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Mainstream health professionals' stigmatising attitudes towards people with intellectual disabilities: a systematic review

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Abstract

Background Equal access to mainstream healthcare services for people with intellectual disabilities (ID) still requires attention. Although recent studies suggest that health professionals hold positive attitudes towards people with ID, stigmatising attitudes may influence their efforts to serve people with ID in community healthcare practice. To stimulate inclusion in mainstream healthcare services, this systematic review focussed on barriers in attitudes of mainstream health professionals towards people with ID.

Method Five electronic databases were systematically searched and references in full text articles were checked for studies published in the English language between January 1994 and January 2016. A social-psychological triad of cognitive, affective and behavioural dimensions of stigmatising attitudes is used to structure and discuss the results.

Results The literature search generated 2190 records with 30 studies that passed our exclusion

criteria. Studies were mostly cross-sectional and of moderate quality. With respect to stigma, a lack of familiarity with and knowledge about people with ID was found. ID was considered as a stable condition not under personal control. Moreover, mainstream health professionals had either low or high expectations of the capabilities of people with ID. Professionals reported stress, lack of confidence, fear and anxiety, a tendency to treat people with ID differently and a lack of supporting autonomy.

Conclusions Stigmatising attitudes towards people with ID appeared to be present among mainstream health professionals. This might affect the ongoing challenges regarding inclusion in mainstream healthcare services. To facilitate inclusion in mainstream healthcare services, it is recommended to include contact and collaboration with experts-by-experience in education programs of health professionals. Future research should progress beyond descriptive accounts of stigma towards exploring relationships between cognitive, affective and behavioural dimensions as pointers for intervention. Finally, inclusion would benefit from an understanding of 'equal' treatment that means reasonable adjustments instead of undifferentiated treatment.

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Keywords attitudes, health professionals, intellectual disability, social inclusion, stigma

Current western policy stresses the importance of equal access to mainstream healthcare services for people with intellectual disabilities (ID). Article 25 of the United Nations Convention on the Rights of Persons with Disabilities specifies that persons with disabilities have ‘*the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability*’ (United Nations 2006). This implicates that persons with disabilities receive care of the same quality and the same range as provided to other persons. Preferably, care is provided as close as possible to one’s own community and denial of health services should be prevented.

Health professionals are key persons in living up to the principle of inclusion in mainstream healthcare services and are, therefore, particularly mentioned in Article 25 of the convention. Health professionals should provide care of the same quality, ‘*including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care*’ (Article 25d). However, attitudes of health professionals towards people with ID may influence their effort to support inclusion in mainstream healthcare services (Mansell *et al.* 2002; Cobigo & Stuart 2010).

Overall, positive attitudes towards providing mainstream healthcare towards people with ID have been reported (Gill *et al.* 2002; Melville *et al.* 2005). For example, primary care staff and hospital staff indicated that people with ID have the same rights for health services as other people (McIlpatrick *et al.* 2011). Next, professionals reported positive feelings about providing care for people with ID (Gill *et al.* 2002; Lewis & Stenfert-Kroese 2010; Wilkinson *et al.* 2013; Flynn *et al.* 2015) and, in one study, even perceived their contacts with people with ID as stimulating experiences (Slevin & Sines 1996). Despite these positive attitudes, the ideal of inclusion in mainstream healthcare services for people with ID is not considered as being sufficiently achieved (Krahn *et al.* 2006).

Without negating the presence of positive attitudes among health professionals, (e.g. Gill *et al.* 2002; Melville *et al.* 2005), stigmatising attitudes that

counteract inclusion in mainstream healthcare services might be present (Iacono *et al.* 2014). Preliminary evidence indeed affirms that stigmatising attitudes of mainstream health professionals can be a barrier for people with ID in the access to good quality, mainstream healthcare services (Lindsey 2002; Gill *et al.* 2002; Krahn *et al.* 2006). For example, studies describe the tendency of clinicians to overlook symptoms of mental health problems and attribute them to being part of ‘having an intellectual disability’ (diagnostic overshadowing) (Mason & Scior 2004; Werner *et al.* 2013). Also, people with ID and their carers have reported perceived discrimination and negative comments as a significant experience in general hospitals (Gibbs *et al.* 2008). It is thus crucial to examine the stigmatising attitudes of health professionals, and to create awareness to further improve inclusion in mainstream healthcare services.

The ID field, in contrast to the field of mental illness, however lacks a systematic conceptualisation of stigma (Ditchman *et al.* 2013). Stigma refers to the possession of a powerful label that conveys a devalued social identity within a certain context (Goffman 1963; Link & Phelan 2001). From a social-psychological perspective, stigmatising attitudes are related to cognitions, as well as to affective reactions and discriminatory behaviour (Dovidio *et al.* 2000; Link & Phelan 2001; Corrigan & Watson 2002). The cognitive dimension reflects the lack of knowledge and perceptions of, in this case, health professionals about people with ID (e.g. negative stereotypes, attributions). The affective dimension entails the emotional reactions of health professionals to people with ID (e.g. fear, pity). The behavioural dimension reflects the discriminatory behaviour or the behavioural intentions towards people with ID (e.g. social distance, discrimination) (Dovidio *et al.* 2000).

Stigmatising attitudes towards people with ID have received limited research attention and that only recently (Ditchman *et al.* 2013). This recent attention is apparent in stigma reviews concerning members of the general public (Scior 2011), medical students (Ryan & Scior 2014) and people with ID themselves (Ali *et al.* 2012). Research into the stigmatising attitudes of mainstream health professionals is also scarce. In the present review, we therefore aimed to appraise the findings of studies to address the following questions: (1) do mainstream health

professionals hold stigmatising attitudes towards people with ID? and (2) what is the nature of these attitudes? The social–psychological triad is used as a guideline to structure and discuss the results within the present review.

Method

Search strategy

The databases PubMed, Psych INFO, CINAHL and ProQuest (i.e. Social Services Abstracts and Sociological Abstracts) were systematically searched. These databases were chosen to include medical literature from both PubMed and CINAHL as well as psychological literature from Psych INFO. The ProQuest databases were included to cover all ID peer-reviewed journals. The aim was to discover studies evaluating stigmatising attitudes of mainstream health professionals towards people with ID. Studies were published in the English language in peer reviewed journals from January 1994 to January 2016.

Search terms were based on the PICO approach specifying Population, Intervention/exposure, and Comparison and Outcome (Liberati *et al.* 2009) (see Table 1). In this study a comparison component was irrelevant because of the descriptive nature of the research question. Similarly, study designs were not specified because various empirical designs could provide relevant information regarding the research questions. Studies could be either qualitative or quantitative in nature. *Population* was specified as health professionals with direct patient or client contact. Professionals with direct contact were defined as those professionals for whom treatment and/or care of patients/clients was an important part of their job description (e.g. nurses, GP's, dentists). Therefore, participants holding jobs like household staff, managers and directors, were excluded. Direct contact was assumed based on job titles and context information of the article. In case of uncertainty, the authors of an article were contacted to obtain this information. When articles included a mix of professionals with (e.g. nurses) and without (e.g. directors) direct patient or client contact, results were only included when: (1) separate results were provided for the different groups of professionals; or (2) it was demonstrated that there were no

Table 1 Search strategy PubMed using Medical Subject Headings [MeSH] and text words

PUBMED final search strategy	
1	<i>Population: health professionals</i>
#1	Health Personnel [MeSH]
#2	Staff [TI/AB]
#3	Service-provider* [TI/AB]
#4	#1 OR #2 OR #3
2	<i>Exposure: intellectual disability</i>
#5	Intellectual disability [MeSH]
#6	Mentally disabled person [MeSH]
#7	Developmental Disabilities [MeSH]
#8	Learning Disorders [MeSH]
#9	Intellectual Disab* [TI/AB]
#10	#5 OR #6 OR #7 OR #8 OR #9
3	<i>Outcomes: stigmatising attitudes</i>
#11	Social stigma [MeSH]
#12	Stereotyping [MeSH]
#13	Attitude [MeSH]
#14	Knowledge [MeSH]
#15	Social distance [MeSH]
#16	Social discrimination [MeSH: NoExp]
#17	Prejudice [MeSH: NoExp]
#18	Rejection [MeSH]
#19	Social Marginalization [MeSH]
#20	Attitude*[TI/AB]
#21	#11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20
4	<i>Outcomes & Exposure: stigmatising attitudes toward disability*</i>
5	<i>Outcomes & Population: stigmatising attitudes of health professionals</i>
#22	Attitude of Health Personnel [MeSH]
6	<i>Combining search term groups</i>
#23	#4 AND #10 AND #21 (health professionals & intellectual disability & stigmatising attitudes)
#24	#10 AND #22 (intellectual disability & stigmatising attitudes of health professionals)
#25	#25 OR #26

Note. TI/AB refers to the search for text words within title and abstract; MeSH refers to the search for Medical Subject Headings, the thesaurus terms that were used in PubMed. All thesaurus terms, unless stated otherwise, were expanded to various lower level terms. For example the term 'health personnel' encompassed all health personnel from dentists to psychotherapist to nurses. Similar search strategies were used for Psych Info, ProQuest and CINAHL
*Not applicable within PubMed, but for example the thesaurus term 'attitude to disability' was used in CINAHL.

(statistically significant) differences between these groups. Furthermore, students were excluded

because their stigmatising attitudes have been recently reviewed (Ryan & Scior 2014). Regarding the *intervention/exposure*, studies should concern people with ID. The *outcome* of research should include cognitive, affective or behavioural dimensions of stigmatising attitudes by which people are viewed or treated as devalued. Table 2 presents an overview of the inclusion and exclusion criteria.

Table 1 provides an overview of the search terms and strategy applied in PubMed using both Medical Subject Headings (MeSH) and additional text words. MeSH is the controlled vocabulary thesaurus that PubMed uses for indexing articles. Other databases have similar thesauri. The use of thesaurus terms did have two benefits. First, thesaurus terms enabled us to

find articles about stigmatising attitudes independent of the words that articles used to describe stigma.

Second, because of the hierarchical tree structure of thesaurus terms, it was possible to search for several specific terms under the heading of higher order terms. For example, by using the MeSH term 'health personnel', we automatically searched using approximately 100 specific terms (e.g. orthodontist, physical therapist). We repeatedly tested our search strategy to discover which text words were necessary in addition to thesaurus terms to find all relevant articles. The text words intellectual disab*, staff, service-provider* and attitude* were added to the search strategy. Similar search strategies were used in the other databases.

Table 2 Inclusion and exclusion criteria

Inclusion criteria

- Main participants of the study were mainstream health professionals who have direct client or patient contact. Direct contact was defined as treatment-related contact (e.g. contact between nurses/therapists and patients).
- Outcome of the study comprised cognitive, affective or behavioural dimensions of stigmatising attitudes by which people are viewed or treated as devalued
- The study concerned people with ID

Exclusion criteria

Participants:

- Studies solely focusing on students
- Studies in which the sample included health professionals without direct client contact (e.g. managers or directors) and/or no separate statistics for health professionals with direct client contact were provided
- Studies about specialist ID staff¹

Exposure:

- Studies focusing on disability in general
- Studies focusing exclusively on children with ID²
- Studies focusing exclusively on sexuality and parenthood of people of ID
- Studies focusing on a specific subset of disability which was not necessarily related to ID (e.g. acquired brain injury; autism; epilepsy) and in which ID was not discussed

Outcome:

- Studies focusing on perception of training needs or need for support for staff
- Studies focusing on perception or attitudes toward a specific intervention, special care or special services
- Studies focusing on sexual behaviour or challenging behaviour or bereavement without attention to attitude to people with ID themselves.
- Studies focusing on opinions about care for people with ID
- Studies focusing on attitudes toward specific prenatal screening tests
- Studies focusing on structural discrimination (e.g. structural barriers in accessing healthcare) without attention to stigmatising attitudes of health professionals

General

- No original research
 - Studies presenting merely psychometric data (i.e. validity and reliability of a measure)
-

Note. ¹(1) we have used this criterion within the full text selection, (2) articles about specialist ID staff are separately archived for future research and (3) specialist ID staff was defined as health professionals working for a specialist ID organisation. ²Articles referring to 'people with ID' without specifying life-stage or age were included.

Study selection

The selection process for studies consisted of four phases: identification, screening, eligibility and inclusion (see Fig. 1). In the identification phase, records were identified in four different databases. The screening phase involved title and abstract selection, in which duplicates, essays and review studies were excluded. The titles were independently screened by two reviewers (HP and PE, WvO or JvW) based on the inclusion criteria. Records were retained

when the title fulfilled all three inclusion criteria, or when there was uncertainty about the presence of a criterion. This strategy resulted in 84% agreement on average between the different reviewer-dyads. The reviewers discussed differences until full consensus was reached. Thereupon, the remaining records proceeded to the abstract selection where exclusion criteria were independently assessed by two reviewers (HP and WvO) who achieved 77% agreement. Disagreements were again discussed until full

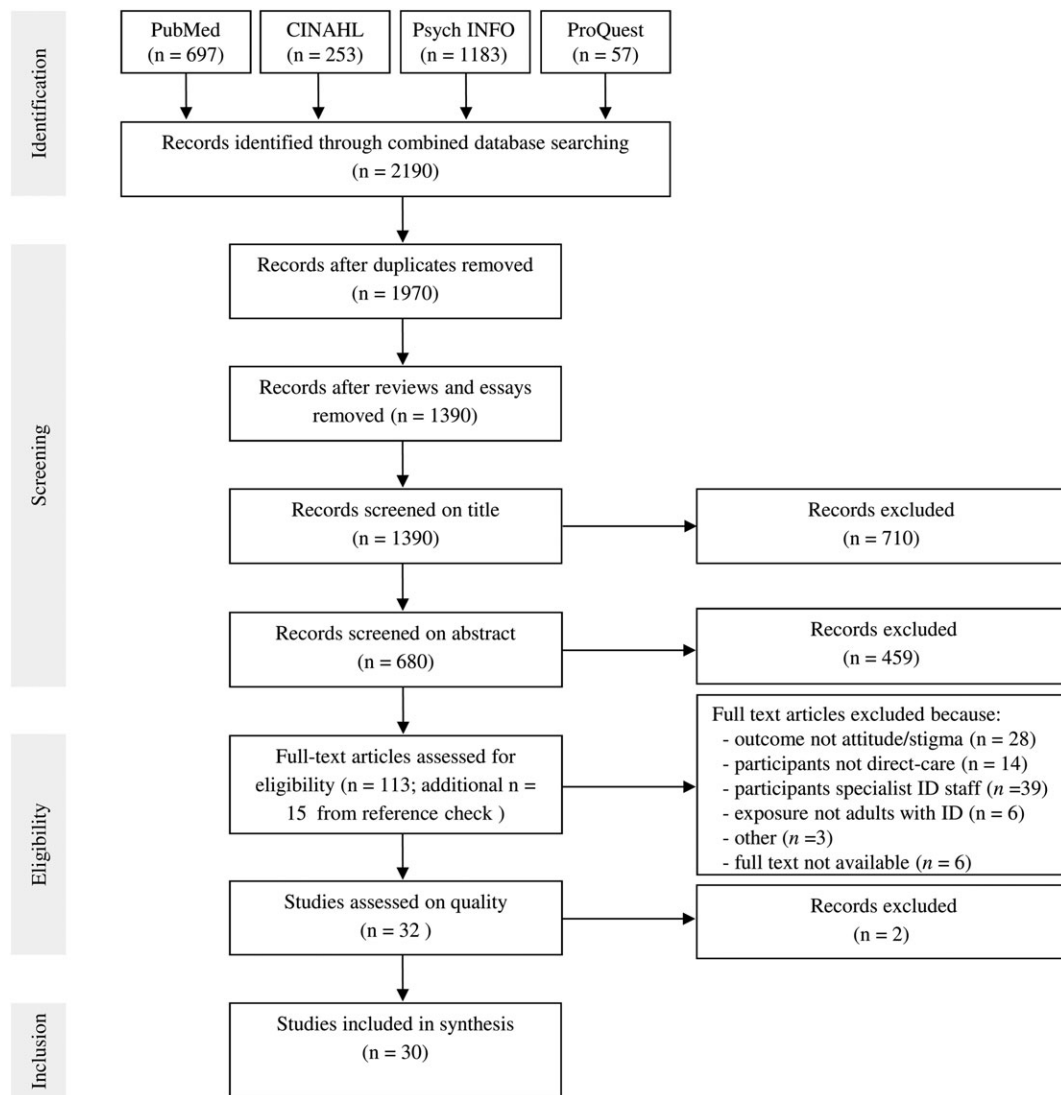


Figure 1 Flowchart of the literature selection process.

consensus was reached. The other reviewers (PE and JvW) were consulted regarding complex decisions.

In the eligibility phase, full text articles were scrutinised for the presence of inclusion and exclusion criteria. These criteria were then extensively discussed by two reviewers (HP and WvO). In case of uncertainty about criteria, authors of the original article were contacted for clarification. The quality of the remaining studies was assessed using the Multi Method Appraisal Tool (MMAT, Pluye *et al.* 2011), an instrument to assess the quality of studies with various research designs (i.e. qualitative, quantitative randomised, quantitative non-randomised, descriptive and mixed method studies). This instrument has demonstrated good content validity and reliability (Pluye *et al.* 2011). Appraisal was discussed by a senior researcher (WvO), experienced in conducting and supervising systematic reviews, and the first author (HP). Quality criteria could be rated as 'present', 'absent' or 'can't tell'. In calculating scores, 'can't tell' evaluations were considered to be absent. Studies with a zero total score on the screening questions or a zero total score on the four quality criteria were independently assessed by a third researcher with experience in conducting systematic reviews. If there was a consensus about the absence of positive scores, the study was removed from further analysis. Percentage scores of the quality appraisal are presented in Table 3. Finally, reference lists of the remaining articles were screened for potentially relevant studies. As a result, 15 additional full text articles were assessed for eligibility. Studies that were suitable based on the screening and eligibility phase were included in the present review.

Data extraction and analysis

Both general information and main results were extracted from the selected studies and summarised in Table 3. Because of the heterogeneity of the design, population, and setting of the included studies, a narrative synthesis rather than a structured analysis (e.g. meta-analysis) was most feasible.

Results

Figure 1 depicts the selection process and includes the number of studies screened, assessed for eligibility, and included in the review. The databases search

generated a total of 2190 records of which 30 studies were identified for final inclusion.

Background and research quality

With respect to background information, 10 studies were conducted in the United Kingdom, six in the United States, five in Australia, two in Ireland, two in the Netherlands and one each in New Zealand, India, Italy, Canada and Sweden. Professionals involved in the studies were dentistry-related practitioners [$n = 4$], general practitioners [GPs; $n = 9$], nurses ($n = 5$), practitioners working in psychiatry ($n = 4$), midwives ($n = 1$), rehabilitation service providers ($n = 1$), community service workers ($n = 1$) or a mix of different practitioners ($n = 4$).

Included studies used various designs and were of diverse quality. Twenty-five studies used a quantitative approach, four studies were qualitative and one study used a mixed methods design. Generally, studies were of moderate quality as assessed using the MMAT. Quality assessment found two studies of lower than acceptable quality which were therefore removed from further analyses. The main methodological limitation of the remaining quantitative studies concerned the sampling. Mostly convenience samples from a medical association or congress were used. Studies, however, that sampled widely in a certain area or large database generally obtained a small response rate. In descriptive studies, measures with unclear origin were often used. Methodological limitations of qualitative studies mainly concerned the limited attention towards reflexivity on how findings relate to the researchers' influence (e.g. researchers perspective, role and interaction with participant), and a limited description of the context of the study and its influence on the results.

The content of the studies will be discussed following the triad of cognitive, affective and behavioural dimensions of stigma. Because of the focus on barriers in attitudes, positive attitudes have not been reported.

Cognitive dimension

Knowledge and familiarity

A lack of knowledge about and familiarity with ID was found. Most nurses reported little knowledge of the

Table 3 Main characteristics of the studies included and summary of relevant results

#	Authors	Country	Design	Setting	Participants	Outcome instrument	Stigmatising attitudes—results	Quality appraisal*
1	Bedi <i>et al.</i> 2001	UK	I	General post-graduate dental course	General Dental Practitioners (GDP's) (<i>n</i> = 74) Professionals complementary to dentistry (PCD's) (<i>n</i> = 89)	Attitude scale about discriminatory views towards dental care for patients with ID	GDP's were concerned with treatment effectiveness, stress related to treatment and whether people with ID should be treated in general practice. PCDs concerned with human rights; expressed high expectations about capabilities. GDP's vs. PCD's GDP's less positive attitudes than PCD's.	(2/4) 50%
2	Bekkema <i>et al.</i> 2014	NL	I	National registration of GPs; research panel of registered ID care staff; Dutch professional association of ID physicians.	GPs (<i>n</i> = 377) ID physicians (<i>n</i> = 145) Care staff (<i>n</i> = 196)	Questionnaire about— case-related considerations about end-of-life care 2—beliefs about medical interventions	GPs score lower than care staff and similar to ID physicians on statement 'client wishes about whether to use medical interventions should always be leading' GPs score lower than care staff on the item 'if a clients' wishes are not in line with the opinion of the caregivers, the clients' wishes prevail.' GPs score higher than ID physicians and similar to care staff on item: 'clients should always be informed about options for interventions, even if possibilities for communication are limited'.	(2/4) 50%
3	Bekkema <i>et al.</i> 2015	NL	I	National registration of GPs; research panel of registered ID care staff; Dutch	GPs (<i>n</i> = 377) ID physicians (<i>n</i> = 145) Care staff (<i>n</i> = 196)	Questionnaire about— place of end-of-life care for recent patient with ID	GPs score lower than care staff on the item: 'the clients' wishes as to where	(2/4) 50%

(Continues)

Table 3. (Continued)

#	Authors	Country	Design	Setting	Participants	Outcome instrument	Stigmatising attitudes—results	Quality appraisal*
4	Brown & Inglehart 2009	US	1	professional association of ID physicians. Active members of the American Association of Orthodontists and orthodontic residents	Orthodontic residents (n = 135) Orthodontists (n = 568)	2—beliefs about appropriate environment for end-of-life care Questionnaire about 1—educational experiences 2—attitudes concerning treatment 3—provision of care	they want to live at the end of life should always be leading' 41.4% of orthodontists disagreed with item: 'I like to treat patients with mental retardation. 38.1% was neutral, 20.6% agreed. 23.6% of orthodontists disagreed with the item: 'I am confident treating patients with mental retardation; 25.9% is neutral, 48% agrees. The more positive attitudes the more likely to treat patients with ID.	(1/4) 25%
5	Brown & Inglehart 2011	US	1	Orthodontic residents and active members of the American Association of Orthodontists	Orthodontic residents (n = 135) Orthodontists (n = 568)	Questionnaire about 1—educational experiences 2—attitudes concerning treatment 3—behavioural intentions Questionnaire about 1—behavioural medication 2—specialist support 3—organisation of care 4—rural/urban trends 5—open question	62% GPs agreed they are responsible for medical care of people with ID in community; 30.7% is neutral, 7.3% disagrees. 15.3% of GP's agree that all people with an ID should live in the community, 32.8% is neutral and 49.6% disagrees. Open comments: some people are better cared for in an institution; community living depends on severity and family support available.	(1/4) 25%
6	Dovey & Webb 2000	NZ	2	Registered GP's in the southern region of New Zealand	GP (n = 137)	Questionnaire about 1—behavioural medication 2—specialist support 3—organisation of care 4—rural/urban trends 5—open question	58% of psychiatrists agree they prefer not to treat people with ID; 34%	(3/4) 75%
7	Edwards <i>et al.</i> 2007	AU	2	Royal Australian and New Zealand Council of	Psychiatrists (n = 306) Psychiatric registrars (n = 104)	Questionnaire about 1—management of adults with ID	58% of psychiatrists agree they prefer not to treat people with ID; 34%	(1/4) 25%

(Continues)

Table 3. (Continued)

#	Authors	Country	Design	Setting	Participants	Outcome instrument	Stigmatising attitudes—results	Quality appraisal ^a
8	Flynn <i>et al.</i> 2015	UK	I	Psychiatrists residing in Queensland UK Oncology Nursing Society	Nurses working in oncology or related field (i.e. palliative care) (n = 83)	2—training needs 1—Care perceptions and attitudes scale 2—Perceived stress scale	disagrees. 90% supports need to investigate psychiatric symptoms in more intellectually disabled; 78% agrees individual psychotherapy is useful treatment. Caring for people with ID compared to other patients perceived as more difficult. In reaction to vignettes less comfortable talking to people with ID about their illness compared to other patients; less positively about providing care for them. Caring for people with ID would more easily cause stress. Medium to large effect sizes found. Previous experience with people with ID related to positive attitudes.	(2/4) 50%
9	Gill <i>et al.</i> 2002	UK	I	Practicing GPs registered within three health authorities	GP (n = 226)	1—Attitude scale 2—Emotional experience scale	Positive attitudes towards providing primary healthcare. Behavioural intentions (e.g. adapting communication, or allowing more time) lower than general beliefs (e.g. working with people with ID is part of GP's role). Few negative emotions, moderate occurrence positive emotions associated with providing care. Most frequent: confident, relaxed; moderate frequency:	(2/4) 50%

(Continues)

Table 3. (Continued)

#	Authors	Country	Design	Setting	Participants	Outcome instrument	Stigmatising attitudes—results	Quality appraisal ^a
10	Gilmore & Malcolm 2014	Au	I	Practicing GPs in the state of Queensland	GP (n = 106)	1—ASQ-General Population 2—ASQ-ID	frustration, optimism. Negative and positive attitudes within open questions. Less support for sexual freedom of adults with than without ID. Views positive for sexual rights, non-reproductive sexual behaviour, self-control, less positive about parenting. For men with ID 23%, for women with ID 41% of the GPs endorsed sterilisation as desirable practice. Attitudes to male and female sexuality similar. Older GP's more support for sterilisation. Majority believe sterilisation desirable in nine conditions, e.g. when individual is unable to parent, or when available parenting support is limited or costly.	(2/4) 50%
11	Höglund <i>et al.</i> 2013	Se	I	Antenatal care and labour wards	Midwives (n = 375)	Questionnaire about 1—Knowledge 2—Attitudes 3—Experiences 4—Education (needs)	1/3 of midwives had good knowledge about women with ID. 1/3 felt women with ID should not be pregnant and become mothers; 2/3 agreed they cannot manage the mother role satisfactorily. Midwives felt uncertainty how to adapt advice to people with ID (85%); find it difficult to give advice (80.1%). Most agreed that children of people with ID should grow up with parents and accompanying support. 1/5	(3/4) 75%

(Continues)

Table 3. (Continued)

#	Authors	Country	Design	Setting	Participants	Outcome instrument	Stigmatising attitudes—results	Quality appraisal ^a
12	Lennox & Chaplin 1995	Au	2	Public psychiatric services in Victoria	Psychiatric trainees and medical officers (n = 116)	Questionnaire about people with ID seen; opinions management; improvement of services; interest ID	agreed children should grow up in foster care. More professional years and experience with ID related to more knowledge. 1/3 of psychiatrist prefer not to treat people with dual disabilities; 90% support need to investigate psychiatric symptoms in more intellectually disabled; 81% agrees individual psychotherapy is useful treatment.	(2/4) 50%
13	Lennox <i>et al.</i> 1997	Au	2	Full- and part-time medical practitioners acknowledged and registered as GP in Australia	GPs (n = 526)	Questionnaire about 1—work environment 2—level of training 3—willingness for education 4—personal experiences 5—barriers in providing care	69% knew a person with ID outside practice work. Last six months 60% saw between 0–5 persons with ID. 15% of GPs would personally prefer not to treat people with ID. 62% of GPs felt confident treating people with ID. 80% agrees it is harder to provide good quality healthcare. Many GPs reported lack of knowledge about conditions common in people with ID.	(3/4) 75%
14	Lewis & Stenfort-Kroese 2010	UK	1	General medical and surgical wards from six general hospitals	Nursing staff (n = 268)	Questionnaire on 1—Attitudes 2—Positive emotions 3—Negative emotions	Generally positive attitudes; frequent positive emotions infrequent negative emotions associated with caring. Less positive attitudes, fewer positive emotions, more negative emotions towards people with ID than physical disabilities.	(2/4) 50%

(Continues)

Table 3. (Continued)

#	Authors	Country	Design	Setting	Participants	Outcome instrument	Stigmatising attitudes—results	Quality appraisal ^a
15	McConkey & Truesdale 2000	Ire	1	1—Hospital and community; 2—Occupational/physio therapists; 3—ID day/residential care; 4—University courses	1—Post-qualified nurse (n = 269) 2—Therapist (n = 169) 3—ID Staff (n = 270) 4—Undergraduate student (n = 261)	Questionnaire on 1—Previous contact 2—Confidence at meeting 3—Willingness for social contact	Therapists and nurses more confident meeting people with physical disabilities than ID. Positive scores on willingness for social contact in their personal lives with people with ID.	(1/4) 25%
16	McIlpatrick <i>et al.</i> 2011	UK	3	Three Health and Social Care Trusts across Northern Ireland; primary care group for a local cancer network	1—Primary care staff (e.g. GPs and practice nurses) (n = 9) 2—Breast screening staff (n = 9)	Focus group and telephone interviews 1—knowledge of risk factors 2—experience supporting women with ID in breast cancer screening 3—barriers and solutions	Participants reported low cognitive functioning as main risk factor associated with breast cancer; this risk factor related to low expectations of capabilities of people with ID, e.g. lack of ability to self-examine, poor literacy skills to understand the invitation for screening, and poor attendance for screening.	(2/4) 50%
17	Melville <i>et al.</i> 2005	UK	2	Healthcare practices for health promotion, health monitoring and disease-specific clinics	Practice nurses (n = 201)	Questionnaire about knowledge, attitudes, self-efficacy and training needs	Practice nurses feel they have an important role in meeting health needs of people with ID (75.2% agree); although ID nurses should have the main role in meeting nursing needs according to 43.7%.	(2/4) 50%
18	Mesa & Tsakanikos 2014	UK	1	Qualified staff from an acute inpatient psychiatric ward	Staff (i.e. nurses, occupational therapists, psychiatrists, social workers) (n = 68)	1—CLAS 2—Self-efficacy scale	70.6% of psychiatric staff agreed that people with mild ID should be admitted to general psychiatric inpatient care. Psychiatric staff demonstrated no differences in attitudes of similarity, sheltering and exclusion between mental illness and ID; scores for empowerment	(1/4) 25%

(Continues)

Table 3. (Continued)

#	Authors	Country	Design	Setting	Participants	Outcome instrument	Stigmatising attitudes—results	Quality appraisal*
19	Nagarajappa <i>et al.</i> 2013	In	I	Private practitioners at 60 dental clinics, faculty and postgraduate students of dental institutions	Dentists (n = 247)	Questionnaire about 1—Experience 2—Attitudes (beliefs, capabilities, discrimination, social behaviour, quality of care)	were higher in MI than ID group. 61% of dentists say that treating people with ID causes too much stress. Dentists doubted capabilities, e.g. people with ID can reach same standard of oral hygiene as other people (78% disagrees); able to make own healthcare decisions (22.8% agrees). 83% of dentists find treating people with ID highly rewarding. Discrimination should not occur. Social behaviour may be disturbing. Positive attitudes towards community living. Sheltering scores neutral. Residents feel people with ID should somewhat be protected.	(3/4) 75%
20	Ouellette-Kuntz <i>et al.</i> 2003	Ca	I	Preparatory session for the certification examination of the Royal College of Physicians and Surgeons	Senior psychiatry residents (n = 58)	1—Exposure-scale 2—CLAS (short form)	24.2% agreed that including students with DS in classes with typically developing students is distracting, 36.7% responded neutral and 39% disagreed. 76% comfortable providing medical care to a person with DS, 14.3% neutral, 9.8% uncomfortable. Most physicians agree that people with DS should be able to work (89.1%).	(2/4) 50%
21	Pace <i>et al.</i> 2011	US	I	Opt-in verified panel of 135 000 medical practitioners	1—Paediatricians (n = 250) 2—Obstetricians/gynaecologist (n = 250) 3—Internist (n = 490) 4—Family practitioner (n = 510)	5 questions about inclusion of people with Down Syndrome (DS)	16% agrees therapy could not be offered in	(1/4) 25%
22		UK	I		IAPT therapists (n = 55)	Questionnaire on attitudes, confidence, self-efficacy		(1/4) 25%

(Continues)

Table 3. (Continued)

#	Authors	Country	Design	Setting	Participants	Outcome instrument	Stigmatising attitudes—results	Quality appraisal ^a
	Shankland & Dagnan 2015			National Health Service Trusts in North West England		towards working with people with ID; open questions about opinion towards providing therapy to people with ID	mainstream services; themes mentioned by participants: therapists should adapt, even if more difficult (62.5%); difficult to treat people with ID without extra training (100%); not possible for severe impairment (35.7%); people with ID less ability to make changes based on therapy (70%); rigidity of thinking (30%). Therapists have lack of confidence (33%) and knowledge (25%) in treating people with ID. Several patient-based limitations mentioned.	
23	Slevin & Sines 1996	Ire	4(3)	General hospital setting	Graduate/Non-graduate nurses (<i>n</i> = 10)	Semi-structured interviews about knowledge, perceived differences, need for ID carer, perceived fears, location in ward, contacts with people with ID, communication, perceived education need.	Cognitive: labelling of ID as low intelligence (30%) or as Down syndrome/altered brain structure, not social impairment; 31% people with ID totally different, having poor expectations, expecting bizarre behaviour; Affective: 47% fear related to violence; 35% felt awkward, not able to cope or frightened about contacts; 27.5% contacts brilliant stimulating experiences; 50% felt not competent communicating 28% felt competent; behavioural: 31%	(7/11) 64%

(Continues)

Table 3. (Continued)

#	Authors	Country	Design	Setting	Participants	Outcome instrument	Stigmatising attitudes—results	Quality appraisal ^a
24	Sowney & Barr 2006	Ire UK	4(1) 3	General hospital setting Accident and emergency departments in general hospitals	Graduate/Non-graduate nurses (n = 31) Nurses (n = 27)	ATDP Focus groups on previous opportunities to work with people with ID; previous experiences in the A & E with people with ID; challenges; views on what helped them to provide care	people with ID in side room because of their behaviour; 60% no social contacts with people with ID. No general mean scores provided. Fear and vulnerability because of: not knowing how to respond, embarrassment if you don't know how to react; not knowing about ID; diagnostic overshadowing or over-investigation; missing out serious problem; treating them differently. Lack of knowledge about ID related to fear. Misunderstanding that carers could consent for adult with ID for examination treatment and care; reduces right to assert control over own bodies and make decisions about examination care and treatment.	(1/4) 25%
25	Stein 2000	UK	2	64 practices of GPs in a district	GPs (n = 48)	Questionnaire about 1—Demands of people with ID 2—Confidence and training needs; 3—Provision of services; 4—Attitudes to screening	Majority of GPs willing to meet primary care needs in general medical services yet need time, funds and cooperation with ID service. All aspects of care for people with ID	(3/4) 75%

(Continues)

Table 3. (Continued)

#	Authors	Country	Design	Setting	Participants	Outcome instrument	Stigmatising attitudes—results	Quality appraisal ^a
26	Strauser <i>et al.</i> 2009	US	I	Community-based rehabilitation	Rehabilitation service providers (<i>n</i> = 98)	Psychiatric Disabilities Attribution Questionnaire	should be met by professionals working with ID services (29.7% agree; 21.3% undecided; 48.9% disagree); GPs should meet the primary healthcare needs of people with ID as part of general medical services. (62.2% agree; 10.6% undecided; 27.7% disagree). Stability: ID scored above the threshold on the subscale of stability indicating a stigmatising view that people are not likely to benefit from treatment or are likely to recover. Controllability: For controllability people with ID scored lowest compared to other disabilities indicating that people with ID are not held responsible for their condition.	(1/4) 25%
27	Tartakovsky <i>et al.</i> 2013	II	I	NGO community services for people with ID and people with severe mental illness (SMI)	1—Community service workers in ID (<i>n</i> = 126) 2—Community service workers in SMI (<i>n</i> = 96)	1—CLAS2—Value preference scale 3—Burn out-scale	High scores on value of power was related to lower levels of empowerment and similarity and higher levels of exclusion. Self-direction and similarity positively related; benevolence and similarity positively related.	(3/4) 75%

(Continues)

Table 3. (Continued)

#	Authors	Country	Design	Setting	Participants	Outcome instrument	Stigmatising attitudes—results	Quality appraisal ^a
28	Torr <i>et al.</i> 2008	Au	I	Fellows of Victorian branch of Royal Australian and New Zealand College of Psychiatrists	Psychiatrists (n = 170)	Questionnaire about people with ID seen; opinions management; improvement of services; interest ID	I would prefer not to treat people with ID; neutral mean scores and a higher score in 2004 compared to 1994. Individual supportive psychotherapy can be a useful intervention, high mean score. Inpatient psychiatric care should be provided in units dedicated to adults with ID, mean score indicates moderate agreement.	(1/4) 25%
29	Wilkinson <i>et al.</i> 2012	US	3	Academic practice, private practice, ID-focused practice; national e-mail list and conference attendees list	GPs (n = 22)	Experience caring for people with ID and needed resources; previous experience; medical training; recommendations	GPs felt unfamiliarity with daily lives of people with ID. Discomfort and lack of confidence when interacting with people with ID: main issue leading to frustration. Sometimes stereotyping as beautiful people, not being locked up. Feeling overwhelmed and out of control about interactions with people with ID. Not knowing what to expect from patients with ID, perceived as different and somewhat intimidating. Sometimes anxiety about challenging behaviours.	(2/4) 50%
30	Wilkinson <i>et al.</i> 2013	US	3	Community-based organisations; local list	Women with ID >40 years of age (n = 27) GP (n = 22)	Experience with ID; resources needed; previous life	Physicians felt frustration at time needed to see patients with ID; time =	(1/4) 25%

(Continues)

Table 3. (Continued)

#	Authors	Country	Design	Setting	Participants	Outcome instrument	Stigmatising attitudes—results	Quality appraisal*
				practices and national email list.		experience with ID and training needs	luxury; and felt regret and guilt about not spending as much time as necessary to provide high quality care. Physicians expressed positive feelings about relationship with people with ID. Positive feelings related to being perceived positively by others because of working with this potentially challenging population. A feel-good population. Physicians trying to say something nice about patients with ID but comments indicated seeing people with ID as children (like kids, simple), or people who following commands.	

Note. Study design: 1 = cross sectional; 2 = descriptive; 3 = qualitative; 4 = mixed method. Questionnaires: Community Living Attitude Scale (CLAS); Attitudes to Sexuality Questionnaire (ASQ); Attitude Towards Disabled Persons scale (ATDP). More results are presented within articles; however, only results which were relevant and dealt with health professionals with direct patient or client contact were subtracted from the article.

*Quality scores are based on information available within the article when answering the MMAT questions.

nature of ID and associated healthcare issues (Sowney & Barr 2006). Only one third of midwives had good knowledge about women with ID (Höglund *et al.* 2013), and GPs commonly mentioned a lack of knowledge about conditions common in people with ID (Lennox *et al.* 1997). Moreover, GPs felt unfamiliar with the daily lives of people with ID (Wilkinson *et al.* 2012). Also, McConkey and Truesdale (2000) reported that up to a quarter of nurses and therapists in their study have had no contact at all with people with ID. A third of the GPs did not know anyone with ID outside their practice, and almost two thirds had seen between zero and five patients with ID during the previous six months (Lennox *et al.* 1997). Lack of familiarity is especially important because several studies found that previous contact with people with ID is associated with less stigmatising attitudes (Slevin & Sines 1996; McConkey & Truesdale 2000; Bedi *et al.* 2001; Gill *et al.* 2002; Ouellette-Kuntz *et al.* 2003; Höglund *et al.* 2013; Nagarajappa *et al.* 2013; Flynn *et al.* 2015).

Attributions of stability and controllability

Attributions of ID differ from the attributions of other medical conditions. Rehabilitation service providers perceived ID as the most stable condition not under personal control when compared to depression, cocaine addiction, cancer, AIDS or psychosis. That is, people with ID were not held responsible for their condition and were also not likely to benefit from treatment or to recover (Strauser *et al.* 2009). Additionally, many psychotherapists doubted the ability of people with ID to make changes in their lives based on psychological treatment (Shankland & Dagnan 2015).

Expected capabilities

Although dental auxiliaries in the UK and physicians in the USA demonstrated high expectations of the capabilities of people with ID (Bedi *et al.* 2001; Pace *et al.* 2011), opposite attitudes were also reported. For example, over three quarters of dentists in India doubted the capabilities of people with ID to maintain oral hygiene, make healthcare decisions or understand the explanation of their treatment plan (Nagarajappa

et al. 2013). Breast cancer screening staff reported low expectations as well, for example about people's understanding and awareness of breast care, the ability to self-examine and attendance for screening (McIlfatrick *et al.* 2011). Moreover, in the study of Höglund *et al.* (2013), two third of the midwives thought that mothers with ID could not manage the mother-role satisfactorily.

Stereotypical perceptions

Most nurses viewed people with ID as more difficult to care for than people with physical disabilities because they would less easily comply with requests, would be more easily distressed, would be more emotional, possibly aggressive and less cooperative (Lewis & Stenfert-Kroese 2010). Similarly, GPs in a qualitative study by Wilkinson *et al.* (2012) perceived people with ID as different and somewhat intimidating. Some physicians in a qualitative study referred to people with ID as 'children or people who follow commands', and also as 'pleasant, delightful and funny people' (Wilkinson *et al.* 2013). Two studies reported that health professionals expected strange or intimidating behaviour from people with ID. A third of the interviewed nurses referred to people with ID as being totally different and demonstrating bizarre behaviour (Slevin & Sines 1996).

Affective dimension

Feelings of stress and confidence

Mainstream health professionals reported stress and a lack of confidence in providing care for people with ID. Health professionals were less confident and more stressed in relation to patients with ID than patients without ID or with physical disabilities (McConkey & Truesdale 2000; Lewis & Stenfert-Kroese 2010; Flynn *et al.* 2015). About half of the orthodontists and a third of GPs did not feel confident in treating people with ID (Brown & Inglehart 2009; Lennox *et al.* 1997). In a study of Nagarajappa *et al.* (2013), two thirds of participating dentists reported that caring for people with ID would cause them to be stressed. GPs reported this lack of confidence to be a main issue leading to frustration when working with people with ID (Wilkinson *et al.* 2012).

Feelings of fear and anxiety

Fear and anxiety were reported among professionals. Two studies reported that half of the nurses and some GPs feared the possibility of challenging behaviour (Slevin & Sines 1996; Wilkinson *et al.* 2012) and not knowing what to expect from people with ID (Wilkinson *et al.* 2012). In addition, several nurses reported a fear of missing a serious problem because of diagnostic overshadowing, a fear of treating people with ID differently and some reported a fear of embarrassment if they did not know how to react (Sowney & Barr 2006).

Behavioural dimension*Supporting autonomy*

Several studies indicated insufficient support of autonomy and decision making of people with ID. Mainstream health professionals focussed on the carer accompanying people with ID to gain information because it was seen as more efficient (e.g. Gill *et al.* 2002; Sowney & Barr 2006; Nagarajappa *et al.* 2013). Furthermore, GPs had lower scores than specialist ID staff on items relating to whether the wishes of clients should be paramount in decisions about medical interventions or residency (Bekkema *et al.* 2014; Bekkema *et al.* 2015). Also, Sowney and Barr (2006) reported that, for accident and emergency unit nurses, there was a common but misguided assumption that carers could consent to treatment and care on behalf of an adult with ID. Finally, the support of empowerment by psychiatric staff was found to be lower for people with ID than for people with a mental illness (Mesa & Tsakanikos 2014). Psychiatric staff believed that, to some extent, people with ID must be protected (Ouellette-Kuntz *et al.* 2003).

Treating differently

Results indicate that professionals sometimes have the tendency to treat patients with ID differently compared to patients without ID. A third of the nurses interviewed in a general hospital would for example place people with ID on a side ward so as not to disturb other patients (Slevin & Sines 1996). In a comparable study, nurses indicated that they were on average more willing to place people with ID on a side ward than people with physical disabilities. The same

group of nurses would also avoid invasive interventions more easily with people with ID than people with physical disabilities because they would be more difficult to carry out (Lewis & Stenfort-Kroese 2010).

Providing access to mainstream healthcare services

Most health professionals agreed with the right of people with ID to be treated in mainstream healthcare practice (e.g. Stein 2000; Melville *et al.* 2005); stigmatising attitudes were found for a minority of health professionals. Sometimes, health professionals were negative because people with ID were seen as a burden on their time and that their cases were complex (Stein 2000; Wilkinson *et al.* 2013). Three similar studies indicated that 58% of psychiatrists, 33% of psychiatrists and 15% of GPs would personally prefer not to treat people with ID (Lennox & Chaplin 1995; Lennox *et al.* 1997; Edwards *et al.* 2007). Almost half of GPs agreed that not all people with ID should live within the community and indicated that some people are better cared for in institutions dependent on the severity of ID and the level of family support available (Dovey & Webb 2000). Finally, GPs achieved higher ratings to general beliefs (e.g. GP's responsibility for the primary care of people with ID) and lower ratings to items regarding the willingness to adjust their care practice to people with ID (e.g. adapting communication or allowing patients with ID to use more time) (Gill *et al.* 2002).

Discussion

To facilitate future improvement of inclusion of people with ID in mainstream healthcare services, this systematic review focussed on stigmatising attitudes of professionals working in these services. Despite existing positive attitudes, the ideal of equal inclusion is not considered as being sufficiently achieved. Therefore, we questioned whether mainstream health professionals hold attitudes that stigmatise people with ID and what the nature of these attitudes is. The 30 studies included in this review were mainly cross-sectional self-report studies of moderate quality and conducted in Western countries. Results were structured following the social-psychological triad of cognitive, affective and behavioural dimensions of stigmatising attitudes.

Methodologically, the interpretation and generalisation of the results might be affected by the quality of the studies that were included in this review. In quantitative studies, samples were mostly selective or, measures with unclear origin were used. Few studies had a clear theoretical foundation or a systematic approach using conceptual models. In qualitative studies, insufficient attention was paid to reflexivity regarding the influence of researchers and contexts on the results. This limited the reliability of the results. Other reviews of stigmatising attitudes have reported similar problems with the quality of primary studies (Werner & Stawski 2012; Ryan & Scior 2014). The use of direct self-report measures may have provoked socially desirable answers to questions. Indirect measures of stigmatising attitudes may elicit less positive attitudes from health professionals (Werner 2015). Moreover, primary studies were mainly conducted in western countries and, therefore, lacked cultural diversity. This is relevant because it has been shown that cultural differences exist in stigmatising attitudes towards ID (Scior *et al.* 2013). The present review itself has also some limitations. Because we aimed to focus on stigmatising attitudes of mainstream health professionals, outcomes are not useful for proportional comparisons between positive and stigmatising attitudes. Next, the search was limited to only articles written in English, thereby excluding possible relevant articles in other languages. Our search strategy could have been improved by making more extensive use of text words alongside thesaurus terms. Finally, no structured analysis of the results could be conducted because of the variety of research methodologies, content subjects and samples within the primary studies.

Despite general agreement that people with ID have the right to be included in mainstream healthcare practice, and despite the willingness of mainstream health professionals to increase their knowledge about people with ID (e.g. Melville *et al.* 2005; Flynn *et al.* 2015), the actual attitudes of health professionals seem to be rather complex (e.g. Gill *et al.* 2002). Present results showed that stigmatising attitudes towards people with ID are found among professionals. A lack of familiarity with and knowledge about people with ID was found. Moreover, people with ID were perceived as different compared to other patients and as well as childlike,

funny, strange or intimidating. Professionals reported low or high expectations of the capabilities of people with ID. They also reported stress, lack of confidence, fear and anxiety in caring for people with ID. A tendency to treat people with ID differently from other patients and a lack of addressing autonomy of people with ID was reported. In addition, professionals were ambiguous in their willingness to change and adapt their daily care practices to people with ID.

One explanation for the complex nature of attitudes might be related to professionals' experiences of complex ethical dilemmas. They are challenged to maintain a delicate balance between avoiding stigmatisation of and favouring equal rights for people with ID on the one hand, and protecting them from exploitation and harm on the other (Jenkins & Davies 2011). Therefore, stigmatising attitudes that were reported in this review may sometimes reveal actual dilemmas in care practice. For example, genuine concerns were expressed about whether the highest quality of healthcare for people with ID could be provided in community settings or not (e.g. Bedi *et al.* 2001).

When integrating the results of this review, three findings with clear implications for improving inclusion of people with ID in mainstream healthcare services can be described. First, anti-stigma interventions for mainstream health professionals should include both education and contact as key components. Educational interventions may improve the self-efficacy of health professionals to provide healthcare to people with ID (Bandura 1977; Dagnan *et al.* 2015; Hemm *et al.* 2015). Several studies demonstrated a perceived lack of knowledge in professionals, ranging from knowledge about the nature of ID to common health needs in this population. Education has been proposed to increase the confidence of professionals in treating people with mental illness (Henderson *et al.* 2014), and similar might be expected for the treatment of people with ID. In addition to education, interpersonal contact is known to be efficient in reducing prejudice between majority and minority groups (e.g. Pettigrew 1998). For example, within psychiatry contact has demonstrated consistent results in counteracting stigmatising attitudes (Corrigan *et al.* 2002) with even filmed social contact being effective (Clement *et al.* 2012). Comparably, contact and collaboration with

experts-by-experience with ID seemed to improve medical student's attitudes as well as health researchers' awareness of the needs of people with ID (Ryan & Scior 2014; Frankena *et al.* 2015). Prerequisites for contact being effective in counteracting stigmatising attitudes have frequently been studied: the contact should be positive, non-hierarchical and in a context focused on cooperation (Pettigrew 1998). The frequency and quality of contact should also be taken into account (Morin *et al.* 2013). These factors of contact may be well represented within a humanistic approach to healthcare (Embregts 2011).

A second implication is that future studies should progress beyond descriptive accounts of stigma towards exploring the relationship between cognitive, affective and behavioural dimensions of stigma (e.g. Gill *et al.* 2002). Studies should attempt to unravel the processes involved in stigma that can negatively affect people with ID and their social inclusion (Ditchman *et al.* 2013). These relationships could be pointers for interventions, for example to reduce segregation (i.e. behaviour), a focus on preceding fears (i.e. affect) or perceptions of the dangers that people with ID pose (i.e. cognition) is needed (Corrigan *et al.* 2002). Qualitative studies may provide hypotheses for relationships because these studies aim to describe the processes of a phenomenon rather than the prevalence. For example, Sowney and Barr (2006) indicated that professionals' lack of confidence (i.e. affect) in working with people with ID was related to a lack of knowledge (i.e. cognition).

Finally, although many health professionals support the equal right of people with ID to be treated in mainstream healthcare services (e.g. Stein 2000; Melville *et al.* 2005), stigmatising attitudes towards people with ID were also found. The finding that nurses feared that they would treat people with ID differently as well as the finding that GPs were ambiguous about adjusting healthcare practice seem to be characteristic in this context (Gill *et al.* 2002; Sowney & Barr 2006). These findings advocate the assumption that social inclusion of people with ID would benefit from an understanding that 'equal' treatment means reasonable adjustments instead of undifferentiated treatment. This understanding is often lacking among mainstream health professionals (Tuffrey-Wijne *et al.* 2014). Thus, discussion about a social justice framework might be needed where

additional resources for people with ID are justified to reach a similar capability (e.g. Reindal 2009).

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