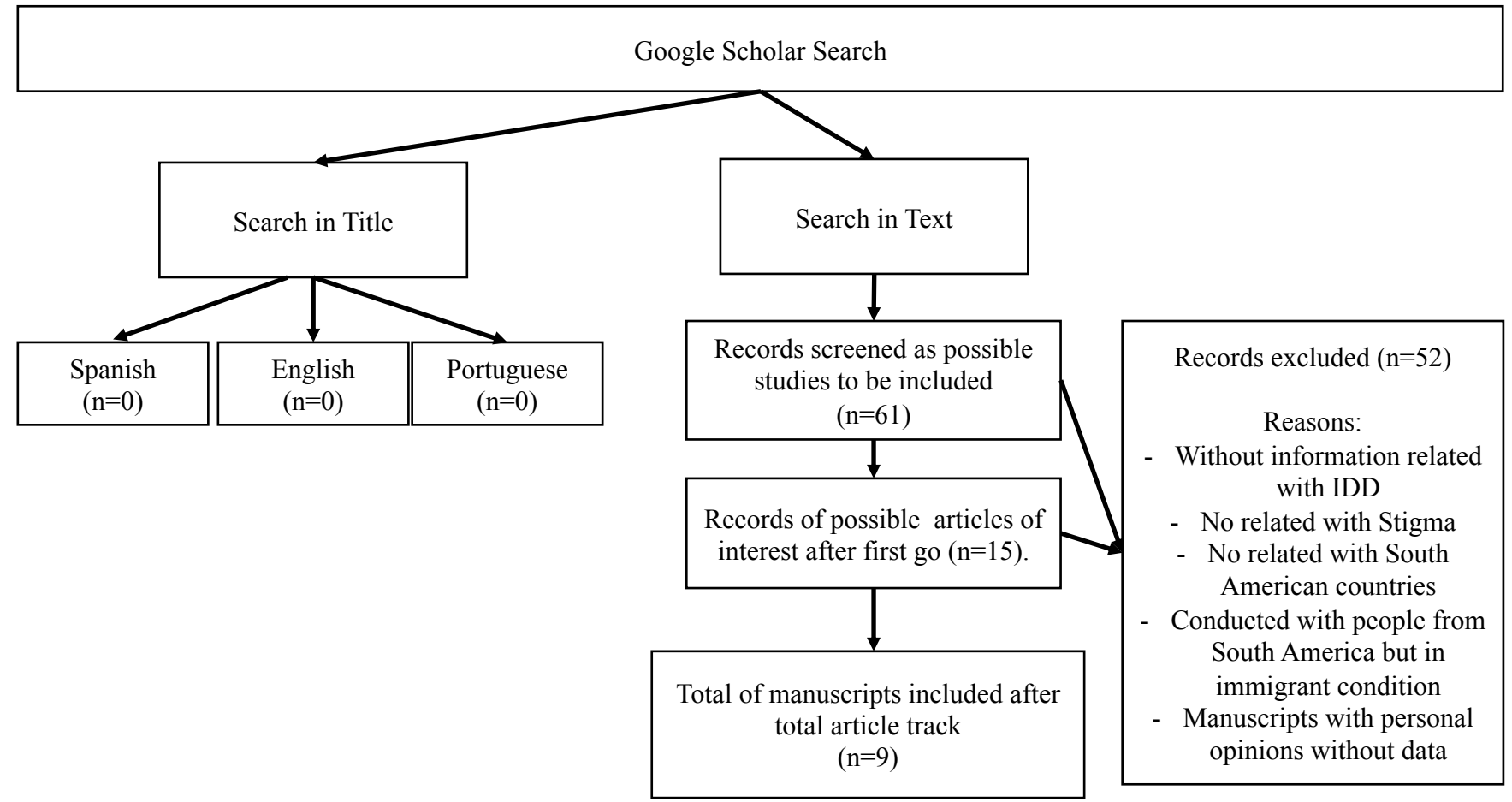
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Table 3

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) Hartmann et al. (2018)	Lopera-Escobar & Bastidas-Acevedo (2018) Cerreta (2018)	Polanco-Valenzuela & Martín-Ayala (2017)
	Ratazzi, Valdez, & Cukier (2016)	Furstenberg, Iriarte, & Navarro (2012) Huiracocha et al. (2013) Huiracocha et al. (2017) O'Shea, Maziél 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)		





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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

<p>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.</p>	<p>We offer some thoughts about the global situation Pp19-P4</p>
<p>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.</p>	<p>The information was incorporated as part of the results to contextualise the discussion Pp11 -P5</p>
<p>You state 'some authors have already suggested' - include some references for these authors?</p>	<p>References were incorporated Pp21 - P1</p>
<p>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</p>	<p>We checked and corrected grammar. Lopera's reference was corrected</p>
<p>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.</p>	<p>Done. Pp10-p1</p>

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

1
2
3 Intellectual disability (ID) is characterised by significant limitations in cognitive
4 functions and in adaptive behaviour in a wide range of daily activities, **originating before**
5 **eighteen years of age** (Schalock, Luckasson, Tassé, & Verdugo, 2018). ID is a
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7
8 neurodevelopmental disorder, and in the current international classifications, it is categorised
9
10 under “Intellectual and Developmental Disabilities (IDD)” with other conditions such as Autism
11
12 Spectrum Disorders (ASD), Attention Hyperactivity Disorder (ADHD), Learning Disabilities,
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14 Motor Developmental Disabilities and Communication Disorders (American Psychiatric
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16 Association, 2013). Several studies have **shown** that people with IDD are a group that are
17
18 commonly the victims of stigma and prejudice (i.e. Hamdani, Ary, & Lunsky, 2017; Mitter, Ali,
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20 & Scior, 2018) and, some of these studies noted that persons with ID are one of the most
21
22 underserved/stigmatised groups in society (i.e. Walker & Scior, 2013).
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28 Stigma and prejudice are complex concepts related to individual experiences that emerge
29
30 as a result of the interaction between marginalised and non-marginalised groups (Stuber, Meyer,
31
32 & Link, 2008). The seminal works by Allport (1954) and Goffman (1963) defined stigma as a
33
34 personal attribute that triggers a negative stereotype with undesirable consequences for the daily
35
36 life of the person. Stigma is a useful concept to characterise the social interactions that emerge
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38 from the relationship between people from a group considered typical and another considered
39
40 atypical, such as people with facial scars, physical disability, mental illness, or intellectual and
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42 developmental disabilities. On the other hand, prejudice is understood as a hostile reaction
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44 towards a person because they belong to a specific group. The concept of prejudice appears to be
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46 more focused on categories such as ethnicity, gender or socio-economical level (Phelan, Link, &
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48 Dovidio, 2008). While differently defined, both concepts are related to social barriers, violations
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3 of essential rights, and direct acts of discrimination, among other consequences (Arboleda
4 Flórez, 2005; Drew et al., 2011).

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

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

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3 However, these actions are insufficient as explicit and implicit negative attitudes towards
4 people with IDD are still prevalent in society (Scior, 2011; Wilson & Scior, 2015). Furthermore,
5
6 other disparities arise when considering the social and geopolitical position of people with IDD.
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10 Studies of the different forms of stigma towards people with IDD have been conducted
11
12 mostly in high-income countries. Published data suggests that people with intellectual disabilities
13
14 consistently emerge as the group with the highest stigma, and the stigma expression is higher
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16 towards this group than to other disability groups (Werner, 2015). In these countries, variables
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18 such as age, educational attainment and prior contact predict attitudes towards persons with ID.
19
20 However, there are inconsistent findings in relation to gender (Scior, 2011). Previous studies
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22 conducted in high-income countries also report that people with ID who participate in
23
24 community activities are subject to hostility (i.e. Cummins & Lau, 2003). More recently,
25
26 researchers have focused attention on people with ID being victims of hate crime, alongside
27
28 bullying, abuse and harassment (Walker & Scior, 2013).
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33 In the area of self-perceive stigma, people with IDD who report feeling stigmatised are
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35 more likely to have symptoms of anxiety and depression, a lower quality of life, and increased
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37 contacts with social services and the police (Ali et al., 2015). Self stigma is receiving special
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39 attention from researchers. In a recent review (Logeswaran, Hollett, Zala, Richardson, & Scior,
40
41 2019), authors explored how people with ID view their ascribed label; to what extent they
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43 ascribe it to themselves; and whether they recognize it as devalued in society. The review
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45 included 16 manuscripts, most of them related to studies conducted in Western countries, one
46
47 from Africa, and one from Vietnam. People with ID experience negative feelings about the label,
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49 and report shame, discomfort, anger, powerlessness and frustration towards the label. However,
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51 in some cases it was also possible to report positive views of the label, a core element of the self-
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3 advocacy movement leading to collective actions as a way to combat stigma. Negative feelings
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5 may result from the negative treatment and interactions they have experienced. Some authors
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7 suggest that, in particular, self-perceived stigma could be a precursor for victimisation and
8
9 loneliness in the presence of mental illness (Gilmore & Cuskelly, 2014; Horsseelenberg, van
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11 Busschbach, Aleman, & Pijnenborg, 2016).

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15 Little is known about the expression and consequences of stigma in middle or low-
16
17 income countries. Previous studies conducted in South-Asia (Abraham, Gregory, Wolf, &
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19 Pemberton, 2002; Edwardraj, Mumtaj, Prasad, Kuruvilla, & Jacob, 2010) and Africa (Ali et al.,
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21 2015; Kock et al., 2012) suggest that cultural characteristics influence the social expression of
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23 stigma and prejudice, which are moderated by variables such as religion, personal beliefs about
24
25 the origin of the condition or previous contact with persons with IDD. However, given the
26
27 paucity of research in many regions including Latin America, conclusive actions cannot be
28
29 achieved due to lack of engagement with the topic at population level (Ali et al., 2015; Ali et al.,
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31 2016; Hatzenbuehler, Phelan, & Link, 2013).

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35 New studies are needed to clarify the cultural impact of the expression of stigma towards
36
37 people with IDD and more countries should promote such research to gain a wider, global
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39 comprehension of the problems and the formulation of policies to improve the lives and
40
41 acceptance of people with IDD over the life course.

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45 South America is a region extending from the Caribbean in the north to the Antarctic
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47 region in the south and formed by twelve countries (Argentina, Bolivia, Brazil, Chile, Colombia,
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49 Ecuador, Guyana, Paraguay, Peru, Suriname, Uruguay, and Venezuela). It has a total population
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51 of approximately 600 million with significant cultural differences between countries. Most of the
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3 countries are lower-middle or upper-middle income, except for Argentina, Chile and Uruguay
4
5 classified as high-income economies (World Bank, 2018).
6

7 **Social** inequality, characterised by problems with capital distribution, access to social
8
9 services, education, health, and opportunities, is a major challenge experienced by all South
10
11 American countries. As a consequence, socio-economic status is a pivotal variable for social
12
13 research in the region (Central Intelligence Agency, 2017; Gapminder, 2017). Specific
14
15 information about the geopolitical status for each of the South American countries, as well as the
16
17 estimated population of people with disability, is presented in Table 1 to provide context to the
18
19 review.
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24 **Chile is considered a developed country due to macro-economic indicators and its gross**
25
26 **national product (World Bank, 2018). However, some authors have argued that because of the**
27
28 **low standards of living and human development index (Frey & Temple, 2008; Gapminder,**
29
30 **2017), countries such as Chile should be considered as developing countries.**
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33 <<Insert here table 1>>
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36 Several South American countries have a history of political instability secondary to the
37
38 military coups during the 20th century i.e. Colombia in 1953, Argentina in 1976, Chile in 1973,
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40 Uruguay in 1973, Paraguay in 1989, Brazil in 1964, and Peru in 1992, with well documented
41
42 human rights violations (Sikkink & Walling, 2007). Political violence and human rights
43
44 violations have morphed into social violence (Oxhorn & Jouve-Martín, 2017).
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47 The global prevalence of IDD, and specifically for ID, is unknown due to technical and
48
49 political factors such as problems with surveillance systems, differences in how the condition is
50
51 defined, or lack of governmental programs oriented towards ascertainment. Current data suggests
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53 that in Latin America (Central America, the Caribbean and South American countries), 13.8
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3 million people have IDD (PAHO, 2012). As far as we know, there is no specific prevalence rate
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5 of IDD available for the South American region only.
6

7 People with IDD are common victims of violence at a global level, e.g. they are at high
8
9 risk of being victims of hate crimes, social rejection, violations of rights, and lack of
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11 opportunities (Mikton, Maguire, & Shakespeare, 2014; Sherry, 2010). They are likely to suffer
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13 inequalities in social care, health and education (Ali et al., 2013; Hassiotis, Barron, & O'Hara,
14
15 2000; Rimmer, 1999); they are at a disadvantage in the judicial process and, in general, they
16
17 have worse quality of life than people without disability in the same territory (i.e. Ncube, Perry,
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19 & Weiss, 2018).
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24 This global situation has particular bearing for South America. Public policy about ID in
25
26 the region is scarce and this seems to be a consequence of social and institutionalized stigma
27
28 towards this group. A closer inspection of legislative statements regarding people with ID shows
29
30 that some of the countries have declarations such that an adult with ID does not have legal
31
32 capacity (referred as the capacity of a person to exert rights and duties according to each national
33
34 legislation), and that specific statements about school inclusion. The available policies have not
35
36 been updated since they were written, and they still use pejorative terminology, failing to
37
38 incorporate a rights-based approach to laws affecting people with ID (Silva Barroilhet, 2017).
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42 The global framework for the rights of people with disabilities is the Convention on the Rights of
43
44 Persons with Disabilities (CRPD, UN 2006). This convention was created following discussions
45
46 involving representatives from member states including people with disabilities. Under
47
48 consideration of the CRPD, these situations represent a clear violation of the international law.
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51 Reports published by the United Nations about the implementation of legislation according to
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3 the CRPD, recommends the need to take more active measures to support persons with disability
4
5 in the region (i.e. United Nations, 2016).
6

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8 News and social media are one of the most important sources of documenting rights,
9
10 violations and stigma towards people with ID in South America. A recent example in the Chilean
11
12 context is about the current scandal in the “looked-after children” program, where videos were
13
14 disseminated via social media showing physical maltreatment of children from paid caregivers.
15
16 These types of headlines are frequent, but due to the scarcity of research in the area, as well as
17
18 the lack of general and political interest, almost no action has been taken by the government to
19
20 deal with this situation.
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24 The aim of this paper is to present a narrative review of the expression of stigma and
25
26 prejudice towards people with ID in South America. In this review, we focus on studies relating
27
28 to stigma towards people with ID only, although some may have comorbid conditions. We hope
29
30 that this work will help to improve research on the topic in South America and will be relevant to
31
32 a wide range of stakeholders including professionals, policy makers and Not-for-Profit
33
34 organisations working with disability groups.
35
36

37 38 **Method** 39

40 In this review, we considered evidence available in catalogued journals and the grey
41
42 literature, including academic theses, organisation reports, government papers, etc. (Haddaway,
43
44 Collins, Coughlin, & Kirk, 2015).
45

46
47 We used the 27-item checklist recommended by the Preferred Reporting Items for
48
49 Systematic Reviews and Meta-Analyses (PRISMA) to assess studies included in the review
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51 (Moher, Liberati, Tetzlaff, Altman, & Group, 2009). The four-phase diagram recommended by
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3 PRISMA group and that included identification process, screening, eligibility and definition of
4 included studies, was adapted for the study (Moher et al., 2009).

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

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

16 **Information sources**

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

39 **Search strategy**

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

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3 Search terms related to ID, were combined with stigma, prejudice, attitudes and
4 stereotypes, and with the names of all the South American countries. Due to the known
5 relationship between ID and Autism Spectrum Disorder, this term was included in the search.
6
7 We conducted the search in English, Spanish, and Portuguese. For each language, a native
8 speaker reviewed all the titles and abstracts, and then an independent review was carried out by a
9 second researcher who was fluent in all three languages. The search was conducted as follows:

10
11 Neurodevelopmental disorder OR developmental disorder OR learning disorder OR learning
12 disability OR mental retardation OR intellectual disability OR autism OR down syndrome

13
14 AND stigma OR prejudice OR stereot* OR attitude

15
16 AND Latin America OR South America OR Colombia OR Venezuela OR Guyana OR
17 Suriname OR Ecuador OR Bolivia OR Peru OR Brazil OR Chile OR Argentina OR Uruguay OR
18 Paraguay.

19
20 The Spanish and Portuguese terms selected for clinical conditions were the same as those
21 used in English with the corresponding translation. At the level of stigma, the search in Spanish
22 also included “imaginario”, a common term used in Colombia to describe idiosyncratic ideas
23 about something. “Imaginario” corresponds to stereotyped ideas about groups of individuals that
24 may be held due to particular political or social views.
25
26

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28 The inclusion criteria for the studies were: (a) an explicit mention of ID in any part of the
29 manuscript; (b) an explicit mention of one of the key components of stigma (attitude, stereotype,
30 prejudice, and discrimination) and; (c) the study was conducted in South America. Exclusion
31 criteria considered: (a) mention of conditions not included in the search terms; (b) focus on
32 stigma towards medical conditions such as HIV/AIDS, Epilepsy, Leprosy or Tuberculosis
33 (frequent topics of interest in the region); (c) lack of relation to stigma; and (d) studies of
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3 immigrant populations that are not native to South America as these groups are likely to hold
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5 different cultural values that might influence the expression of stigma.
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8 The final selection of manuscripts was reviewed and validated independently by two of
9
10 the authors and an expert in statistical analysis with a third author arbitrating any disagreements
11
12 that could not be resolved by the reviewers.
13

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15 The MMAT approach was applied by two independent reviewers and in those cases
16
17 where there was disagreement, a third person arbitrated the decision.
18

19 Results

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21 The results are summarised in Figure 1, and in Figure 2 following the PRISMA
22
23 flowchart (Moher et al., 2009).
24

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26 <<Insert here figure 1>>

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28 <<Insert here figure 2>>
29

30
31 Seventeen papers were retained in this review and are presented in Table 2. Twelve
32
33 manuscripts were published in Spanish, four in English and one in Portuguese. The MMAT
34
35 algorithm was used to classify the studies according to their methodological approach. Eight
36
37 studies used a qualitative approach to answer the research questions, seven used a quantitative
38
39 approach, and two used a mixed methods approach. For two qualitative studies (Cerreta, 2018;
40
41 Furstenberg, Iriarte, & Navarro, 2012) and one quantitative study (Retazzi, Valdez & Cukier,
42
43 2016) the MMAT approach was not feasible. However, these studies were included because the
44
45 MMAT authors point out that excluding studies with low methodological quality is discouraged.
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49 Eleven percent (n=2) of the studies obtained the maximum MMAT score (5 points): one
50
51 qualitative study (Lopera-Escobar & Bastidas-Acevedo, 2018) and one of the mixed methods
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53 study (de Menil & Cohen, 2009). Seventeen percent (n=3) of the studies obtained a MMAT
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3 score of 4 points and the remaining seventy one percent (n=12) of the studies scored 3 or fewer
4
5 points on quality.
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7
8 In terms of content, twelve studies explored stigma, attitudes or prejudice towards
9
10 persons with ID (including towards people with Down Syndrome) and five studies explored
11
12 stigma towards people with ID and ASD (the specific target population for each study is
13
14 available in Table 2).
15

16
17 The majority of the included studies were conducted in Chile (35.2%) and Colombia
18
19 (17.6%). The remainder (47.2%) were from Brazil (11.7%), Ecuador (11.7%), Peru (5.8%) and
20
21 Argentina (5.8%). Cross-cultural data are available in 11.7% of the included studies. No studies
22
23 from Bolivia, Guyana, Suriname, Paraguay or Uruguay were found in the search process. Table 2
24
25 presents the specific country included in each study.
26

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28 <<Insert here Table 2>>
29

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31 The narrative synthesis has been organised to present the reported perspective of four
32
33 stakeholder groups: persons with ID; family and caregivers; mental health professionals; and
34
35 community members (Table 3). Ten studies were conducted with families and caregivers, three
36
37 studies considered community members (students and teachers); two with persons with IDD, and
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39 one with mental health workers.
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42 <<Insert here Table 3>>
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44 **Attitudes and beliefs about ID perceived by persons with this condition**

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47 There is only one included study that interviewed participants with ID (Dehays, Hitchins &
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49 Vidal, 2012), which was conducted in Chile. Three mothers with ID reported on their
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51 experiences of being women and mothers. Both the presence of an intellectual disability and the
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53 lack of financial support were identified as the main barriers in their role as mothers, specifically
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3 to look after their children, to have an active social participation, and to be recognised as
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5 productive members in their families and in society. These women report being criticised in the
6
7 way they lived and experienced motherhood, and they perceived this as stigmatisation.

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10 Furthermore, they report that in some cases their families replace them as decision-makers in the
11
12 process of raising their own children.

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15 The main goal of the other study (de Menil & Cohen, 2009) was to describe the obstacles for
16
17 the rational use of psychiatric drugs in a 1000-bed institution for persons with IDD called *La*
18
19 *Colonia*, in Argentina. Authors used patients' charts to present descriptive data about the
20
21 medical situation of the persons who are living in La Colonia and about the institution. They
22
23 refer to the use of an ethnographic approach to collect qualitative data from fourteen individuals
24
25 that included administrators, two psychiatrists, two nurses, two nurses' aids, two inpatients with
26
27 ID, and one pharmacist. However, in the results and discussion sections the text refers mostly to
28
29 staff, ignoring the views of people with ID. The authors mainly mentioned violations of human
30
31 rights, and expression of stigma by caregivers and mental health workers; these results will be
32
33 further discussed in the section about attitudes and beliefs about IDD in that group.
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37 38 **Attitudes and beliefs about ID perceived by families and caregivers**

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40 The first quantitative study was the Caregiver Needs Survey completed by 2965 relatives of
41
42 persons with ASD in Argentina, Brazil, Chile, Uruguay, Venezuela and Dominic Republic
43
44 General. Information about this survey was presented in a congress abstract (Retazzi, Valdez &
45
46 Cukier, 2016). We searched for the original work and part of the results are available in "La
47
48 Nación", an Argentinian national newspaper. According to the survey, families of persons with
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50 ASD in Argentina perceived stigma towards their relatives as a consequence of the diagnosis
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52 and reported higher levels of stigma when ID was present in co-occurrence with behavioural
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3 problems. Fifty-five percent of caregivers reported that they thought their sons and daughters
4 were stigmatised, 50% reported the need to work fewer hours to take care of their relatives and
5
6 were stigmatised, 50% reported the need to work fewer hours to take care of their relatives and
7
8 42% experienced financial difficulties as an indirect consequence of the diagnosis because they
9
10 have to pay for special services. We were unable to find data from the other countries included
11
12 in this survey.
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15 The second quantitative study included data from research which described implicit attitudes
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17 towards persons with DS. In this study, authors compared implicit attitudes towards DS
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19 expressed in relatives of persons with DS and the implicit attitudes towards the condition
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21 presented by college students in Colombia (Bernal, 2016). The data were collected with the
22
23 Relational Responding Task (De Houwer et al., 2015) and the Escala de Pecepción Social Hacia
24
25 Las Personas Con Síndrome de Down (Scale About Perceptions Towards People With Down
26
27 Syndrome, EPSD-1) (Molina Saorín, Nunes Corredeira & Vallejo Ruíz, 2012). In this study, a
28
29 group of twenty relatives was compared with a group of twenty-nine college students. Based on
30
31 the hypothesis that previous contact is associated with more positive attitudes, the authors
32
33 expected lower negative attitudes and perceptions towards people with DS in relatives. Results
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35 showed no differences among groups (college students vs relatives) in relation to negative
36
37 stereotypes or attitudes towards persons with DS. As a possible explanation of their findings,
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39 authors pointed to the sample size (authors compared their sample with the sample included in a
40
41 previous study conducted in France with 165 participants, Enea-Drapeau, Carlier, & Huguet,
42
43 2012) and the high homogeneity of the participants' educational level.
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50 The third quantitative study was conducted in Chile and explored the relationship between
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52 the severity of symptoms in children with ASD and other family characteristics, including
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54 stigma (Hartmann et al., 2018). With a study-specific questionnaire, the authors found stigma to
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3 be positively associated with ASD overall traits, social impairment, language and
4
5 communication deficits, and family stress but not related to restricted and repetitive behaviours
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7 (RRBs). Authors suggested that highly unacceptable behaviour, such as RRBs, may be
8
9 interpreted as poor parenting and for this reason is less associated with ASD. The results showed
10
11 that families who perceive more stigma associated with their child's difficulties, are also the
12
13 families who perceive less support from physicians and other professionals, and experience
14
15 higher levels of stress.
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20 Two Ecuadorian studies included parents of children with DS, exploring the feelings of
21
22 families towards DS (Huiracocha et al., 2013) and the impact of diagnosis (Huiracocha et al.,
23
24 2017). Both studies included the same number of participants (seven mothers and one father)
25
26 and found that the parents were aware of stigma towards their child in Ecuador. The authors
27
28 suggest that stigma influences the parents' perception about the capability of their children and
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30 the importance of support in light of participants reporting lack of social support, widespread
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32 stigmatization, and institutionalised stigma mainly expressed among physicians.
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36 In Chile, one study explored the life experiences of young people with ID and ASD in
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38 Temuco, a small city in the south of the country, based on two mothers' perceptions of their
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40 young son's and daughter's lives (Cerreta, 2018). A second study (von Furstenberg, Iriarte &
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42 Navarro, 2012) identified social factors that prevent the inclusion of people with ID in regular
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44 jobs in Santiago (capital of Chile) based on the opinions of the mothers. Both studies concluded
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46 that it is possible to identify stigma towards persons with IDD in Chile. The study goes beyond
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48 this affirmation and suggests: (a) that Chilean society has difficulties in including persons with
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50 ID due to existing social structures and negative attitudes towards this condition; (b) the most
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52 common parental attitudes are lack of affection and warmth towards their sons and daughters,
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3 which may be a form of active discrimination; (c) the highly segregated educational system of
4 the country (Arango, Aparicio, & Tenorio, 2018) and the scarce governmental resources
5 available to support people with ID, are major barriers to inclusion.
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10 One Brazilian study investigated the experiences of mothers of young people with ID and
11 ASD. They explored the mothers' initial reactions to the diagnosis of autism; the difficulties that
12 children encountered during adolescence and the mothers' expectations about the child's future
13 (Segeren & de Campos Francozo, 2014). The mothers stated that they had to change their
14 routines by avoiding public places due to their child's behavioural problems, which were
15 perceived negatively by the public, resulting in social stigmatisation and exclusion.
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20 In Colombia, Lopera-Escobar & Bastidas-Acevedo (2018) describe the experiences of
21 mothers of children with DS about the medical attention offered to their children. Participants
22 complained that in the health system in Colombia, the identity of their child is based on the
23 condition (with common expressions as: "*the Mongolic children...*"). They also talked about the
24 difficulties in accessing health services for the child's condition, with misinformation and
25 stigmatising attitudes from physicians and other health workers. For example, one of the
26 participants reported that "*With the neurologists I had a very bad experience. I needed the*
27 *authorization for therapies, but he denied it because, according with him, this kind of child*
28 *doesn't need that*". An important finding was the participants' perceived lack of information
29 about rights of persons with DS and the loss of hope and feelings of guilt were prevalent
30 emotions amongst families of children with DS in Colombia.
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49 Also, in Colombia, but with a mixed method approach, Polanco-Valenzuela & Marín-Araya
50 (2017) explored the knowledge, attitudes and practices in terms of decisions in fathers, mothers
51 and caregivers of adolescents with ID, with an emphasis on sexuality. The main finding is that
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3 participants were knowledgeable about the rights of persons with ID; however, the
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5 implementation and the use of mechanisms to support the expression of sexuality was limited
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7 because families and caregivers failed to recognise their children's capacity to make decisions
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9 regarding their sexuality. Mothers and father report ambivalence towards their child's emerging
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11 sexuality. Mothers and father report ambivalence towards their child's emerging
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13 sexuality.

14 **Mental health workers attitudes and beliefs about ID**

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17 Among the seventeen studies included in the review, one presented information about
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19 attitudes and beliefs of mental health workers about ID, carried out in Argentina (de Menil &
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21 Cohen, 2009). The authors describe stigma towards persons with IDD, discriminatory actions,
22
23 and some violations of human rights. The predominance of negative attitudes and stereotypes are
24
25 considered to have direct consequences on the quality of health services offered to this
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27 population. de Menil and Cohen (2009) investigated the over-use of psychiatric drugs in this
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29 context. They found that 83% of patients were taking psychiatric medications, although 67% of
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31 patients had no psychiatric diagnosis. Patients were mostly prescribed antipsychotics. They also
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33 point to mistreatment and inhuman actions such as denying anaesthesia to persons with ID
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35 because "(...) *they are like animals*". Mental health workers had a lack of awareness of ID and
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37 the lack of availability of non-medical treatments and hospitalisation for social reasons were
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39 cited (such as psychoanalytic treatments for psychological symptoms in persons with ID) as the
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41 main reasons for the over use of psychiatric medication.
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46 **Attitudes and beliefs about ID in community members**

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49 Among the quantitative studies, one was carried out in Brazil (Gregoul, Malagodi &
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51 Carraro, 2018) with physical education teachers. The Teacher Inclusion Attitudes Questionnaire
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53 was used to collect data form 35 Physical Education teachers. Findings suggested the presence of
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3 a general positive attitude to inclusion, but a lack of institutional support. Teachers perceived that
4 students with ID were well accepted by their classmates. They also reported gender differences
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6 attributing better abilities to male students. There was a positive correlation between the number
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8 of years of experience of teaching children with special needs and positive attitudes towards their
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10 inclusion.
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15 There were two quantitative studies that were conducted in two types of schools in Chile
16 and explored attitudes (explicit and implicit) towards children with DS (Sirlopú et al., 2008;
17 Sirlopú et al., 2012). In these studies, authors presented overlapping data. One study collected
18 data on implicit and explicit attitudes towards other students with DS from 80 students without
19 disability attending 4 schools in Santiago (2 with an inclusion program and 2 without) (Sirlopú et
20 al., 2012). In the other study (Sirlopú et al., 2008), data were collected with 120 students without
21 ID from four schools (2 with an inclusion program and 2 without). In both of these studies, the
22 authors concluded that the type of school did not have an impact on the prejudice, attitudes and
23 general perceptions of typically developing children towards children with DS. They argued that
24 the attitudes were generally positive. However, an interaction was found between gender and
25 type of school with more prejudice and negative attitudes in males who attended schools without
26 inclusion programs.
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42 Finally, de Menil and Cohen (2009) conducted a study with a mixed approach. Authors
43 reported that they included interviews with community members from La Colonia in their
44 sample. However, the findings from these interviews are not presented in the manuscript.
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49 Discussion

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51 Stigma is considered one of the most important concerns of our era, especially in relation
52 to conditions such as HIV, leprosy, and mental illness. However, scant attention has been paid to
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3 stigma towards people with ID, even when it affects an estimated of 300 million people globally
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5 (Scior et al., 2016). The results of the narrative review are indicative of the limited scientific
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7 study of stigma towards people with ID in South American countries and the clear sense that
8
9 people with ID living in those countries report experience of stigmatising attitudes.
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12 The published studies identified for this narrative review are mainly qualitative. None of
13
14 the studies included a large sample. Families and caregivers are the most frequent stakeholder
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16 group studied. The most important finding is the lack of studies including participants with ID
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18 and their personal experiences of stigma and discrimination, this is consistent with research on
19
20 stigma in other regions, particularly in low income countries where there appears to be very
21
22 limited research on self-reported experiences of stigma. As in previous studies, where the lack of
23
24 inclusion and high level of stigma towards people with ID has been reported (i.e. Mitter, Ali &
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26 Scior, 2019; Pelleboer-Gunnink, Van Oorsouw, Van Weeghel, & Embregts, 2019; Scior, 2011),
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28 our results suggest that there is low participation of persons with ID in research, which is
29
30 reflective of the low social and civil participation of persons with ID in the region.
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35 Whilst stigma towards persons with ID appears to be common in Latin America,
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37 however, there is no information about the mediating influence of socio-demographic variables
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39 such as age and educational level. There is a lack of available information about cultural
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41 differences and specific idiosyncratic characteristics between countries.
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44 As far as we know, this is the first systematic examination of stigma towards persons with ID
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46 in South American context. We have interrogated literature in English, Spanish and Portuguese
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48 languages to ensure that all relevant papers have been identified. We supplemented the databases
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50 search with a specific protocol to identify appropriate published data among grey material. We
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52 think this mixed approach in the search process enriched the final results. However, a degree of
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3 bias in the selections of manuscripts may have been introduced in the review process during
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5 study selection. We implemented different approaches to control for this, i.e. blind reviews and a
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7 systematic process to select documents but this bias could be still present.
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10 In relation to the quality of research, based on the MMAT appraisal system, there is an
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12 urgent need to improve the quality of research in this field in the region.
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14 Future research in the area of stigma towards persons with ID in South America must be
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16 conducted. A total comprehension of this phenomena, as well scientific data, will be very useful
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18 to enable researchers to design and evaluate the impact of different initiatives oriented to change
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20 the cultural attitudes towards people with ID. An increase of intellectual production in Spanish,
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22 available to general public in the South American countries is needed to increase comprehension
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24 and compromise with persons with ID.
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28 The lack of public policies and national planning in favour of social inclusion and
29
30 protection of the rights of people with ID across the South American countries should be a matter
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32 of attention for international agencies and non-profit organizations. As some authors have
33
34 already suggested, there is an urgent need for political coordination to promote better conditions
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36 for persons with ID in the region (Comisión Económica para América Latina y el Caribe
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38 (CEPAL), 2012; Espejo Yaksic & Lathrop Gómez, 2019). People with ID are one of least
39
40 considered groups, they are victims of all forms of violence (Fogden, Thomas, Daffern, &
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42 Ogloff, 2016; Hughes et al., 2012), and specific studies are needed to describe, understand, and
43
44 combat all possible forms of stigma in South America.
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49 **References**

50
51 Abraham, C., Gregory, N., Wolf, L., & Pemberton, R. (2002). Self-esteem, stigma and
52
53 community participation amongst people with learning difficulties living in the community.
54
55
56
57
58
59
60

1
2
3 *Journal of Community & Applied Social Psychology*, 12(6), 430–443.

4
5 <https://doi.org/10.1002/casp.695>

6
7
8 Bernal, M. J. (20106). *Actitudes implícitas y síndrome de Down* (Unpublished master's thesis).

9
10 Pontificia Universidad Javeriana, Bogotá.

11
12 Ali, A., Kock, E., Molteno, C., Mfiki, N., King, M., & Strydom, A. (2015). Ethnicity and self-
13
14 reported experiences of stigma in adults with intellectual disability in Cape Town, South
15
16 Africa. *Journal of Intellectual Disability Research*, 59(6), 530–540.

17
18
19 <https://doi.org/10.1111/jir.12158>

20
21 Ali, A., Hassiotis, A., Strydom, A., & King, M. (2012). Self stigma in people with intellectual
22
23 disabilities and courtesy stigma in family carers: A systematic review. *Research in*
24
25 *Developmental Disabilities*, 33(6), 2122–2140. <https://doi.org/10.1016/j.ridd.2012.06.013>

26
27
28 Ali, A., King, M., Strydom, A., & Hassiotis, A. (2015). Self-reported stigma and symptoms of
29
30 anxiety and depression in people with intellectual disabilities: Findings from a cross
31
32 sectional study in England. *Journal of Affective Disorders*, 187, 224–231.

33
34
35 <https://doi.org/10.1016/j.jad.2015.07.046>

36
37
38 Ali, A., King, M., Strydom, A., & Hassiotis, A. (2016). Self-reported stigma and its association
39
40 with socio-demographic factors and physical disability in people with intellectual
41
42 disabilities: results from a cross-sectional study in England. *Social Psychiatry and*
43
44 *Psychiatric Epidemiology*, 51(3), 465–474. <https://doi.org/10.1007/s00127-015-1133-z>

45
46
47 Ali, A., Scior, K., Ratti, V., Strydom, A., King, M., & Hassiotis, A. (2013). Discrimination and
48
49 other barriers to accessing health care: Perspectives of patients with mild and moderate
50
51 intellectual disability and their carers. *PLoS ONE*, 8(8), e70855.

52
53
54 <https://doi.org/10.1371/journal.pone.0070855>

- 1
2
3 Allport, G. W. (1954). *The Nature of Prejudice*. Garden City, NY: Doubleday.
- 4
5 American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental*
6
7 *Disorders: DSM-5*. Arlington, VA: American Psychiatric Association.
- 8
9
10 Arango, P. S., Aparicio, A., & Tenorio, M. (2018). Developmental trajectories of children with
11
12 Down syndrome by socio-economic status: the case of Latin America. *Journal of*
13
14 *Intellectual Disability Research*, 62(9), 759–774. <https://doi.org/10.1111/jir.12516>
- 15
16
17 Arboleda Flórez, J. (2005). Stigma and discrimination: An overview. *World Psychiatry*, 4(Suppl
18
19 1), 8.
- 20
21 Azmi, S., Hatton, C., Emerson, E., & Caine, A. (1997). Listening to adolescents and adults with
22
23 intellectual disabilities from south asian communities. *Journal of Applied Research in*
24
25 *Intellectual Disabilities*, 10(3), 250–263. [https://doi.org/10.1111/j.1468-](https://doi.org/10.1111/j.1468-3148.1997.tb00020.x)
26
27 [3148.1997.tb00020.x](https://doi.org/10.1111/j.1468-3148.1997.tb00020.x)
- 28
29
30 Birenbaum, A. (1992). Courtesy stigma revisited. *Mental Retardation*, 30(5), 265–268.
- 31
32
33 Birenbaum, A. (1970). On managing a courtesy stigma. *Journal of Health and Social Behavior*,
34
35 11(3), 196. <https://doi.org/10.2307/2948301>
- 36
37
38 Central Intelligence Agency. (2017). Country comparison: GDP - per capita (ppp). Retrieved
39
40 from <https://www.cia.gov/library/publications/the-world-factbook/rankorder/2004rank.html>
- 41
42
43 Cerreta, S. (2018). Vivencias de jóvenes con autismo de la ciudad de Temuco, desde la
44
45 percepción de sus familiares y educadores . Retrived from
46
47 https://digitalcollections.sit.edu/isp_collection/2895/
- 48
49
50 Coles, S., & Scior, K. (2012). Public attitudes towards people with intellectual disabilities: a
51
52 qualitative comparison of white british & south asian people. *Journal of Applied Research*
53
54 *in Intellectual Disabilities*, 25(2), 177–188. <https://doi.org/10.1111/j.1468->
55
56
57
58
59
60

1
2
3 3148.2011.00655.x
4

5 Cooper, C., Booth, A., Varley-Campbell, J., Britten, N., & Garside, R. (2018). Defining the
6 process to literature searching in systematic reviews: A literature review of guidance and
7 supporting studies. *BMC Medical Research Methodology*, 18(1), 85.
8

9
10 <https://doi.org/10.1186/s12874-018-0545-3>
11

12
13
14 Corrigan, P. W., Watson, A. C., & Barr, L. (2006). The self-stigma of mental illness:
15 implications for self-esteem and self-efficacy. *Journal of Social and Clinical Psychology*,
16
17 25(9), 875–884. <https://doi.org/10.1521/jscp.2006.25.8.875>
18
19

20
21 Cummins, R. A., & Lau, A. L. (2003). Community integration or community exposure? A
22 review and discussion in relation to people with an intellectual disability. *Journal of applied*
23
24 *research in intellectual disabilities*, 16(2), 145-157. DOI: 10.1046/j.1468-
25

26 3148.2003.00157.x
27
28

29
30
31 Dang, M. T. (2010). The history of legislation and regulations related to children with
32 developmental disabilities. *The Journal of School Nursing*, 26(4), 252–259.
33

34
35 <https://doi.org/10.1177/1059840510368162>
36

37
38 de Menil, V., & Cohen, A. (2009). Rational use and rationale for use: psychiatric medication at
39 an argentine institution for intellectual disability. *Transcultural Psychiatry*, 46(4), 651–671.
40

41
42 <https://doi.org/10.1177/1363461509351377>
43

44
45 Dehays P., M., Hichins A., M., & Vidal C., V. (2012). Análisis del significado de las
46 ocupaciones atribuidas a ser mujer y madre para mujeres con discapacidad intelectual en la
47 ciudad de Punta Arenas. *Revista Chilena de Terapia Ocupacional*, 12(2), 1–13.
48

49
50 <https://doi.org/10.5354/0719-5346.2012.25301>
51

52
53
54 Drew, N., Funk, M., Tang, S., Lamichhane, J., Chávez, E., Katontoka, S., ... Saraceno, B.
55
56
57
58
59
60

- (2011). Human rights violations of people with mental and psychosocial disabilities: An unresolved global crisis. *The Lancet*, 378(9803), 1664–1675. [https://doi.org/10.1016/S0140-6736\(11\)61458-X](https://doi.org/10.1016/S0140-6736(11)61458-X)
- Edwardraj, S., Mumtaj, K., Prasad, J. H., Kuruvilla, A., & Jacob, K. S. (2010). Perceptions about intellectual disability: A qualitative study from Vellore, South India. *Journal of Intellectual Disability Research*, 54(8), 736–748. <https://doi.org/10.1111/j.1365-2788.2010.01301.x>
- Fogden, B. C., Thomas, S. D. M., Daffern, M., & Ogloff, J. R. P. (2016). Crime and victimisation in people with intellectual disability: A case linkage study. *BMC Psychiatry*, 16(1), 170. <https://doi.org/10.1186/s12888-016-0869-7>
- Frey, G. C., & Temple, V. A. (2008). Health promotion for Latin Americans with intellectual disabilities. *Salud Pública de México*, 50(S2), 167-177.
- Fujiura, G.T., Park, H.J., & Rutkowski-Kmitta, V. (2005). Disability statistics in the developing world: A reflection on the meanings in our numbers. *Journal of Applied Research in Intellectual Disabilities*, 18(4), 295–304. <https://doi.org/10.1111/j.1468-3148.2005.00268.x>
- Furstenberg, M.T. von, Iriarte, F., & Navarro, D. (2012). Búsqueda e inclusión laboral de personas con discapacidad cognitiva en Chile: una mirada desde sus madres. *Revista Chilena de Terapia Ocupacional*, 12(1), ág. 17-31.
- Gapminder. (2017). GINI coefficient.
- Gilmore, L., & Cuskelly, M. (2014). Vulnerability to loneliness in people with intellectual disability: An explanatory model. *Journal of Policy and Practice in Intellectual Disabilities*, 11(3), 192–199. <https://doi.org/10.1111/jppi.12089>
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. New York, NY: Simon and Schuster.

- 1
2
3 Gregoul, M., Malagodi, B. M., & Carraro, A. (2018). Inclusão de alunos com deficiência nas
4 aulas de educação física: atitudes de professores nas escolas regulares. *Revista Brasileira de*
5 *Educação Especial*, 24(1), 33–44. <https://doi.org/10.1590/s1413-65382418000100004>
6
7
8
9
10 Haddaway, N. R., Collins, A. M., Coughlin, D., & Kirk, S. (2015). The role of google scholar in
11 evidence reviews and its applicability to grey literature searching. *Plos One*, 10(9),
12 e0138237. <https://doi.org/10.1371/journal.pone.0138237>
13
14
15
16
17 Hamdani, Y., Ary, A., & Lunsy, Y. (2017). Critical analysis of a population mental health
18 strategy: effects on stigma for people with intellectual and developmental disabilities.
19 *Journal of Mental Health Research in Intellectual Disabilities*, 10(2), 144–161.
20
21 <https://doi.org/10.1080/19315864.2017.1281362>
22
23
24
25
26 Hartmann, K., Kozikowski, C. T., Urbano, M. R., Williams, T. V., Ba, C. L.-T., & Peterkin, A.
27 (2018). Autism spectrum disorder in Latin American families: Experiences in Chile.
28 *Families, Systems, & Health*, 36(2), 169–174. <https://doi.org/10.1037/fsh0000340>
29
30
31
32
33 Hassiotis, A., Barron, P., & O’Hara, J. (2000). Mental health services for people with learning
34 disabilities. A complete overhaul is needed with strong links to mainstream services. *BMJ*
35 *(Clinical Research Ed.)*, 321(7261), 583–584. <https://doi.org/10.1136/BMJ.321.7261.583>
36
37
38
39
40 Hatzenbuehler, M. L., Phelan, J. C., & Link, B. G. (2013). Stigma as a fundamental cause of
41 population health inequalities. *American Journal of Public Health*, 103(5), 813–821.
42
43 <https://doi.org/10.2105/AJPH.2012.301069>
44
45
46
47 Horsseelenberg, E. M. A., van Busschbach, J. T., Aleman, A., & Pijnenborg, G. H. M. (2016).
48 Self-stigma and its relationship with victimization, psychotic symptoms and self-esteem
49 among people with schizophrenia spectrum disorders. *Plos One*, 11(10), e0149763.
50
51 <https://doi.org/10.1371/journal.pone.0149763>
52
53
54
55
56
57
58
59
60

1
2
3 Hughes, K., Bellis, M.A., Jones, L., Wood, S., Bates, G., Eckley, L., ... Officer, A. (2012).

4
5 Prevalence and risk of violence against adults with disabilities: a systematic review and
6
7 meta-analysis of observational studies. *The Lancet*, 379(9826), 1621–1629.

8
9
10 [https://doi.org/10.1016/S0140-6736\(11\)61851-5](https://doi.org/10.1016/S0140-6736(11)61851-5)

11
12 Huiracocha, L., Almeida, C., Huiracocha, K., Arteaga, A., Arteaga, J., Barahona, P., & Quezada,

13
14 J. (2013). Explorando los sentimientos de los padres, la familia y la sociedad a las personas
15
16 con Síndrome de Down: estudio observacional. *Maskana*, 4(2), 47–57.

17
18
19 <https://doi.org/10.18537/mskn.04.02.04>

20
21 Huiracocha, L., Almeida, C., Huiracocha, K., Arteaga, J., Arteaga, A., & Blume, S. (2017).

22
23 Parenting children with Down syndrome: Societal influences. *Journal of Child Health*
24
25 *Care : For Professionals Working with Children in the Hospital and Community*, 21(4),

26
27 488–497. <https://doi.org/10.1177/1367493517727131>

28
29
30 Knesebeck, O. von dem, Kofahl, C., & Makowski, A. C. (2017). Differences in depression

31
32 stigma towards ethnic and socio-economic groups in Germany - Exploring the hypothesis of
33
34 double stigma. *Journal of Affective Disorders*, 208, 82–86.

35
36
37 <https://doi.org/10.1016/j.jad.2016.08.071>

38
39
40 Kock, E., Molteno, C., Mfiki, N., Kidd, M., Ali, A., King, M., & Strydom, A. (2012). Cross-

41
42 cultural validation of a measure of felt stigma in people with intellectual disabilities.

43
44 *Journal of Applied Research in Intellectual Disabilities*, 25(1), 11–19.

45
46
47 <https://doi.org/10.1111/j.1468-3148.2011.00644.x>

48
49 Liberati, A., Altman, D. G., Tetzlaff, J., Mulrow, C., Gøtzsche, P. C., Ioannidis, J. P. A., ...

50
51 Moher, D. (2009). The PRISMA statement for reporting systematic reviews and meta-
52
53 analyses of studies that evaluate health care interventions: Explanation and elaboration.

- 1
2
3 *PLoS Medicine*, 6(7), e1000100. <https://doi.org/10.1371/journal.pmed.1000100>
- 4
5 Lopera-Escobar, A., Bastidas-Acevedo, M., & Lopera Escobar, A. (2018). Experiencias en la
6
7 atención médica de madres de niños y niñas con síndrome de Down. Estudio cualitativo con
8
9 técnicas etnográficas. *Acta Pediátrica Mexicana*, 39(2), 1-12.
10
11 <http://dx.doi.org/10.18233/APM39No2pp109-1201572>
- 12
13
14 Meijer, M. M., Carpenter, S., & Scholte, F. A. (2004). European manifesto on basic standards of
15
16 health care for people with intellectual disabilities. *Journal of Policy and Practice in*
17
18 *Intellectual Disabilities*, 1(1), 10–15. <https://doi.org/10.1111/j.1741-1130.2004.04002.x>
- 19
20
21 Mikton, C., Maguire, H., & Shakespeare, T. (2014). A systematic review of the effectiveness of
22
23 interventions to prevent and respond to violence against persons with disabilities. *Journal of*
24
25 *Interpersonal Violence*, 29(17), 3207–3226. <https://doi.org/10.1177/0886260514534530>
- 26
27
28 Mitter, N., Ali, A., & Scior, K. (2018). Stigma experienced by family members of people with
29
30 intellectual and developmental disabilities: multidimensional construct. *BJPsych Open*,
31
32 4(5), 332–338. <https://doi.org/10.1192/bjo.2018.39>
- 33
34
35 Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & Group, T. P. (2009). Preferred reporting
36
37 items for systematic reviews and meta-analyses: The prisma statement. *PLoS Medicine*,
38
39 6(7), e1000097. <https://doi.org/10.1371/journal.pmed.1000097>
- 40
41
42 Ncube, B. L., Perry, A., & Weiss, J. A. (2018). The quality of life of children with severe
43
44 developmental disabilities. *Journal of Intellectual Disability Research*, 62(3), 237–244.
45
46 <https://doi.org/10.1111/jir.12460>
- 47
48
49 Nha Hong, Q., Pluye, P., Fàbregues, S., Bartlett, G., Boardman, F., Cargo, M., ... Vedel, I.
50
51 (2018). *Mixed methods appraisal tool (mmat) version 2018-User guide*. Retrieved from
52
53 <http://mixedmethodsappraisaltoolpublic.pbworks.com/>
- 54
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59
60

- 1
2
3 O’Byrne, C., & Muldoon, O. (2017). Stigma, self-perception and social comparisons in young
4 people with an intellectual disability. *Irish Educational Studies*, 36(3), 307–322.
5
6 <https://doi.org/10.1080/03323315.2017.1327363>
7
8
9
10 O’Shea, M. S., Maziel Girón, J., Cabrera, L., Lescano, A. G., & Taren, D. L. (2012). Public
11 perceptions of intellectual disability in a shantytown community in Lima, Peru.
12
13 *International Health*, 4, 253–259. <https://doi.org/10.1016/j.inhe.2012.07.001>
14
15
16
17 Organization, P. A. H. (2012). *Health in the Americas*. Washington, DC: WHO.
18
19
20 O’horn, P., & Jouve-Martín, J. R. (2017). Inequality and Inclusion in Latin America. *Latin*
21
22 *American Research Review*, 52(2), 203–207. <https://doi.org/10.25222/larr.62>
23
24
25 Phelan, J. C., Link, B. G., & Dovidio, J. F. (2008). Stigma and prejudice: One animal or two?
26
27 *Social Science & Medicine*, 67(3), 358–367.
28
29 <https://doi.org/10.1016/J.SOCSCIMED.2008.03.022>
30
31
32 Polanco Valenzuela, M., Luis, J., & Ayala, M. (2017). Conocimientos, actitudes y prácticas de
33 familias de adolescentes con discapacidad cognitiva en sexualidad y afectividad.
34
35 *Diversidad: Perspectiva Psicológica*, 13(2), 187–199. [https://doi.org/10.15332/s1794-](https://doi.org/10.15332/s1794-9998.2017.0002.04)
36
37
38
39
40 Rimmer, J. H. (1999). Health promotion for people with disabilities: the emerging paradigm shift
41 from disability prevention to prevention of secondary conditions. *Physical Therapy*, 79(5),
42
43
44
45
46 495–502. <https://doi.org/10.1093/ptj/79.5.495>
47
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2
3 Schalock, R. L., Luckasson, R., Tassé, M. J., & Verdugo, M. A. (2018). A holistic theoretical
4 approach to intellectual disability: going beyond the four current perspectives. *Intellectual*
5 *and Developmental Disabilities*, 56(2), 79–89. <https://doi.org/10.1352/1934-9556-56.2.79>
6
7
8
9
10 Scior, K. (2011). Public awareness, attitudes and beliefs regarding intellectual disability: A
11 systematic review. *Research in Developmental Disabilities*, 32(6), 2164–2182. Retrieved
12 from <https://www.sciencedirect.com/science/article/pii/S0891422211002617>
13
14
15
16
17 Scior, K., Addai-Davis, J., Kenyon, M., & Sheridan, J. (2012). Stigma, public awareness about
18 intellectual disability and attitudes to inclusion among different ethnic groups. *Journal of*
19 *Intellectual Disability Research*, no-no. <https://doi.org/10.1111/j.1365-2788.2012.01597.x>
20
21
22
23
24 Scior, K., Hamid, A., Hastings, R., Werner, S., Belton, C., Laniyan, A., ... Kett, M. (2016).
25
26 Consigned to the margins: a call for global action to challenge intellectual disability stigma.
27 *The Lancet Global Health*, 4(5), e294–e295. [https://doi.org/10.1016/S2214-](https://doi.org/10.1016/S2214-109X(16)00060-7)
28
29
30
31
32
33 Sherry, M. (2010). *Disability Hate Crimes*. Routledge. <https://doi.org/10.4324/9781315577371>
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- Sikkink, K., & Walling, C. B. (2007). The impact of human rights trials in latin america. *Journal of Peace Research*, 44(4), 427–445. <https://doi.org/10.1177/0022343307078953>
- Sirlopú, D., González, R., Bohner, G., Siebler, F., Millar, A., Ordóñez, G., ... de Tezanos-Pinto, P. (2012). Actitudes implícitas y explícitas hacia personas con síndrome de Down: un estudio en colegios con y sin programas de integración de Chile. *Revista de Psicología Social*, 27(2), 199–210.
- Sirlopú, D., González, R., Bohner, G., Siebler, F., Ordóñez, G., Millar, A., ... de Tezanos-Pinto, P. (2008). Promoting positive attitudes toward people with down syndrome: the benefit of school inclusion programs. *Journal of Applied Social Psychology*, 38(11), 2710–2736.

<https://doi.org/10.1111/j.1559-1816.2008.00411.x>

Stuber, J., Meyer, I., & Link, B. (2008). Stigma, prejudice, discrimination and health. *Social Science & Medicine* (1982), 67(3), 351–357.

<https://doi.org/10.1016/j.socscimed.2008.03.023>

The World Bank. (2018). Lower middle income | Data. Retrieved June 26, 2018, from

<https://data.worldbank.org/income-level/lower-middle-income>

Walker, J., & Scior, K. (2013). Tackling stigma associated with intellectual disability among the general public: A study of two indirect contact interventions. *Research in Developmental Disabilities*, 34(7), 2200–2210.

Werner, S. (2015). Public stigma and the perception of rights: Differences between intellectual and physical disabilities. *Research in Developmental Disabilities*, 38, 262–271.

<https://doi.org/10.1016/j.ridd.2014.12.030>

Wilson, M. C., & Scior, K. (2015). Implicit attitudes towards people with intellectual disabilities: Their relationship with explicit attitudes, social distance, emotions and contact. *Plos One*, 10(9), ArtID: e0137902.

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

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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

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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 N.F

-The authors suggested that it is possible to identify stigma towards people with ASD expressed in their families

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 N.F

-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.

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 4
-This stigma **influences** the family perception and support offered to their children with DS
-Specific competences should be **trained** in health teams

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3	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
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11	Peru						
12	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
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24	Quantitative Studies						
25	Brazil						
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27	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
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3	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), EPSP-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
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11	Chile						
12	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
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21	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 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	3
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34	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
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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 financial 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

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-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 & Marin-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
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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) Hartmann et al. (2018)	Lopera-Escobar & Bastidas-Acevedo (2018) Cerreta (2018)	Polanco-Valenzuela & Martín-Ayala (2017)
	Ratazzi, Valdez, & Cukier (2016)	Furstenberg, Iriarte, & Navarro (2012) Huiracocha et al. (2013) Huiracocha et al. (2017) O'Shea, Maziél 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

For Peer Review

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

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

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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).

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3 Across the world, minority groups are victims of both stigma and prejudice (Knesebeck,
4 Kofahl, & Makowski, 2017), and some of those groups have received more attention in research
5 than others. People with IDD have been identified as one of the most segregated groups in
6 society (Ali, King, Strydom, & Hassiotis, 2015), and several studies demonstrated that people
7 with ID are subject to different forms of stigma including public, courtesy, and self-perceived
8 (Ali, Hassiotis, Strydom, & King, 2012; Scior, 2011; Scior, Addai-Davis, Kenyon, & Sheridan,
9 2012; Werner, 2015). Public stigma refers to the general public's response towards people with
10 IDD as a result of negative attitudes and prejudice (Scior, 2011; Walker & Scior, 2013; Werner,
11 2015). Courtesy stigma affects the closest family members, friends, and professionals that work
12 with a person with ID who may develop negative self-evaluations and emotions related with the
13 condition (Ali, Hassiotis, Strydom, & King, 2012; Birenbaum, 1992; Birenbaum, 1970). Self-
14 perceived stigma refers to the extent to which a person with ID is aware of stigma and
15 discrimination from the public or from individuals (Ali et al., 2012; Corrigan, Watson, & Barr,
16 2006; O'Byrne & Muldoon, 2017).

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

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27 However, these actions are insufficient as explicit and implicit negative attitudes towards
28 people with IDD are still prevalent in society (Scior, 2011; Wilson & Scior, 2015). Furthermore,
29 other disparities arise when considering the social and geopolitical position of people with IDD.
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3 Studies of the different forms of stigma towards people with IDD have been conducted
4 mostly in high-income countries. Published data suggests that people with intellectual disabilities
5 consistently emerge as the group with the highest stigma, and the stigma expression is higher
6 towards this group than to other disability groups (Werner, 2015). In these countries, variables
7 such as age, educational attainment and prior contact predict attitudes towards persons with ID.
8 However, there are inconsistent findings in relation to gender (Scior, 2011). Previous studies
9 conducted in high-income countries also report that people with ID who participate in
10 community activities are subject to hostility (i.e. Cummins & Lau, 2003). More recently,
11 researchers have focused their attention on people with ID being victims of hate crime, alongside
12 bullying, abuse, and harassment (Walker & Scior, 2013).
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26 In the area of self-perceive stigma, people with IDD who report feeling stigmatised are
27 more likely to have symptoms of anxiety and depression, a lower quality of life, and increased
28 contacts with social services and the police (Ali et al., 2015). Self stigma is receiving special
29 attention from researchers. In a recent review (Logeswaran, Hollett, Zala, Richardson, & Scior,
30 2019), authors explored how people with ID view their ascribed label, to what extent they
31 ascribe it to themselves, and whether they recognize it as devalued in society. The review
32 included 16 manuscripts, most of them related to studies conducted in Western countries, one
33 from **Africa**, and one from Vietnam. People with ID experience negative feelings about the label,
34 and report shame, discomfort, anger, powerlessness, and frustration towards the label. However,
35 in some cases it was also possible to report positive views of the label, a core element of the self-
36 advocacy movement leading to collective actions as a way to combat stigma. Negative feelings
37 may result from the negative treatment and interactions they have experienced. Some authors
38 suggest that, in particular, self-perceived stigma could be a precursor for victimisation and
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3 loneliness in the presence of mental illness (Gilmore & Cuskelly, 2014; Horsselenberg, van
4 Busschbach, Aleman, & Pijnenborg, 2016).

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8 Little is known about the expression and consequences of stigma in middle or low-
9
10 income countries. Previous studies conducted in South-Asia (Abraham, Gregory, Wolf, &
11 Pemberton, 2002; Edwardraj, Mumtaj, Prasad, Kuruvilla, & Jacob, 2010) and Africa (Ali et al.,
12 2015; Kock et al., 2012) suggest that cultural characteristics influence the social expression of
13
14 stigma and prejudice, which are moderated by variables such as religion, personal beliefs about
15
16 the origin of the condition or previous contact with persons with IDD. However, given the
17
18 paucity of research in many regions including Latin America, conclusive actions cannot be
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20 achieved due to lack of engagement with the topic at population level (Ali et al., 2015; Ali et al.,
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22 2016; Hatzenbuehler, Phelan, & Link, 2013).

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29 New studies are needed to clarify the cultural impact of the expression of stigma towards
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31 people with IDD and more countries should promote such research to gain a wider, global
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33 comprehension of the problems and the formulation of policies to improve the lives and
34
35 acceptance of people with IDD over the life course.

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

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

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3 opportunities (Mikton, Maguire, & Shakespeare, 2014; Sherry, 2010). They are likely to suffer
4 inequalities in social care, health and education (Ali et al., 2013; Hassiotis, Barron, & O'Hara,
5 2000; Rimmer, 1999); they are at a disadvantage in the judicial process and, in general, they
6 have worse quality of life than people without disability in the same territory (i.e. Ncube, Perry,
7 & Weiss, 2018).

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10 This global situation has particular bearing for South America. Public policy about ID in
11 the region is scarce and this seems to be a consequence of social and institutionalized stigma
12 towards this group. A closer inspection of legislative statements regarding people with ID shows
13 that some of the countries have declarations such that an adult with ID does not have legal
14 capacity (referred as the capacity of a person to exert rights and duties according to each national
15 legislation), and that specific statements about school inclusion. The available policies have not
16 been updated since they were written, and they still use pejorative terminology, failing to
17 incorporate a rights-based approach to laws affecting people with ID (Silva Barroilhet, 2017).
18
19 The global framework for the rights of people with disabilities is the Convention on the Rights of
20 Persons with Disabilities (CRPD, UN 2006). This convention was created following discussions
21 involving representatives from member states including people with disabilities. Under
22 consideration of the CRPD, these situations represent a clear violation of the international law.
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24 Reports published by the United Nations about the implementation of legislation according to the
25 CRPD, recommends the need to take more active measures to support persons with disability in
26 the region (i.e. United Nations, 2016).

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29 News and social media are one of the most important sources of documenting rights,
30 violations and stigma towards people with ID in South America. A recent example in the Chilean
31 context is about the current scandal in the “looked-after children” program, where videos were
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3 disseminated via social media showing physical maltreatment of children from paid caregivers.
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5 These types of headlines are frequent, but due to the scarcity of research in the area, as well as
6
7 the lack of general and political interest, almost no action has been taken by the government to
8
9 deal with this situation.
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12 The aim of this paper is to present a narrative review of the expression of stigma and
13
14 prejudice towards people with ID in South America. In this review, we focus on studies relating
15
16 to stigma towards people with ID only, although some may have comorbid conditions. We hope
17
18 that this work will help to improve research on the topic in South America and will be relevant to
19
20 a wide range of stakeholders including professionals, policy makers and Not-for-Profit
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22 organisations working with disability groups.
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25 26 **Method**

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28 In this review, we considered evidence available in catalogued journals and the grey
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30 literature, including academic theses, organisation reports, government papers, etc. (Haddaway,
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32 Collins, Coughlin, & Kirk, 2015).
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35 We used the 27-item checklist recommended by the Preferred Reporting Items for
36
37 Systematic Reviews and Meta-Analyses (PRISMA) to assess studies included in the review
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39 (Moher, Liberati, Tetzlaff, Altman, & Group, 2009a). The four-phase diagram recommended by
40
41 PRISMA group and that included identification process, screening, eligibility and definition of
42
43 included studies, was adapted for the study (Moher et al., 2009a).
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47 The protocol recommended by Haddaway et al. (2015) to conduct systematic reviews in
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49 Google Scholar was implemented for the grey literature search.
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52 The Mixed Method Appraisal Tool version 2018 (MMAT; Hong et al., 2008) was used to
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54 critically appraise the methodological quality of the included studies.
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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:

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3 Neurodevelopmental disorder OR developmental disorder OR learning disorder OR learning
4 disability OR mental retardation OR intellectual disability OR autism OR down syndrome
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7 AND stigma OR prejudice OR stereot* OR attitude
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10 AND Latin America OR South America OR Colombia OR Venezuela OR Guyana OR
11
12 Suriname OR Ecuador OR Bolivia OR Peru OR Brazil OR Chile OR Argentina OR Uruguay OR
13
14 Paraguay.

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17 The Spanish and Portuguese terms selected for clinical conditions were the same as those
18 used in English with the corresponding translation. At the level of stigma, the search in Spanish
19 also included “imaginario”, a common term used in Colombia to describe idiosyncratic ideas
20 about something. “Imaginario” corresponds to stereotyped ideas about groups of individuals that
21 may be held due to particular political or social views.
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28 The inclusion criteria for the studies were: (a) an explicit mention of ID in any part of the
29 manuscript, (b) an explicit mention of one of the key components of stigma (attitude, stereotype,
30 prejudice, and discrimination), and (c) the study was conducted in South America. Exclusion
31 criteria considered: (a) mention of conditions not included in the search terms, (b) focus on
32 stigma towards medical conditions such as HIV/AIDS, Epilepsy, Leprosy or Tuberculosis
33 (frequent topics of interest in the region), (c) lack of relation to stigma, and (d) studies of
34 immigrant populations that are not native to South America as these groups are likely to hold
35 different cultural values that might influence the expression of stigma.
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47 The final selection of manuscripts was reviewed and validated independently by two of
48 the authors and an expert in statistical analysis with a third author arbitrating any disagreements
49 that could not be resolved by the reviewers.
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3 The MMAT approach was applied by two independent reviewers and in those cases
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5 where there was disagreement, a third person arbitrated the decision.
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7 8 **Results** 9

10 The results are summarised in Figure 1, and in Figure 2 following the PRISMA flowchart
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12 (Moher, Liberati, Tetzlaff, Altman, & Group, 2009b).
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14 <<Insert here figure 1>>
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16 <<Insert here figure 2>>
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19 Seventeen papers were retained in this review and are presented in Table 2. Twelve
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21 manuscripts were published in Spanish, four in English and one in Portuguese. The MMAT
22
23 algorithm was used to classify the studies according to their methodological approach. Eight
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25 studies used a qualitative approach to answer the research questions, seven used a quantitative
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27 approach, and two used a mixed methods approach. For two qualitative studies (Cerreta, 2018;
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29 Furstenberg, Iriarte, & Navarro, 2012) and one quantitative study (Retazzi, Valdez & Cukier,
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31 2016) the MMAT approach was not feasible. However, these studies were included because the
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33 MMAT authors point out that excluding studies with low methodological quality is discouraged.
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37 Two studies (11.8%) obtained the maximum MMAT score (5 points): one qualitative
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39 study (Lopera-Escobar & Bastidas-Acevedo, 2018) and one mixed methods study (de Menil &
40
41 Cohen, 2009). Three (17.6%) studies obtained a MMAT score of 4 points, and the remaining 12
42
43 studies (70.6%) scored 3 or fewer points on quality.
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46 In terms of content, 12 studies explored stigma, attitudes or prejudice towards persons
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48 with ID (including towards people with Down Syndrome) and five studies explored stigma
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50 towards people with ID and ASD (the specific target population for each study is available in
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52 Table 2).
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3 The majority of the included studies were conducted in Chile (35.2%) and Colombia
4 (17.6%). The remainder (35.5%) were from Brazil (11.7%), Ecuador (11.7%), Peru (5.8%) and
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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.

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

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28 The first quantitative study was the Caregiver Needs Survey completed by 2965 relatives
29 of persons with ASD in Argentina, Brazil, Chile, Uruguay, Venezuela and **Dominic Republic.**
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31 **General** information about this survey was presented in a congress abstract (Retazzi, Valdez &
32 Cukier, 2016). We searched for the original work and part of the results are available in "La
33 Nación", an Argentinian national newspaper. According to the survey, families of persons with
34 ASD in Argentina perceived stigma towards their relatives as a consequence of the diagnosis
35 and reported higher levels of stigma when ID was present in co-occurrence with behavioural
36 problems. Fifty-five percent of caregivers reported that they thought their sons and daughters
37 were stigmatised, 50% reported the need to work fewer hours to take care of their relatives and
38 42% experienced financial difficulties as an indirect consequence of the diagnosis because they
39 have to pay for special services. We were unable to find data from the other countries included
40 in this survey.
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3 The second quantitative study included data from research which described implicit
4 attitudes towards persons with DS. In this study, authors compared implicit attitudes towards DS
5 expressed in relatives of persons with DS and the implicit attitudes towards the condition
6 presented by college students in Colombia (Bernal, 2016). The data were collected with the
7 Relational Responding Task (De Houwer et al., 2015) and the Escala de Pecepción Social Hacia
8 Las Personas Con Síndrome de Down (Scale About Perceptions Towards People With Down
9 Syndrome, EPSD-1; Molina Saorín, Nunes Corredeira & Vallejo Ruíz, 2012). In this study, a
10 group of 20 relatives was compared with a group of 29 college students. Based on the
11 hypothesis that previous contact is associated with more positive attitudes, the authors expected
12 lower negative attitudes and perceptions towards people with DS in relatives. Results showed no
13 differences among groups (college students vs relatives) in relation to negative stereotypes or
14 attitudes towards persons with DS. As a possible explanation of their findings, authors pointed
15 to the sample size (authors compared their sample with the sample included in a previous study
16 conducted in France with 165 participants; Enea-Drapeau, Carlier, & Huguet, 2012) and the
17 high homogeneity of the participants' educational level.
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37 The third quantitative study was conducted in Chile and explored the relationship between
38 the severity of symptoms in children with ASD and other family characteristics, including
39 stigma (Hartmann et al., 2018). With a study-specific questionnaire, the authors found stigma to
40 be positively associated with ASD overall traits, social impairment, language and
41 communication deficits, and family stress but not related to restricted and repetitive behaviours
42 (RRBs). Authors suggested that highly unacceptable behaviour, such as RRBs, may be
43 interpreted as poor parenting and for this reason is less associated with ASD. The results showed
44 that families who perceive more stigma associated with their child's difficulties, are also the
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3 families who perceive less support from physicians and other professionals, and experience
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5 higher levels of stress.
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8 Two Ecuadorian studies included parents of children with DS, exploring the feelings of
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10 families towards DS (Huiracocha et al., 2013) and the impact of diagnosis (Huiracocha et al.,
11
12 2017). Both studies included the same number of participants (seven mothers and one father)
13
14 and found that the parents were aware of stigma towards their child in Ecuador. The authors
15
16 suggest that stigma influences the parents' perception about the capability of their children and
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18 the importance of support in light of participants reporting lack of social support, widespread
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20 stigmatization, and institutionalised stigma mainly expressed among physicians.
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24 In Chile, one study explored the life experiences of young people with ID and ASD in
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26 Temuco, a small city in the south of the country, based on two mothers' perceptions of their
27
28 young son's and daughter's lives (Cerreta, 2018). A second study (von Furstenberg, Iriarte &
29
30 Navarro, 2012) identified social factors that prevent the inclusion of people with ID in regular
31
32 jobs in Santiago (capital of Chile) based on the opinions of the mothers. Both studies concluded
33
34 that it is possible to identify stigma towards persons with IDD in Chile. The study goes beyond
35
36 this affirmation and suggests: (a) that Chilean society has difficulties in including persons with
37
38 ID due to existing social structures and negative attitudes towards this condition, (b) the most
39
40 common parental attitudes are lack of affection and warmth towards their sons and daughters,
41
42 which may be a form of active discrimination, (c) the highly segregated educational system of
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44 the country (Arango, Aparicio, & Tenorio, 2018) and (d) the scarce governmental resources
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46 available to support people with ID, are major barriers to inclusion.
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51 One Brazilian study investigated the experiences of mothers of young people with ID and
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53 ASD. They explored the mothers' initial reactions to the diagnosis of autism, the difficulties that
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3 children encountered during adolescence, and the mothers' expectations about the child's future
4 (Segeren & de Campos Francozo, 2014). The mothers stated that they had to change their
5 routines by avoiding public places due to their child's behavioural problems, which were
6 perceived negatively by the public, resulting in social stigmatisation and exclusion.
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12 In Colombia, Lopera-Escobar and Bastidas-Acevedo (2018) describe the experiences of
13 mothers of children with DS about the medical attention offered to their children. Participants
14 complained that in the health system in Colombia, the identity of their child is based on the
15 condition (with common expressions as: "*the Mongolic children...*"). They also talked about the
16 difficulties in accessing health services for the child's condition, with misinformation and
17 stigmatising attitudes from physicians and other health workers. For example, one of the
18 participants reported that "*With the neurologists I had a very bad experience. I needed the*
19 *authorization for therapies, but he denied it because, according with him, this kind of child*
20 *doesn't need that*". An important finding was the participants' perceived lack of information
21 about rights of persons with DS and the loss of hope and feelings of guilt were prevalent
22 emotions amongst families of children with DS in Colombia.
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38 Also, in Colombia, but with a mixed method approach, Polanco-Valenzuela & Marín-Araya
39 (2017) explored the knowledge, attitudes and practices in terms of decisions in fathers, mothers
40 and caregivers of adolescents with ID, with an emphasis on sexuality. The main finding is that
41 participants were knowledgeable about the rights of persons with ID; however, the
42 implementation and the use of mechanisms to support the expression of sexuality was limited
43 because families and caregivers failed to recognise their children's capacity to make decisions
44 regarding their sexuality. Mothers and father report ambivalence towards their child's emerging
45 sexuality.
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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 from 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.

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3 There were two quantitative studies that were conducted in two types of schools in Chile
4 and explored attitudes (explicit and implicit) towards children with DS (Sirlopú et al., 2012;
5 2008). In these studies, authors presented overlapping data. One study collected data on implicit
6 and explicit attitudes towards other students with DS from 80 students without disability
7 attending four schools in Santiago (two with an inclusion program and two without; Sirlopú et
8 al., 2012). In the other study (Sirlopu et al., 2008), data were collected with 120 students without
9 ID from four schools (two with an inclusion program and two without). In both of these studies,
10 the authors concluded that the type of school did not have an impact on the prejudice, attitudes
11 and general perceptions of typically developing children towards children with DS. They argued
12 that the attitudes were generally positive. However, an interaction was found between gender and
13 type of school with more prejudice and negative attitudes in males who attended schools without
14 inclusion programs.

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

20 21 22 Discussion

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

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3 The published studies identified for this narrative review are mainly qualitative. None of
4 the studies included a large sample. Families and caregivers are the most frequent stakeholder
5 group studied. The most important finding is the lack of studies including participants with ID
6 and their personal experiences of stigma and discrimination, this is consistent with research on
7 stigma in other regions, particularly in low income countries where there appears to be very
8 limited research on self-reported experiences of stigma. As in previous studies, where the lack of
9 inclusion and high level of stigma towards people with ID has been reported (i.e. Mitter, Ali &
10 Scior, 2019; Pelleboer-Gunnink, Van Oorsouw, Van Weeghel, & Embregts, 2019; Scior, 2011),
11 our results suggest that there is low participation of persons with ID in research, which is
12 reflective of the low social and civil participation of persons with ID in the region.
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26 Whilst stigma towards persons with ID appears to be common in Latin America,
27 however, there is no information about the mediating influence of socio-demographic variables
28 such as age and educational level. There is a lack of available information about cultural
29 differences and specific idiosyncratic characteristics between countries.
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35 As far as we know, this is the first systematic examination of stigma towards persons with ID
36 in South American context. We have interrogated literature in English, Spanish and Portuguese
37 languages to ensure that all relevant papers have been identified. We supplemented the databases
38 search with a specific protocol to identify appropriate published data among grey material. We
39 think this mixed approach in the search process enriched the final results. However, a degree of
40 bias in the selections of manuscripts may have been introduced in the review process during
41 study selection. We implemented different approaches to control for this, i.e. blind reviews and a
42 systematic process to select documents but this bias could still be present.
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3 In relation to the quality of research, based on the MMAT appraisal system, there is an
4 urgent need to improve the quality of research in this field in the region.
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8 Future research in the area of stigma towards persons with ID in South America must be
9 conducted. A total comprehension of this phenomena, as well scientific data, will be very useful
10 to enable researchers to design and evaluate the impact of different initiatives oriented to change
11 the cultural attitudes towards people with ID. An increase of intellectual production in Spanish,
12 available to general public in the South American countries is needed to increase comprehension
13 and compromise with persons with ID.
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22 The lack of public policies and national planning in favour of social inclusion and
23 protection of the rights of people with ID across the South American countries should be a matter
24 of attention for international agencies and non-profit organizations. As some authors have
25 already suggested, there is an urgent need for political coordination to promote better conditions
26 for persons with ID in the region (Comisión Económica para América Latina y el Caribe
27 (CEPAL), 2012; Espejo Yaksic & Lathrop Gómez, 2019). People with ID are one of least
28 considered groups, they are victims of all forms of violence (Fogden, Thomas, Daffern, &
29 Ogloff, 2016; Hughes et al., 2012), and specific studies are needed to describe, understand, and
30 combat all possible forms of stigma in South America.
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53
54
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56
57
58
59
60

References

- Abraham, C., Gregory, N., Wolf, L., & Pemberton, R. (2002). Self-esteem, stigma and community participation amongst people with learning difficulties living in the community. *Journal of Community & Applied Social Psychology, 12*(6), 430–443. <https://doi.org/10.1002/casp.695>
- Actitudes implícitas y síndrome de Down 2 Tabla de Contenido.* (n.d.). Retrieved from <https://repository.javeriana.edu.co/bitstream/handle/10554/21350/BernalGiraldoMariaJose2016.pdf?sequence=1&isAllowed=y>
- Ali, A., Kock, E., Molteno, C., Mfiki, N., King, M., & Strydom, A. (2015). Ethnicity and self-reported experiences of stigma in adults with intellectual disability in Cape Town, South Africa. *Journal of Intellectual Disability Research, 59*(6), 530–540. <https://doi.org/10.1111/jir.12158>
- Ali, A., Hassiotis, A., Strydom, A., & King, M. (2012). Self stigma in people with intellectual disabilities and courtesy stigma in family carers: A systematic review. *Research in Developmental Disabilities, 33*(6), 2122–2140. <https://doi.org/10.1016/j.ridd.2012.06.013>
- Ali, A., King, M., Strydom, A., & Hassiotis, A. (2015). Self-reported stigma and symptoms of anxiety and depression in people with intellectual disabilities: Findings from a cross sectional study in England. *Journal of Affective Disorders, 187*, 224–231. <https://doi.org/10.1016/j.jad.2015.07.046>
- Ali, A., King, M., Strydom, A., & Hassiotis, A. (2016). Self-reported stigma and its association with socio-demographic factors and physical disability in people with intellectual disabilities: results from a cross-sectional study in England. *Social Psychiatry and Psychiatric Epidemiology, 51*(3), 465–474. <https://doi.org/10.1007/s00127-015-1133-z>

- 1
2
3 Ali, A., Scior, K., Ratti, V., Strydom, A., King, M., & Hassiotis, A. (2013). Discrimination and
4
5 Other Barriers to Accessing Health Care: Perspectives of Patients with Mild and Moderate
6
7 Intellectual Disability and Their Carers. *PLoS ONE*, 8(8), e70855.
8
9 <https://doi.org/10.1371/journal.pone.0070855>
10
11
12 Allport, G. W. (1954). *The nature of prejudice*. Garden City, NY: Doubleday.
13
14
15 American Association on Intellectual and Developmental Disabilities. (2010). *Intellectual*
16
17 *disability: definition, classification, and systems of supports*. Silver Spring, MD: American
18
19 Association on Intellectual and Developmental Disabilities.
20
21
22 American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental*
23
24 *Disorders: DSM-5*. Arlington, VA: American Psychiatric Association.
25
26
27 Arango, P. S., Aparicio, A., & Tenorio, M. (2018). Developmental trajectories of children with
28
29 Down syndrome by socio-economic status: the case of Latin America. *Journal of*
30
31 *Intellectual Disability Research*, 62(9), 759–774. <https://doi.org/10.1111/jir.12516>
32
33
34 Arboleda Flórez, J. (2005). Stigma and discrimination: an overview. *World Psychiatry*, 4(Suppl
35
36 1), 8-10.
37
38
39 Azmi, S., Hatton, C., Emerson, E., & Caine, A. (1997). Listening to Adolescents and Adults with
40
41 Intellectual Disabilities from South Asian Communities. *Journal of Applied Research in*
42
43 *Intellectual Disabilities*, 10(3), 250–263. [https://doi.org/10.1111/j.1468-](https://doi.org/10.1111/j.1468-3148.1997.tb00020.x)
44
45 [3148.1997.tb00020.x](https://doi.org/10.1111/j.1468-3148.1997.tb00020.x)
46
47
48 Birenbaum, A. (1970). On Managing a Courtesy Stigma. *Journal of Health and Social Behavior*,
49
50 11(3), 196-206. <https://doi.org/10.2307/2948301>
51
52
53 Birenbaum, A. (1992). Courtesy stigma revisited. *Mental Retardation*, 30(5), 265–268.
54
55
56
57
58
59
60 Central Intelligence Agency. (2017). Country comparison: GDP - per capita (ppp). Retrieved

1
2
3 April 21, 2017, from <https://www.cia.gov/library/publications/the-world-factbook/rankorder/2004rank.html>

4
5
6
7
8 Cerreta, S. (2018). Vivencias de jóvenes con autismo de la ciudad de Temuco, desde la
9
10 percepción de sus familiares y educadores / Experiences of young people with autism in the
11
12 city of Temuco, from the perception of their relatives and educators. *Independent Study*
13
14 *Project (ISP) Collection*. Retrieved from
15
16 https://digitalcollections.sit.edu/isp_collection/2895

17
18
19 Coles, S., & Scior, K. (2012). Public Attitudes towards People with Intellectual Disabilities: A
20
21 Qualitative Comparison of White British & South Asian People. *Journal of Applied*
22
23 *Research in Intellectual Disabilities*, 25(2), 177–188. [https://doi.org/10.1111/j.1468-](https://doi.org/10.1111/j.1468-3148.2011.00655.x)
24
25 [3148.2011.00655.x](https://doi.org/10.1111/j.1468-3148.2011.00655.x)

26
27
28 Cooper, C., Booth, A., Varley-Campbell, J., Britten, N., & Garside, R. (2018). Defining the
29
30 process to literature searching in systematic reviews: a literature review of guidance and
31
32 supporting studies. *BMC Medical Research Methodology*, 18(1), 85.
33
34 <https://doi.org/10.1186/s12874-018-0545-3>

35
36
37 Corrigan, P. W., Watson, A. C., & Barr, L. (2006). The self-stigma of mental illness:
38
39 implications for self-esteem and self-efficacy. *Journal of Social and Clinical Psychology*,
40
41 25(9), 875–884.
42
43

44
45 Dang, M. T. (2010). The History of Legislation and Regulations Related to Children With
46
47 Developmental Disabilities. *The Journal of School Nursing*, 26(4), 252–259.
48
49 <https://doi.org/10.1177/1059840510368162>

50
51 de Menil, V., & Cohen, A. (2009). Rational Use and Rationale for Use: Psychiatric Medication
52
53 at an Argentine Institution for Intellectual Disability. *Transcultural Psychiatry*, 46(4), 651–
54
55
56
57
58
59
60

1
2
3 671. <https://doi.org/10.1177/1363461509351377>

4
5 Dehays P., M., Hichins A., M., & Vidal C., V. (2012). Análisis del significado de las
6 ocupaciones atribuidas a ser mujer y madre para mujeres con discapacidad intelectual en la
7 ciudad de Punta Arenas. *Revista Chilena de Terapia Ocupacional*, 12(2), 1–13.
8
9
10
11
12 <https://doi.org/10.5354/0719-5346.2012.25301>

13
14 Drew, N., Funk, M., Tang, S., Lamichhane, J., Chávez, E., Katontoka, S., ... Saraceno, B.
15 (2011). Human rights violations of people with mental and psychosocial disabilities: an
16 unresolved global crisis. *The Lancet*, 378(9803), 1664–1675. [https://doi.org/10.1016/S0140-](https://doi.org/10.1016/S0140-6736(11)61458-X)
17
18
19
20
21
22
23 6736(11)61458-X

24 Edwardraj, S., Mumtaj, K., Prasad, J. H., Kuruvilla, A., & Jacob, K. S. (2010). Perceptions about
25 intellectual disability: a qualitative study from Vellore, South India. *Journal of Intellectual*
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
Disability Research, 54(8), 736–748. <https://doi.org/10.1111/j.1365-2788.2010.01301.x>

Espejo Yaksic, N., & Lathrop Gómez, F. (2019). *Discapacidad Intelectual y Derecho*. Santiago,
Chile: Thomson Reuters

Fogden, B. C., Thomas, S. D. M., Daffern, M., & Ogloff, J. R. P. (2016). Crime and
victimisation in people with intellectual disability: a case linkage study. *BMC Psychiatry*,
16(1), 170. <https://doi.org/10.1186/s12888-016-0869-7>

Frey, G. C., & Temple, V. A. (2008). Health promotion for Latin Americans with intellectual
disabilities. *Salud Pública Mex*, 50(S2), 167-177.

Fujiura, G. T., Park, H. J., & Rutkowski-Kmitta, V. (2005). Disability Statistics in the
Developing World: A Reflection on the Meanings in our Numbers. *Journal of Applied*
Research in Intellectual Disabilities, 18(4), 295–304. [https://doi.org/10.1111/j.1468-](https://doi.org/10.1111/j.1468-3148.2005.00268.x)
3148.2005.00268.x

- 1
2
3 Furstenberg, M. T. von, Iriarte, F., & Navarro, D. (2012). Búsqueda e inclusión laboral de
4 personas con discapacidad cognitiva en Chile: una mirada desde sus madres. *Revista*
5 *Chilena de Terapia Ocupacional*, 12(1), 17-31.
6
7
8
9
10 Gajminder. (2017). GINI coefficient.
11
12 Gilmore, L., & Cuskelly, M. (2014). Vulnerability to Loneliness in People with Intellectual
13 Disability: An Explanatory Model. *Journal of Policy and Practice in Intellectual*
14 *Disabilities*, 11(3), 192–199. <https://doi.org/10.1111/jppi.12089>
15
16
17
18
19 Goffman, E. (1963). *Stigma: notes on the management of spoiled identity*. New York, NY:
20 Simon and Schuster.
21
22
23
24 Gregoul, M., Malagodi, B. M., & Carraro, A. (2018). Inclusão de Alunos com Deficiência nas
25 Aulas de Educação Física: Atitudes de Professores nas Escolas Regulares. *Revista*
26 *Brasileira de Educação Especial*, 24(1), 33–44. [https://doi.org/10.1590/s1413-](https://doi.org/10.1590/s1413-65382418000100004)
27
28
29
30
31
32
33 Haddaway, N. R., Collins, A. M., Coughlin, D., & Kirk, S. (2015). The Role of Google Scholar
34 in Evidence Reviews and Its Applicability to Grey Literature Searching. *PLOS ONE*, 10(9),
35 e0138237. <https://doi.org/10.1371/journal.pone.0138237>
36
37
38
39
40 Hamdani, Y., Ary, A., & Lunsky, Y. (2017). Critical Analysis of a Population Mental Health
41 Strategy: Effects on Stigma for People With Intellectual and Developmental Disabilities.
42 *Journal of Mental Health Research in Intellectual Disabilities*, 10(2), 144–161.
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

- Hassiotis, A., Barron, P., & O'Hara, J. (2000). Mental health services for people with learning disabilities. A complete overhaul is needed with strong links to mainstream services. *BMJ (Clinical Research Ed.)*, *321*(7261), 583–584. <https://doi.org/10.1136/BMJ.321.7261.583>
- Hatzenbuehler, M. L., Phelan, J. C., & Link, B. G. (2013). Stigma as a fundamental cause of population health inequalities. *American Journal of Public Health*, *103*(5), 813–821. <https://doi.org/10.2105/AJPH.2012.301069>
- Hong, Q. N., Pluye, P., Fàbregues, S., Bartlett, G., Boardman, F., Cargo, M., ... Vedel, I. (2018). *Mixed Methods Appraisal Tool (MMAT) version 2018. User guide*. Retrieved from <http://mixedmethodsappraisaltoolpublic.pbworks.com/>
- Horsseelenberg, E. M. A., van Busschbach, J. T., Aleman, A., & Pijnenborg, G. H. M. (2016). Self-Stigma and Its Relationship with Victimization, Psychotic Symptoms and Self-Esteem among People with Schizophrenia Spectrum Disorders. *PLOS ONE*, *11*(10), e0149763. <https://doi.org/10.1371/journal.pone.0149763>
- Hughes, K., Bellis, M. A., Jones, L., Wood, S., Bates, G., Eckley, L., ... Officer, A. (2012). Prevalence and risk of violence against adults with disabilities: a systematic review and meta-analysis of observational studies. *The Lancet*, *379*(9826), 1621–1629. [https://doi.org/10.1016/S0140-6736\(11\)61851-5](https://doi.org/10.1016/S0140-6736(11)61851-5)
- Huiracocha, L., Almeida, C., Huiracocha, K., Arteaga, A., Arteaga, J., Barahona, P., & Quezada, J. (2013). Explorando los sentimientos de los padres, la familia y la sociedad a las personas con Síndrome de Down: Estudio observacional. *MASKANA*, *4*(2), 47–57. <https://doi.org/10.18537/mskn.04.02.04>
- Huiracocha, L., Almeida, C., Huiracocha, K., Arteaga, J., Arteaga, A., & Blume, S. (2017). Parenting children with Down syndrome: Societal influences. *Journal of Child Health*

- 1
2
3 *Care : For Professionals Working with Children in the Hospital and Community*, 21(4),
4
5 488–497. <https://doi.org/10.1177/1367493517727131>
6
7
8 Knesebeck, O. von dem, Kofahl, C., & Makowski, A. C. (2017). Differences in depression
9
10 stigma towards ethnic and socio-economic groups in Germany - Exploring the hypothesis of
11
12 double stigma. *Journal of Affective Disorders*, 208, 82–86.
13
14 <https://doi.org/10.1016/j.jad.2016.08.071>
15
16
17 Kock, E., Molteno, C., Mfiki, N., Kidd, M., Ali, A., King, M., & Strydom, A. (2012). Cross-
18
19 Cultural Validation of a Measure of Felt Stigma in People with Intellectual Disabilities.
20
21 *Journal of Applied Research in Intellectual Disabilities*, 25(1), 11–19.
22
23 <https://doi.org/10.1111/j.1468-3148.2011.00644.x>
24
25
26 Liberati, A., Altman, D. G., Tetzlaff, J., Mulrow, C., Gøtzsche, P. C., Ioannidis, J. P. A., ...
27
28 Moher, D. (2009). The PRISMA Statement for Reporting Systematic Reviews and Meta-
29
30 Analyses of Studies That Evaluate Health Care Interventions: Explanation and Elaboration.
31
32 *PLoS Medicine*, 6(7), e1000100. <https://doi.org/10.1371/journal.pmed.1000100>
33
34
35 Lopera-Escobar, A., & Bastidas-Acevedo, M. (2018). Experiencias en la atención médica de
36
37 madres de niños y niñas con síndrome de Down. Estudio cualitativo con técnicas
38
39 etnográficas. *Acta Pediátrica Mex*, 39(2), 109-120.
40
41
42 Meijer, M. M., Carpenter, S., & Scholte, F. A. (2004). European Manifesto on Basic Standards
43
44 of Health Care For People with Intellectual Disabilities. *Journal of Policy and Practice in*
45
46 *Intellectual Disabilities*, 1(1), 10–15. <https://doi.org/10.1111/j.1741-1130.2004.04002.x>
47
48
49 Mikton, C., Maguire, H., & Shakespeare, T. (2014). A Systematic Review of the Effectiveness of
50
51 Interventions to Prevent and Respond to Violence Against Persons With Disabilities.
52
53 *Journal of Interpersonal Violence*, 29(17), 3207–3226.
54
55
56
57
58
59
60

1
2
3 <https://doi.org/10.1177/0886260514534530>

4
5 Mitter, N., Ali, A., & Scior, K. (2018). Stigma experienced by family members of people with
6
7 intellectual and developmental disabilities: multidimensional construct. *BJPsych Open*,
8
9 4(5), 332–338. <https://doi.org/10.1192/bjo.2018.39>

10
11 Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & The PRISMA Group (2009). Preferred
12
13 Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement.
14
15 *PLoS Medicine*, 6(7), e1000097. <https://doi.org/10.1371/journal.pmed.1000097>

16
17 Ncube, B. L., Perry, A., & Weiss, J. A. (2018). The quality of life of children with severe
18
19 developmental disabilities. *Journal of Intellectual Disability Research*, 62(3), 237–244.
20
21
22 <https://doi.org/10.1111/jir.12460>

23
24 O’Byrne, C., & Muldoon, O. (2017). Stigma, self-perception and social comparisons in young
25
26 people with an intellectual disability. *Irish Educational Studies*, 36(3), 307–322.
27
28
29 <https://doi.org/10.1080/03323315.2017.1327363>

30
31 O’Shea, M. S., Maziél Girón, J., Cabrera, L., Lescano, A. G., & Taren, D. L. (2012). Public
32
33 perceptions of intellectual disability in a shantytown community in Lima, Peru.
34
35
36 *International Health*, 4, 253–259. <https://doi.org/10.1016/j.inhe.2012.07.001>

37
38 Oxhorn, P., & Jouve-Martín, J. R. (2017). Inequality and Inclusion in Latin America. *Latin*
39
40
41
42 *American Research Review*, 52(2), 203–207. <https://doi.org/10.25222/larr.62>

43
44 Pan American Health Organization (2012). *Health in the Americas*. Washington, DC: WHO.

45
46 Pelleboer-Gunnink, H. A., Van Oorsouw, W. M. W. J., Van Weeghel, J., & Embregts, P. J. C.
47
48
49 M. (2019). Stigma research in the field of intellectual disabilities: a scoping review on the
50
51 perspective of care providers. *International Journal of Developmental Disabilities*.
52
53
54 <https://doi.org/10.1080/20473869.2019.1616990>

1
2
3 Phelan, J. C., Link, B. G., & Dovidio, J. F. (2008). Stigma and prejudice: One animal or two?
4
5 *Social Science & Medicine*, 67(3), 358–367.

6
7
8 <https://doi.org/10.1016/J.SOCSCIMED.2008.03.022>
9

10 Polanco Valenzuela, M., Luis, J., & Ayala, M. (2017). Conocimientos, actitudes y prácticas de
11
12 familias de adolescentes con discapacidad cognitiva en sexualidad y afectividad*

13
14 Knowledge, attitudes and practices of families of teenagers with cognitive disabilities in
15
16 sexuality and affectivity, 13(2), 187–199. <https://doi.org/10.15332/s1794->

17
18
19 9998.2017.0002.04
20

21 Rimmer, J. H. (1999). Health Promotion for People With Disabilities: The Emerging Paradigm

22
23 Shift From Disability Prevention to Prevention of Secondary Conditions. *Physical Therapy*,
24
25 79(5), 495–502. <https://doi.org/10.1093/ptj/79.5.495>
26
27

28 Schalock, R. L., Luckasson, R., Tassé, M. J., & Verdugo, M. A. (2018). A Holistic Theoretical
29
30 Approach to Intellectual Disability: Going Beyond the Four Current Perspectives.

31
32 *Intellectual and Developmental Disabilities*, 56(2), 79–89. <https://doi.org/10.1352/1934->
33
34 9556-56.2.79
35
36

37 Scior, K. (2011). Public awareness, attitudes and beliefs regarding intellectual disability: A
38
39 systematic review. *Research in Developmental Disabilities*, 32(6), 2164–2182.
40
41

42 Scior, K., Addai-Davis, J., Kenyon, M., & Sheridan, J. (2012). Stigma, public awareness about
43
44 intellectual disability and attitudes to inclusion among different ethnic groups. *Journal of*

45
46 *Intellectual Disability Research*, 57(11), 1014–1026. <https://doi.org/10.1111/j.1365->
47
48 2788.2012.01597.x
49
50

51 Scior, K., Hamid, A., Hastings, R., Werner, S., Belton, C., Laniyan, A., ... Kett, M. (2016).

52
53
54 Consigned to the margins: a call for global action to challenge intellectual disability stigma.
55
56
57
58
59
60

1
2
3 *The Lancet Global Health*, 4(5), e294–e295. [https://doi.org/10.1016/S2214-109X\(16\)00060-7](https://doi.org/10.1016/S2214-109X(16)00060-7)

7 Sherry, M. (2010). *Disability Hate Crimes. Does Anyone Really Hate Disabled People?*.
8
9 Abingdon, UK: Routledge.

12 Sikkink, K., & Walling, C. B. (2007). The Impact of Human Rights Trials in Latin America.
13
14 *Journal of Peace Research*, 44(4), 427–445. <https://doi.org/10.1177/0022343307078953>

17 Silva Barroilhet, P. (2017). *La Capacidad Jurídica de las Personas con Discapacidad Intelectual*.
18
19 Santiago, Chile: Thomson Reuters.

21 Sirlopú, D., González, R., Bohner, G., Siebler, F., Millar, A., Ordóñez, G., ... de Tezanos-Pinto,
22
23 P. (2012). Actitudes implícitas y explícitas hacia personas con síndrome de Down: un
24
25 estudio en colegios con y sin programas de integración de Chile. *Revista de Psicología*
26
27 *Social*, 27(2), 199–210.

30 Sirlopú, D., González, R., Bohner, G., Siebler, F., Ordóñez, G., Millar, A., ... de Tezanos-Pinto,
31
32 P. (2008). Promoting Positive Attitudes Toward People With Down Syndrome: The Benefit
33
34 of School Inclusion Programs. *Journal of Applied Social Psychology*, 38(11), 2710–2736.
35
36 <https://doi.org/10.1111/j.1559-1816.2008.00411.x>

39 Stuber, J., Meyer, I., & Link, B. (2008). Stigma, prejudice, discrimination and health. *Social*
40
41 *Science & Medicine* (1982), 67(3), 351–357.
42
43 <https://doi.org/10.1016/j.socscimed.2008.03.023>

46 The World Bank. (2018). Lower middle income | Data. Retrieved June 26, 2018, from
47
48 <https://data.worldbank.org/income-level/lower-middle-income>

51 Walker, J., & Scior, K. (2013). Tackling stigma associated with intellectual disability among the
52
53 general public: A study of two indirect contact interventions. *Research in Developmental*
54
55

1
2
3 *Disabilities*, 34(7), 2200–2210.

4
5 Werner, S. (2015). Public stigma and the perception of rights: Differences between intellectual
6 and physical disabilities. *Research in Developmental Disabilities*, 38, 262–271.
7
8 <https://doi.org/10.1016/j.ridd.2014.12.030>
9
10

11
12 Wilson, M. C., & Scior, K. (2015). Implicit attitudes towards people with intellectual disabilities:
13 Their relationship with explicit attitudes, social distance, emotions and contact. *PLoS One*,
14 10(9), e0137902.
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
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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.		
8	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
15	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
35	Ecuador						
37	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

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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	<ul style="list-style-type: none"> - 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	<ul style="list-style-type: none"> - 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	<ul style="list-style-type: none"> - 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						

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3	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), EPSP-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
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11	Chile						
12	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
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21	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 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	3
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34	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
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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 financial 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 own 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 & Marin-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
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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)		