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Stigma research in the field of intellectual disabilities: a scoping review on the perspective of care providers

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Objectives: Care providers are key agents in the lives of individuals with an intellectual disability (ID). The quality of their support can be affected by manifestations of stigma. This scoping review was conducted to explore studies that provide indications of care providers' stigmatization of people with ID.

Methods: A structured search was made in four databases to identify relevant studies in English-language peer-reviewed journals. Records were systematically and independently screened by the researchers.

Results: The 40 articles included in this review were mainly conducted in Western countries and used Likert-type self-report measures of explicit attitudes. Stigmatization seemed more distinct concerning people with high support needs. The few studies on public stigma preliminary suggest that staff may also stigmatize people with ID based on other social identities. Regarding the support of structural stigma, staff reported skepticism regarding community inclusion for people with high support needs, and tended to be ambivalent about the protection-or-empowerment balance in the support of people with ID. Possible indications of stigmatization regarding sexuality were found on specific issues, such as self-determination and privacy. Agreement of staff with certain rights did not necessarily lead to staff acting in accordance with such rights.

Conclusion: Indications of stigmatization of people with ID by care providers were found. Stigmatizing attitudes might affect the quality of care providers' support. Potential leads for future interventions concern creating awareness, sharing power, addressing diagnostic overshadowing, and providing explicit policy translations. Directions for future research concern strengthening the methodology of studies and enriching the studied topics.

Keywords: stigma, attitudes, intellectual disability, support staff, care providers, review

Most people with an intellectual disability (ID) need life-long support in one or more areas of life (e.g. Wehmeyer *et al.* 2012). This support is, for a significant part, provided by care providers (e.g. support staff) (Sanderson *et al.* 2017) who fulfill a broad range of needs in the lives of people with ID. For example, care providers are a source of emotional and practical support (Giesbers *et al.* 2019, Van Asselt-Goverts *et al.* 2013), can increase possibilities for choice and independence (Channon 2014, Felce 1998), manage

situations of social participation and social roles (Bigby and Wiesel 2015, Todd 2000), and expand and strengthen social networks of people with ID (Van Asselt-Goverts *et al.* 2014). Thus, care providers are key agents in the lives of individuals with ID and the quality of the support they provide is important (Giesbers *et al.* 2019).

Studies in related care fields have demonstrated that the quality of care provider's support can be affected by their stigmatization of the group of clients involved. For example, stigmatization by professionals in mental health care has been shown to affect service delivery (e.g. Lauber *et al.* 2006, Van Boekel *et al.* 2013), the recovery of patients (Schomerus *et al.* 2011), and the accuracy of diagnoses (Thornicroft *et al.* 2007). Stigma is an overarching term that refers to problems of knowledge (ignorance), attitude (prejudice), and behavior (discrimination) (Thornicroft *et al.*, 2007).

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Various reasons have been reported that can explain why care providers may hold stigmatizing attitudes toward their clients. First, care providers are part of the general public. This is a sphere in which stigmatization toward minority groups (including people with ID) is present and forms a subtle barrier to social inclusion (for a review: see Scior 2011). Therefore, it is possible that care providers, even though working with people with ID, may hold stigmatizing attitudes toward people with ID (e.g. having similar concerns regarding the vulnerability of people with ID as the general public reports). Likewise, stigmatization toward people with ID was found within mainstream health professionals (Pelleboer-Gunnink *et al.* 2017). Moreover, care providers may especially have more intense and more frequent contact with people with the highest support needs. Such clinician bias may lead to a more pessimistic view on people's life chances (e.g. Thornicroft *et al.* 2007, Horsfall *et al.* 2010, Hugo 2001). Finally, the tendency to include attitudes and regard in the content of staff training programs is still limited, which may not benefit the awareness and combatting of stigma (Hastings 2010, Smidt *et al.*, 2009, van Oorsouw *et al.*, 2013). Possible stigmatization by care providers is particularly significant when considering that staff are key agents in supporting people with ID to fully participate in society (e.g. Stevens and Harris 2017) and to cope with stigmatization (Craig *et al.* 2002).

Two specific forms of stigmatization might be relevant with respect to care providers: (1) public stigma, and (2) structural stigma. Public stigma refers to negative cognitions (e.g. stereotypes) and negative emotions (e.g. prejudice), followed by discriminatory behavior toward people with ID in the general public (e.g. Corrigan and Watson 2002, Link and Phelan 2001). For example, stereotypes regarding the incompetency to learn new skills (Werner 2015, Meppelder *et al.* 2014) may prove a challenge to people with ID who are seeking to enter competitive employment (Skelton and Moore 1999). With respect to the second form of stigma, staff can be supportive of social norms and policies that (un-)intentionally restrict opportunities for individuals with ID (i.e. structural stigma) (Corrigan *et al.* 2004). For example, staff members may support social norms (e.g. the belief that people with ID must be protected/sheltered) that may inhibit community inclusion for people with ID (e.g. Venema *et al.* 2015).

In the field of ID, research on stigma is limited, especially concerning care providers. Alternatively, indications of possible stigmatization by care providers might be found in the more prevalent literature on "attitudes" of care providers regarding people with ID. For example, studies on the attitudes of care providers toward community inclusion may provide indications of support of social norms that restrict opportunities for people with ID (i.e. structural stigma) (e.g. Henry *et al.*

2004). This scoping review aims to (i) explore the volume and characteristics of research that may provide indications of possible stigmatization of people with ID by care providers, and (ii) explore the nature of possible stigmatization by care providers (i.e. public stigma and support of structural stigma).

The present article displays the characteristics of a scoping review. Scoping studies still lack a uniform definition, and guidelines for procedure and reporting (Pham *et al.* 2014). Yet, scoping reviews have been described as systematic literature reviews that aim to map primary research in a field of interest in terms of the volume, nature, and characteristics, to provide directions for future research (Arksey and O'Malley 2005). Results are presented following this scoping-review aim due to our broad research question and the highly heterogeneous nature of the available literature (Arksey and O'Malley 2005, Pham *et al.* 2014).

Method

Search strategy

A structured search was made (January 1994 to April 2017) in four databases (i.e. PubMed, PsychINFO, CINAHL, and ProQuest [i.e. Social Services Abstracts and Sociological Abstracts]) to identify relevant studies in English-language peer-reviewed journals. An update in the two main databases—PubMed and PsychINFO—was performed by the first author in February 2019. Search terms were structured following the PICO approach by specifying a population, intervention/exposure, comparison, and outcome component (Liberati *et al.* 2009). However, for the present study, no comparison component was specified due to the descriptive nature of the research aim. Also, the type of study design was not conditional, since various empirical designs (including qualitative and quantitative studies) could provide relevant information related to the research aim.

The *population* under study were care providers with direct client contact. This was defined as care providers working for an ID-service provider for whom treatment, care, or support of clients was an important part of their job description (e.g. support staff, direct-care staff, social workers, therapists). Studies were excluded when participants were, for instance, employed as household staff, managers, or directors. "Direct client contact" was assumed to be present based on the participants' job titles and the context/information provided by each study. In case of uncertainty about the nature of participants' contacts with clients, the authors of the original article were contacted. When a mix of professionals with and without direct client contact participated in a study (e.g. care providers and managers), either the results of subgroups were reported, or in case no subgroup means were provided, results for the whole group were included, but only when statistical tests had demonstrated no significant differences on the outcome

Table 1. Search strategy in PubMed using medical subject headings [MeSH] and text words.

<i>Pubmed final search strategy</i>	
1	<i>Population: care providers</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: stigmatizing 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 and exposure: stigmatizing attitudes toward disability*</i>
5	<i>Outcomes and population: stigmatizing attitudes of healthcare providers</i>
#22	Attitude of health personnel [MeSH]
6	<i>Combining search term groups</i>
#23	#4 AND #10 AND #21 (care providers and intellectual disability and stigmatizing attitudes)
#24	#10 AND #22 (intellectual disability and stigmatizing attitudes of care providers)
#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 healthcare personnel from dentists to psychotherapist to nurses. Similar search strategies were used for PsychINFO, ProQuest, and CINAHL.*Not applicable within PubMed but, for example, the thesaurus term "attitude to disability" was used in CINAHL.

measures between the subgroups. Furthermore, all studies focusing on students were excluded.

Concerning *exposure*, studies had to focus on people with ID.

The *outcome* investigated in the studies had to include *public stigma* (i.e. the cognitive, affective, or behavioral dimensions by which people are viewed or treated as devalued), or *structural stigma* (i.e. support of social norms and policies that may reduce opportunities for people). Therefore, attitude studies were included when attitudes were reported that are supportive of restrictive social norms or policies (i.e. negative attitudes).

Table 1 presents an overview of the search terms and strategy applied in PubMed, using medical subject headings (MeSH) and additional text words. Our search strategy was repeatedly tested to reveal which text words were necessary (in addition to the thesaurus terms) in the aim to include all relevant studies. The following text words were added: intellectual disab*, staff, service-provider*, and attitude*. Search strategies similar to the one used in PubMed were applied in the other three databases.

Study selection

Figure 1 is a flowchart showing the process of identifying and selecting relevant studies.

In the identification phase, records were identified in four databases; then, during screening, duplicates, essays, and reviews were excluded. Next, the remaining records were independently screened on title by two reviewers (HP and PE, WvO or JvW) using the inclusion criteria (Table 2). When all inclusion criteria were met, or when there was uncertainty about an inclusion criterion, the records were retained; this strategy resulted in 84% inter-rater agreement. Full consensus on inclusion or exclusion was reached through discussion between the reviewers. Then, abstracts were independently assessed by two reviewers (HP and WvO) based on the exclusion criteria; this resulted in 77% inter-rater agreement. Again, full consensus was reached through discussion between the reviewers. In case of complex decisions, the remaining authors (PE and JvW) were consulted. Full-text articles were assessed on exclusion and inclusion criteria by the first author. Reasons for inclusion or exclusion were then extensively discussed by two reviewers (HP and WvO).

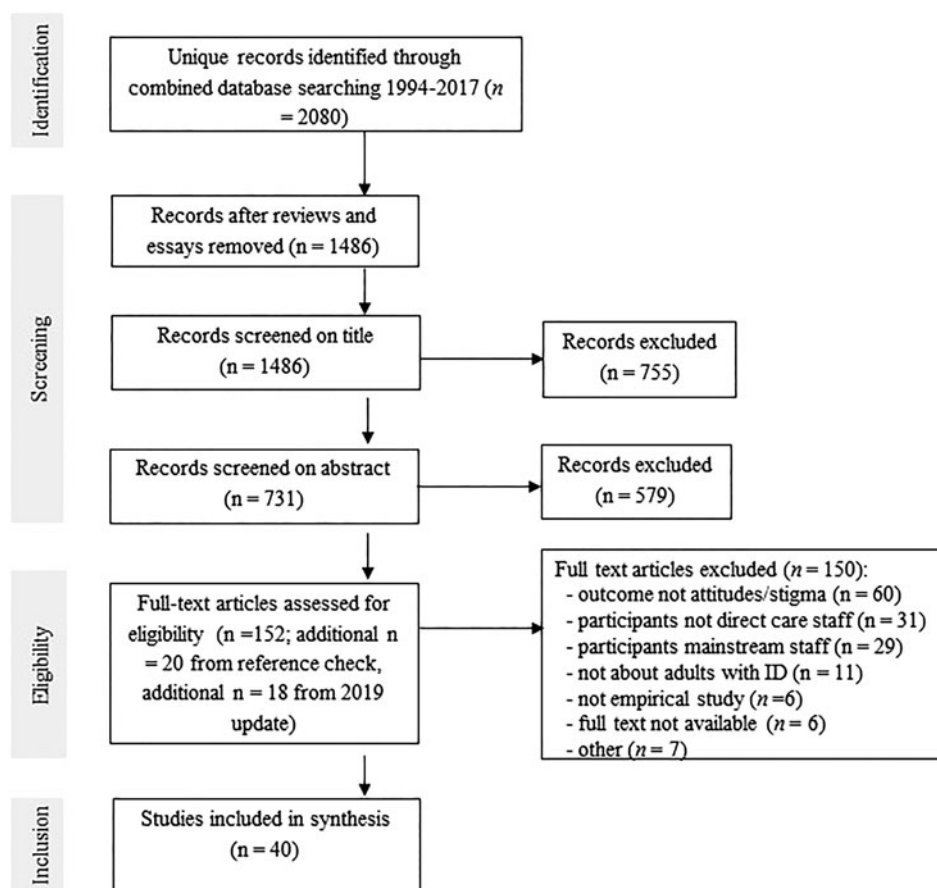


Figure 1. Flowchart of the study selection process.

Table 2. Inclusion and exclusion criteria.

Inclusion criteria

- Participants: care providers with direct client contact working in ID services.
- Outcome: results could be interpreted as public stigma (i.e. cognitive, affective, or behavioral dimensions by which people are viewed or treated as devalued) or structural stigma (i.e. support of social norms and policies that may reduce opportunities for people).
- Exposure: study concerned people with ID.

Exclusion criteria

Participants:

- Students
- Staff without direct client contact (e.g. directors)
- Mainstream health professionals¹

Exposure:

- Disability in general
- Children with ID²
- Disability possibly related to ID (e.g. acquired brain injury) but presence of ID not specified

Outcome:

- Perceptions of training needs for staff
- Attitudes toward specific issues like interventions, special care, special services, deviant sexual behavior, challenging behavior, bereavement, or prenatal screening tests
- Opinions about care for people with ID
- Structural discrimination (e.g. barriers in accessing health care)

General:

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

Note. ¹criterion was used within full text selection, see Pelleboer-Gunnink et al. 2017 for a review on studies investigating mainstream health professionals; ²“people with ID” without specifying life stage or age, were included.

In case of lack of clarity about the presence/absence of inclusion/exclusion criteria, the authors of the original article were contacted.

Moreover, the bibliographies of all eligible full-text articles were screened for additional eligible studies. Finally, the quality of studies was assessed using the multi method appraisal tool (MMAT) (Pace et al. 2012). This

instrument assesses the quality of studies with various research designs, and has demonstrated good content validity and reliability (Pace et al. 2012). Appraisal was discussed by a senior researcher WvO (experienced in conducting and supervising systematic reviews) and the first author. Because of the scoping nature of the review, no studies were excluded based on quality (Pham et al.,

2014). The MMAT quality appraisal format was used to retrieve descriptive quality information about each individual study.

Charting the data

Information on the following items was extracted from the studies: the country of study, study sample, research design and methods, dependent/independent variables, severity of ID, and the methodological strengths/limitations of the studies. In addition, data were extracted on the nature of the possible stigmatization by care providers concerning both structural and public stigma. Table 3 presents general and methodological information derived from the studies.

Results

This review included 40 articles that reported about 39 studies; the resulting information is presented below in a narrative form (Arksey and O'Malley 2005). The main results are divided into (1) general characteristics of the studies, (2) methodological characteristics, (3) possible moderators of stigma, and (4) reported indications concerning the nature of stigmatization (i.e. both public stigma and support of structural stigma). Concerning the latter part (i.e. the nature of stigmatization), the support of structural stigma is described in the most detail because most studies addressed support of structural stigma and few reported on public stigma.

General characteristics of the studies

Countries

Studies were mainly conducted in Western countries: that is, in the UK ($n=13$), Australia ($n=7$), USA ($n=5$), the Netherlands ($n=3$), Ireland ($n=2$), Canada ($n=2$), and Israel ($n=2$). Single studies were found in Greece, Belgium, Poland, and Italy. Two studies were conducted in non-Western countries, namely Pakistan and Japan. In two of the studies, comparisons were made between two countries, which are Japan and USA, and Israel and USA, respectively.

Participants and setting

In most studies, care providers with direct client contact comprised support staff ($n=30$). In the remaining studies, participants were specialized ID nurses ($n=3$), specialized ID speech and language therapists ($n=1$), social workers ($n=1$), or a combination of different specialized ID care providers ($n=4$). Studies were mainly conducted in a combination of different settings (e.g. day care, outpatient treatment, and residential services) ($n=14$), or in an unspecified setting (e.g. client and community services) ($n=11$). Qualitative studies mostly described the setting of a community group home ($n=4$ out of 7 studies).

Methodological characteristics

Concerning the critical appraisal of the included studies, Table 3 provides methodological strengths and limitations for each individual study. Following, trends in methodological strengths and limitations are described.

Designs and sampling

Quantitative, cross-sectional designs were mostly used ($n=26$), but also descriptive ($n=4$), qualitative ($n=8$), and mixed method ($n=1$) designs were applied. Sampling in quantitative studies was mostly selective using convenience or opportunity samples ($n=21$), whereby several studies sampled within one service organization ($n=9$ studies). Response rates were not always reported, or were relatively limited (<60%). Only within five studies a (stratified) random sampling procedure was followed. In qualitative studies, three studies used a purposive sample, and three studies presented no inclusion criteria and/or self-selection into the sample (Table 3). Thus, the sampling strategy used within studies in this field of research has significant limitations.

Measures

With the exception of three studies, two of which employed semantic differential scales (Harris and Brady 1995, Parchomiuk 2012) and the other a repertory grid technique (Hare *et al.* 2012), all quantitative studies used Likert-scale self-report measures of explicit attitudes. Most measures did not specifically aim to capture stigmatization, but tended to address general attitudes. Although some validated outcome measures were used (e.g. CLAS-ID; SMRAI), most studies used self-developed questionnaires and reported only on Cronbach's alpha as a measure of internal consistency of the measure, but no other indicators of reliability (e.g. test-retest reliability) were described. Regarding qualitative studies, semi-structured interviews ($n=3$), focus groups ($n=2$), open-ended questions ($n=1$), and observations with additional interviews ($n=1$) were used.

Independent variables: possible moderators of stigmatization

In cross-sectional studies, mainly demographic variables (e.g. gender, age, and education) were examined as moderators of attitudes; in most studies, these demographic variables were not related to stigmatization. Moreover, a minority of studies examined job-related variables, such as work setting, professional role, and prior contact with people with ID. Finally, three studies examined structural relations between attitudes and other outcome variables (i.e. value preference, burnout levels, social norms, effort to facilitate inclusion, experienced competencies, role identity, and meta-

Table 3. Main characteristics of the included studies.

Article	C*	D*	Setting	Care providers	Outcome Instrument	Methodological strengths and limitations
Bazzo et al. (2007)	IT	1	ID residential centers, day centers, outpatient treatment services	Direct care staff (n = 94)	Questionnaire: SMRAI (sexual rights and stereotypes subscale)	Selective convenience sample (i.e. questionnaires handed out during a meeting), measures with clear origin
Bekkema et al. (2014)	NL	1	Research panel of registered ID care staff; Dutch professional association of ID physicians.	ID physicians (n = 145) Care staff (n = 196)	Questionnaire: case-related considerations about end-of-life care, beliefs about medical interventions	Use of national research panel, response rate staff 67%, ID physicians 53%; extensive measurement description
Bekkema et al. (2015)	NL	1	Research panel of registered ID care staff; Dutch professional association of ID physicians.	ID physicians (n = 145) Care staff (n = 196)	Questionnaire: place end-of-life care for recent patient with ID, beliefs about appropriate environment for end-of-life care	Use of national research panel, response rate staff 67%, ID physicians 53%; extensive measurement description
Bigby et al. (2009)	AU	4 (3)	Community houses for 4-6 residents with severe/profound ID; staffed 24h; assistance with personal care	1- Residents-staff dyads (n = 25) 2- Staff (n = 8)	1- Observation 2- Interviews	Mixed method with quantitative part answering question from qualitative part. Extensive description of context, sources of data and process of research. Purposive sample Opportunity sample
Christian et al. (2002)	US	2	Residential, home support or day services	Direct care staff and first-line managers (n = 144)	Questionnaire: staff experience and satisfaction	
Clement and Bigby (2009)	AU	3	ID agency providing supported living, employment and education, and day services Group home in a mixed residential and commercial neighborhood for five middle-aged men having severe-profound ID	Full- and part time support staff (n = 43) Support staff (n = 7)	Questionnaire: community care reproductive rights and care; education and support Observation, field notes, discussion of data with staff, activity logs (diary of the activities that residents had taken part in)	Staff of one agency, random selection, 57% response rate, measure of unclear origin Context of research and influence of researcher is clearly described, clear analysis.
Crook et al. (2016)	UK	3	Two team bases of the severe-profound ID learning disability service	Clinicians (n = 34)	6 open-ended questions regarding clinician's attitudes toward research participation	Low response rate (36%), no member check or independent researchers involved in analyses, no information about impact of context on findings.
Cuskelly and Bryde (2004)	AU	1	NGO supporting ID people	Support staff (n = 62)	Questionnaire: attitude on sexual feelings, sex education, masturbation, relationships, intercourse, sterilization, marriage, parenthood	Sample is unclear, one agency, no response rate provided. Clear origin of the measures used.
Doody et al. (2013)	IE	3	Voluntary ID community and residential services	Registered Nurses Intellectual Disability (RNID) (n = 7)	Semi-structured interviews: experience of caring for elderly with ID	Purposive sampling, clear analysis, participants were known to the interviewer 7 out of 20 approached nurses participated.
Evans et al. (2009)	IE	1	Community-based service for people with mild, moderate or severe ID	Staff carers (n = 155)	Questionnaire: sexuality, education and training, sexual rights, views about relationships	Select sample, response rate of staff was 41%, all staff from one agency. Origin of the measure is clear.

(Continued)

Article	C*	D*	Setting	Care providers	Outcome Instrument	Methodological strengths and limitations
Flatt-Fultz and Phillips (2012)	US	1	Non-profit human service agency	Direct support professionals (n = 43)	Questionnaire: Empowerment subscale CLAS	Convenience sample in one agency, unknown response rate, one subscale of validated questionnaire, random allocation to conditions.
Gilmore and Chambers (2010)	AU	1	NGOs for people with ID	Support staff (n = 169)	Questionnaire: attitudes to sexuality (ID vs general population)	Selective sample: wide sampling in one organization with 14% response rate, clear origin of measures.
Golding and Rose (2015)	UK	3	Charitable organization, small residential homes (5–7 residents)	Support workers/ residential care workers (n = 20)	Focus groups: attitudes covering topics of different attitude scales	Self-selection into sample without inclusion criteria. Researcher is leader and facilitator focus groups. Clear analysis procedure.
Grieve et al. (2009)	UK	1	Community residential facilities, nursing homes, hospital inpatient facilities	Staff members (n = 188)	Questionnaire: sexual attitudes (homo and heterosexuality masturbation, sexual and nonsexual behaviors)	Little information about convenience sampling procedure. Not complete outcome data (29%) is removed and thereby a low response rate. Measurements are appropriate
Hare et al. (2012)	UK	2	Inpatient unit, adults with ID, 7 beds, 24h support, referral for CB, medication reviews, or health	Learning disability nurses (n = 7)	Repertory grid interview about perception of clients with ID and challenging behavior and attributions	Selection of participants is unclear. Strong method using repertory grid technique.
Harper (1994)	UK	1	Independent agency which was to take responsibility for accommodating over 100 people with ID following retraction of hospital.	Clinical support nurses (n = 7)	Program Analysis of Service Systems (PASS); two open-ended questions	Unclear sampling strategy, measurement, and information intervention
Harris and Brady (1995)	UK	1	ID therapists in area of Wales and South-West England. Mild or severe ID	Speech and language therapists (n = 40)	Semantic differential scale: how is a person likely to respond in a relationship	Stratified random sample, response rate 72%, 61% complete responses, clear measurements and random allocation to condition
Henry et al. (2004)	US/IL	1	(1) 46 US ID community residential agencies (2) 4 Israeli ID agencies	Staff (n = 147) Staff (n = 74)	CLAS	Good sampling, valid measurement, but no participant-level response rate
Holmes (1998)	UK	2	Medium secure unit with strict sexuality policy (i.e. no kissing and touching during residency) Patients of unit often suffered abuse	(Non-) clinical staff with direct-patient contact (n = 46) Nurses (n = 17); Support staff (n = 5); Professionals (n = 21)	SMRAI Open-ended questions	No information about sampling strategy
Horner-Johnson et al. (2015)	(1) JP (2) US	1	(1) state funded residential and research institution (2) agencies operating community residences	Staff (n = 76) Staff (n = 151)	CLAS	Selective sample, valid measure
Jones et al. (2008)	CA	1	Community agencies serving people with ID	Frontline staff (n = 166); Non-frontline staff (n = 72)	CLAS (short form)	Stratified sample by region and agency, valid measure, low response rate (41%)

(Continued)

Article	C*	D*	Setting	Care providers	Outcome Instrument	Methodological strengths and limitations
Kordoutis et al. (1995)	GR	1	Greek asylum (Leros PIKPA) with inhumane circumstances international intervention team tried improvement	Care staff (n = 70)	Questionnaire: stereotyping and segregation attitudes	Selective sample of all care staff in one agency within very specific circumstances. Theoretically solid measures.
Lee and Klemle (2015)	UK	3	Specialist ID trust for clients with a forensic history and ID	Qualified ID nurses (n = 9)	Semi-structured interviews: experiences working with people with ID and personality disorder (PD)	Clear method of analysis (IPA), no inclusion criteria participants, little consideration to researchers influence on the findings. Not clear whether sample is representative, clear theoretical framework behind measures
Maes and Van Puyenbroeck (2008)	BE	2	ID services in Flanders, 63.6% residential facilities, 19.7% services living independently/with parents; group home (15.15%)	Coordinating staff members (n = 66)	Questionnaire: accommodations and personnel, staff working methods and staff attitudes	
McConkey and Truesdale (2000)	UK	1	Hospital and community settings: day care and residential setting	Post-qualified nurses (n = 269) Staff in ID service (n = 270)	Questionnaire: previous contact, confidence at meeting, willingness for social contact	Opportunity sample, origin of items is clear, not clear whether groups compared hold comparable participants
Meaney-Tavares and Gavidia-Payne (2012)	AU	1	Day programs, community-based services, and residential settings in metropolis for people with ID	Staff (n = 66)	Questionnaire: attitudes to sexuality (general population and ID version) sexual rights, parenting, non-reproductive sexuality, self-control	Convenience sample of staff in several organizations with low response rate (22%); clear origin of measurement
Murray et al. (1995)	UK	1	Client and community services	Employees working with client and community services (n = 246)	LDAIDS SPLDAI	Random sample, measures with clear origin, response rate 55%
Murray and Minnes (1994)	CA	1	Client and community services	Employees working with client and community services within ID organization (n = 161)	SMRAI	Selective sample (all employees from one organization, response rate 54%); clear origin measure.
Oliver et al. (2002)	US	1	Residential community settings	Direct-care paraprofessionals supporting people with ID (n = 59)	Questionnaire: acceptability of socio-sexual behaviors: adapted from Socio-Sexual Knowledge and Attitudes Test (SSKAT)	Convenience sample, clear origin of measure, but no indication of internal consistency, not clear whether groups are comparable
Parchoimiuk (2012)	PL	1	Various (i.e. social work, special education)	Various, among others, social workers	Semantic differential scale: attitude toward sexuality of people with ID and physical disability	No information about recruitment participants, origin of measures, comparability of groups, and response rate.
Parke (2006)	UK	3	Social services day care facilities for people with ID	Staff members (n = 9)	Focus group interviews: sexuality and people with ID	No selection criteria for participants, method of data collection is clear, no consideration of context and researchers influence on findings
Patka et al. (2013)	PK	1	Two ID focused organizations in Karachi	Disability service providers (n = 190)	GLAS	Staff from 2 organizations, 100% response rate, valid measure

(Continued)

Article	C*	D*	Setting	Care providers	Outcome Instrument	Methodological strengths and limitations
Pebdani (2016)	US	1	Professional organization for individuals who work with ID, and state's ID service agency	Employees in group homes for people with ID (n = 71)	Demographics ASQ-ID	Convenience sample recruited through e-mail so no response rate or outcome data, use of validated questionnaire, no info regarding potential confounders
Redman et al. (2012)	UK	1	Learning disability service	Support staff (n = 23)	Questionnaire: human rights knowledge and attitudes	No information about recruitment of participants, response rate; incomplete data
Tartakovsky et al. (2013)	IL	1	NGO community services for people with ID and people with severe mental illness (SMI)	Community service workers in ID (n = 126)	Questionnaires: CLAS, Value preference, Burnout	Random sampling from three sources (response rate 25, 60 and 40%), valid measures, correction for group differences
Venema et al. (2015)	NL	1	Residential facilities, neighborhood with "ordinary" non-segregation, neighborhood with "reversed" non-segregation	Direct support professionals (n = 336)	Questionnaire: experienced competencies, professional identity	Selective sampling (one organization), response rate 36%, clear theoretical framework for measures, groups not comparable
Venema et al. (2016)	NL	1	Reversed integration project, 20 homes of 3-10 people with ID surrounded by 83 homes of general public.	Direct support professionals (n = 28)	Semi-structured interview: attitudes, perceived social norms about integration, meta-evaluation about work	Stratified sampling, but within one organization; unclear validity and definition of measures, response rate 100%
Wiese et al. (2013)	AU	3	Community group homes	Community living staff	Semi-structured interviews	Purposive sampling with inclusion criteria, constant comparative method of analysis, cross check of results with participants, clear consideration of influence of context on finding
Yazbeck et al. (2004)	AU	1	NGOs and government services providers	Disability service professionals (n = 202)	Questionnaires: MCSDS, AMR&E-R, MRAI, CLAS	Selective/convenience sample, response rate 44, 7, 40, 75, and 50.5%. Valid measures, no correction for group differences, no complete outcome data.
Yool et al. (2003)	UK	3	Medium secure unit for adults with ID	Various, among others, senior care worker (n = 1), advocacy worker (n = 1)	Semi-structured interview: attitudes and training needs regarding sexuality	4 participants randomly selection from different profession groups, method of data collection and analysis is clear, no cross check with participants, or independent reviewers of the data.

Note. *C = Country; *D = design; 1 = cross sectional; 2 = descriptive; 3 = qualitative; 4 = mixed method. Questionnaires: Community Living Attitude Scale (CLAS); Attitudes to Sexuality Questionnaire (ASQ); Attitude toward Disabled Persons scale (ATDP); Sexuality and Mental Retardation Attitude Inventory (SMRAI) The scale of attitudes toward mental retardation and Eugenics-revised (AMR&E-R); The Mental Retardation Attitude Inventory (MRAI); Marlowe-Crown Social Desirability Scale (MCSDS); NGO = non governmental organization.

Table 4. Articles that reported on the level of intellectual disability.

Level of intellectual disability	No. of articles	Method of indicating /using the level of intellectual disability within studies	Main findings	Authors
Not specified	30			
Mild-moderate	1	Respondents were instructed to answer questions with respect to people with a mild to moderate intellectual disability.	Generally positive attitudes toward sexuality, more cautious about parenting, less sexual freedom for women with than without ID	Gilmore and Chambers (2010)
Moderate	1	Support staff respondents were asked to answer the items considering an "adult with moderate support needs and an Intelligence Quotient of 40–55."	Generally positive attitudes toward sexuality, less so about parenthood, parents more conservative than staff	Cuskelly and Bryde (2004)
Severe-profound	3	Qualitative study including staff working with people with severe-profound ID	Service delivery based on community presence not participation, staff adhered different meaning to inclusion than policy meaning; inclusion felt not feasible due to differentness of clients	Clement and Bigby (2009)
		Studies were conducted in a context where the majority of the people were having severe to profound ID or ID and behavior and/or psychiatric problems	Mean of attitudes toward inclusion is relatively negative (below mean). The effort to support inclusion is moderate or slightly positive. Attitudes toward inclusion are a significant predictor of effort to facilitate inclusion. Half of staff were positive about integration (50%), a third were negative (32.1%) and 17.9% neutral. Staff with positive attitudes stressed advantages of integration like contact with neighbors; staff with negative attitudes stressed restrictions due to integration (e.g. less freedom of movement); and that integration does not work for specific groups, for example, those with ID and behavior problems/psychiatric problems. Staff with a neutral attitude were positive about the idea, but stated that results were negative in practice.	Venema et al. (2015) Venema et al. (2016)
(a) Severe-profound (b) comparison	1	(a) Ethnographic study of support staff working in a group home for people with severe intellectual disability; (b) participants were asked to think of an individual they knew, to say whether this person had mild or moderate or severe and profound intellectual disability	Staff doubt offering opportunities for choice/participation would make any difference; residents seen as childlike; dismissive behavior of residents' purposeful choices; physical design of the house (e.g. separate toilet staff and residents) showed them-us value; ideas inclusion ridiculed. Clients did not participate more among others because degree of impairment of residents. Participants with general ID version scored higher than participants with the individual version (people rating a person they knew). Worse attitudes for people with severe/profound ID or challenging behavior.	Bigby et al. (2009)
Comparison	4	Scenario's describing a person with mild or severe intellectual disability	In relationships, people with mild ID seen positive (e.g. kindly, truthful, confident); 16 of 19 agreed relationship be encouraged. Severe ID viewed negatively (e.g. selfishly, false, shy); 4 of 21 believed relationship would succeed with support.	Harris and Brady (1995)
		Support staff answered questions relating to people with mild, moderate or severe/profound intellectual disability	Mean scores around possible median score of scale. Attitudes more positive for heterosexuality than homosexuality. Mean attitude scores decrease with level of ID. No significance testing	Grieve et al. (2009)
		Comparison mild/moderate vs severe/profound, no explanation about criteria for level	Decisions about medical interventions: wishes/preferences of people with mild/moderate were taken into account more often (27.8%) than the wishes/preferences of people with severe/profound ID (2.9%).	Bekkema et al. (2014)
		Comparison of mild, moderate, and severe levels; no explanation about indication of levels in questions	Liberal staff attitudes towards sexuality. Acceptance of non-intimate relationships for all ID levels (63–90%). People with ID (79%), family (73%), staff (70%) should be involved in decisions about relationship; 25% unsure whether to entitle privacy (i.e., unsupervised relationships); 21% unsure whether inform family about relationship. Less acceptance for severe vs moderate vs mild ID of intimate relationships (8% vs. 25% vs. 55%); or marriage (5% vs. 15% vs. 48%).	Evans et al. (2009)

Table 5. Overview of themed stigmatizing attitude outcomes

Article	Stigmatizing attitudes—outcomes
	<i>Public stigma</i>
Hare et al.	Team no stereotyped view of clients with challenging behavior. Different meanings to internal and external causes of CB, clients with internal and external causes of behavior not construed systematically different. Construal of whole person with history most relevant to understanding behavior.
Harris et al.	In relationships, people with mild ID seen positive (e.g. kindly, truthful, confident); 16 of 19 agreed relationship be encouraged. Severe ID viewed negatively (e.g. selfishly, false, shy); 4 of 21 believed relationship would succeed with support. <i>Level of ID</i> more negative toward severe ID.
Kordoutis et al.	Strong negative attitudes. (e.g. [range = 1–6, 1 = totally agree] it is better if they do not associate with normal people [$M = 1.90$, $SD = 1.36$]; They cannot manage even their simplest everyday needs [$M = 2.46$, $SD = 1.41$]).
Lee et al.	Negative traits were mainly attributed to personality disorder (PD). The disorder was overriding the disability because the complexity of the PD minimized the relevance of ID. Staff stressed the importance of getting to know the client behind the labels (ID and PD). This appeared to protect from damaging consequences of the label.
Maes et al.	Three views supported by different staff regarding support elderly with ID; (1) encouragement of participation and involvement in activities and relationships (2) stereotypical attitudes about elderly, for example, should slow down and be inactive (disengagement) can result in lower expectations and ageist assumptions (3) utilizing specific methods and activities.
McConkey et al.	Scores above the mean in confidence at meeting people with ID (e.g. 30% of the nurses and therapists and 42% of ID staff answer “definitely yes” to the question “feel confident”). Positive scores on willingness for social contact in their personal lives with people with ID. <i>Therapists vs nurses vs ID staff</i> ID staff more confident meeting people with ID; no differences in willingness social contact. <i>Physical disability vs ID</i> therapists and nurses more confident meeting people with physical disability than ID. For ID professionals no difference.
	<i>Community inclusion</i>
Bigby et al.	Staff doubt offering opportunities for choice/participation would make any difference; residents seen as childlike; dismissive behavior of residents purposeful choices; physical design of the house (e.g. separate toilet staff and residents) showed them-us value; ideas inclusion ridiculed. Clients did not participate more among others because <i>degree of impairment</i> of residents. <i>Level of ID</i> Participants with general ID version scored higher than participants with the individual version (people rating a person they knew). Worse attitudes for people with severe/profound ID or challenging behavior.
Clement et al.	Support staff interpreted inclusion in various ways but differing from the official meaning of community participation. Support staff had “problems” with the aim of community participation, the pace or the aim itself was seen as not feasible. Staff did not consider themselves to be part of the education process of the general public to include people with ID. Impossibility of participation was also attributed to personal characteristics of clients due to institutionalizations or being too different. People with ID were seen as not ready for community participation and need to get ready in the distant future. Staff’s view on leisure (weekend, evening, day) influenced how staff approached community participation, a consequence was that activities were often group based. Staff did not know how to build relationships for the men in the house.
Doody et al.	Inclusion within society crucial for elderly in being valued members of their community; familiarity may improve societal attitudes; importance of seeing person rather than disability: individualized approach supported, personal aspects that allow for individuality such as personal belongings.
Flatt-Fultz et al.	Mean score of 33 on the empowerment subscale for the group that did not receive training.
Golding et al.	Working with ID made attitudes more positive, before lacked knowledge and afraid to speak with people with ID; attitudes toward integration were positive; staff believed it was possible to offer people with ID choice in everyday life as long as the person has the capacity to make informed choice. Balance between protection and empowerment; staff admitted they become over protective because people with ID are vulnerable. Only the theme “impacts of integration is sufficiently represented in attitudes scales.”
Harper	In response to the question how you would describe people with learning difficulties benevolent and patronizing responses were found. Staff perceived it important for people with ID to be present within the community as it would increase choice, more individual care, and more opportunities for activities.
Henry et al.	Positive attitudes toward community living. Mean scores high for similarity subscale; low on exclusion subscale and neutral on sheltering and empowerment.
Horner-Johnson et al.	No multivariate differences between Japan and USA when adding potential confounders to the model; for empowerment lower and for sheltering higher scores for Japanese staff. Older staff more likely to endorse sheltering and less likely to endorse similarity.
Jones et al.	In general, respondent’s attitudes consistent with ideals of inclusion. Yet, for some items a large proportion showed attitudes that are not according to inclusion philosophy especially concerning empowerment or sheltering.
Patka et al.	Attitudes generally positive with high mean scores on similarity; below average mean scores on exclusion and neutral scores on sheltering and empowerment. <i>Staff vs community</i> staff had higher scores on empowerment and similarity and lower scores on exclusion and sheltering than community members.
Tartakovsky et al.	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. <i>ID vs SMI workers</i> ID workers lower levels of empowerment and similarity, and higher levels of exclusion and sheltering.
Venema et al.	Mean of attitudes toward inclusion is relatively negative (below mean). The effort to support inclusion is moderate or slightly positive. Attitudes toward inclusion are a significant predictor of effort to facilitate inclusion.
Venema et al.	Half of the support staff were positive about integration (50%), a third were negative (32.1%) and 17.9% were neutral. Staff with positive attitudes stressed the advantages of integration such as contact with neighbors; staff with negative attitudes stressed the restrictions that were due to integrations (e.g. less freedom of movement); and that integration does not work for specific groups, for example, those with ID and behavior problems/ psychiatric problems. Staff with a neutral attitude were positive about the idea, but stated that results were negative in practice.
Yazbeck et al.	Generally, positive attitudes to community inclusion. Low on exclusion, above the mean on similarity, and neutral on empowerment and sheltering subscales. <i>Students vs community vs professionals</i> On all attitude scales, more positive attitudes disability service staff and students than general community. Also on subscales sheltering, exclusion, similarity, empowerment, integration /segregation, social distance, privacy and rights, subtle derogatory beliefs.

(Continued)

Article	Stigmatizing attitudes—outcomes
	<i>Sexuality</i>
Bazzo et al.	Staff demonstrated moderately liberal attitude toward sexuality. Staff in outpatient treatment services most liberal. No norm for “liberal” provided.
Christian et al.	Most respondents have positive attitudes, for example, 93% of respondents agreed women with ID have similar sexual desires as women without ID and 90.7% agreed sexuality is important part of who a women is. Some agreement with restrictions: 24% agreed sterilization be supported as method of birth control.
Cuskelly et al.	Generally, positive views regarding sexual expression of people with moderate ID. No norm provided. More conservative concerning parenthood than other aspects. <i>Parent vs staff vs general community</i> Parents more conservative than staff, but not when corrected for age.
Evans et al.	Liberal attitudes of staff toward sexuality for people with ID. No norm provided. Acceptance of non-intimate relationships for all ID levels (63–90%). People with ID (79%), family (73%), staff (70%) should be involved in decisions about relationship; 25% unsure whether to entitle privacy (i.e. unsupervised relationships); 21% unsure whether inform family about relationship. <i>Staff vs family</i> Staff more liberal. <i>Level of ID</i> Less acceptance for severe vs moderate vs mild ID of intimate relationships (8% vs 25% vs 55%); or marriage (5% vs 15% vs 48%).
Gilmore et al.	Generally positive attitudes toward sexual rights, parenting, non-reproductive sexual behavior and self-control. Least positive about parenting. <i>Support staff vs leisure workers</i> Similar attitudes, on parenting support staff more conservative. <i>ID versus non-ID</i> Higher level of sexual freedom appropriate for non-ID than ID. Only applies to women with ID.
Grieve et al.	Mean scores around possible median score of scale. Not tested for significance but attitudes more positive for heterosexuality than homosexuality. <i>Level of ID</i> Not tested for significance, mean attitude scores decrease with level of ID.
Holmes	Generally, liberal attitudes toward sexuality. The 16% of staff who said that intimate relationships between clients should never be allowed were mainly nurses; clients should always be permitted access to condoms (support staff = 100%; other professionals = 90%; nurses = 69%); should always be allowed to masturbate in private (100% nurses agreed).
Meaney-Tavares et al.	Attitudes toward sexuality of people with ID were generally positive. However, although no significance test of difference, the attitudes toward sexuality of the general population appeared to be more positive.
Murray et al.	Staff attitudes toward sexuality highly liberal. Liberal attitudes toward sexuality related to positive attitude to people with ID and AIDS. On item-level also negative: 11.8% of staff agrees people with ID should be stopped from sexual activity to reduce risk AIDS. Similarly, 44.1% of staff agrees with mandatory testing for HIV.
Murray et al.	Staff members reported a moderately liberal attitude toward the sexuality of people with ID with considerable variation (range = 35–100)
Oliver et al.	Staff demonstrated significant differences on acceptable socio-sexual behavior between people with and without ID only for marriage and childcare, but not, for example, concerning kissing, petting, or masturbating.
Parkes et al.	Participants felt angry and frustrated when clients are denied opportunities to express their sexuality. Participants empathized with clients in some cases by comparing themselves to them.
Pebdani	Mean scores were not interpreted by the authors, but seemed relatively positive. Having an immediate family member with ID was related to more positive attitudes toward self-control of people with ID but no difference on sexual rights, parenting and non-reproductive sexual behavior.
Yool et al.	Liberal attitudes to sexuality and masturbation, privacy must be provided. Sexuality seen as shared common need; experienced similarly by people with and without ID. Less liberal toward sexual intercourse, homosexual relationships, and involvement of adults with ID in decisions about sexuality. Client’s involvement in decisions dependent on <i>level of understanding</i> ; ability to express sexuality and ability to provide consent.
	<i>Decision-making and being informed and involved</i>
Bekkema et al.	Decisions about medical interventions: wishes/preferences of people with mild/moderate were taken into account more often (27.8%) than the wishes/preferences of people with severe/profound ID (2.9%).
Bekkema et al.	Despite belief of care staff that wishes of persons with ID should always be leading in deciding of place of care, only 8% of the care staff and ID physicians mentioned that the wishes of the client were taken into account in actual decisions. Wishes of the client were 6 th in the most mentioned considerations about where to receive end-of-life-care after (expertise of team, familiarity with the environment, equipment, possibility to employ extra caregivers, wishes/preferences of family members).
Wiese et al.	Staff unanimously supported the belief that people with ID should know about dying. Yet, clients were hardly involved in the topic.
Crook	Clinicians suggested that people should not be excluded from research because of their ID. However, clinicians reported reluctance to signposting service users to projects if the research intentions are not clear, or if they see no direct benefits for people with ID thereby possibly preventing them from involvement in research.
	<i>Other</i>
Redman et al.	Staff had high attitude scores (also pre-training) toward human rights.

evaluations) (Tartakovsky et al. 2013, Venema et al. 2015, 2016).

Prior personal contact

Within stigma research, the contact hypothesis is prominent and states that becoming more familiar with a minority group relates to less stigmatization, especially when contact takes place under positive conditions (Allport 1954, Pettigrew and Tropp 2006). Therefore, in this review we have looked into the evidence base for this hypothesis within the population of care providers.

First, support staff in the included qualitative study by Golding and Rose (2015), reported that prior to working in the ID field, they felt that they were stigmatizing people with ID by believing that (i) people with ID “did not have the ability to be independent and were like ‘vegetables’,” and that (ii) that they were too scared to speak to them; however, these beliefs positively changed when they started working (i.e. becoming familiar) with individuals with ID (Golding and Rose, 2015). Yet, care providers already working in the ID field will inevitably be familiar with people with ID to

some extent. Therefore, three studies have assessed care providers' familiarity/contact with people with ID within care providers' personal lives, and one study addressed the quality of contact they reported with people with ID. One study found that care providers' regular contact with individuals with ID in their personal life was associated with more willingness to have contact with a group of people with ID living in their neighborhood (McConkey and Truesdale 2000). Yet, having a friend or family member with a disability was not significantly related to attitudes toward inclusion (Patka et al. 2013), and only concerning the subscale self-control related to attitudes toward sexuality (Pebdani, 2016). Self-reported quality of contact with persons with ID was not related to attitudes toward sexuality (Murray et al. 1995). Thus, having personal contact with people with ID might have positive effects on care provider's attitudes, however, evidence is still inconclusive.

Severity of ID

Given the diversity in the population of people with ID, it is relevant to examine whether the nature of stigmatization by staff differs according to different levels of impairment. Of the 40 articles in this review, 30 did not provide details on the severity of ID (Table 4), in six articles the severity of ID was specified, and in five articles staff outcomes were related to the severity of ID. These comparison studies indicated that higher levels of stigma are found when participants are asked to answer questions regarding individuals with severe ID as compared to those with mild ID. For example, Bigby et al. (2009) demonstrated that, irrespective of a general agreement with principles of choice and inclusion, staff found it difficult to envision that this can be applied to people with severe ID or people with challenging behavior. Moreover, Harris and Brady (1995) reported that people with mild ID were more positively perceived within a relationship (e.g. more kind) than were people with severe ID (e.g. more selfish). Finally, no studies addressed other variables known to influence stigmatization, such as the concealability of the disability, or the degree to which the disability/stigma impedes social interactions.

Nature of stigmatization

Table 5 thematically presents the main outcomes of all individual studies.

Public stigmatization

Concerning the nature of possible stigmatization, six studies described elements of public stigma by care providers (e.g. stereotypes, prejudice, and discrimination). These studies mainly discussed the presence of stereotypical perceptions of people with ID ($n = 5$). For example, Hare et al. (2012) examined how care

providers perceive clients with ID who show challenging behavior. They concluded that the team of care providers did not hold a collective or stereotyped view of their clients, but showed a high degree of variability in how they construe their clients (Hare et al. 2012). Besides the relatively positive finding of non-stereotypical perceptions in this study from the UK, other studies indicated the presence of stereotypical views of people with ID. For example, Kordoutis et al. (1995) described clear stereotyping and segregation attitudes in a very specific situation in the Leros asylum in Greece. In that situation, a three-year deinstitutionalization and rehabilitation pilot-intervention project was implemented due to the appalling conditions at the asylum: residents suffered severe deprivation, extreme institutionalization, and violation of basic human rights (see, Tsiantis et al. 2000). In those deprived situations, people with ID were, for example, viewed as "unhappy," and as if "they cannot manage even their simplest needs" (Kordoutis et al. 1995). Moreover, when focusing on particular stereotypes regarding "people with ID being in a relationship," people with mild ID were viewed more favorably (e.g. kindly, truthful or confident) than those with severe ID (e.g. more selfish, false, shy) (Harris and Brady 1995).

In addition to stereotypes regarding ID, staff may have stereotypical perceptions of people with ID based on other social identities. For example, Lee and Kiemle (2015) suggested, based on their findings that, in case of comorbidity of both a personality disorder and ID, the complexity of the personality disorder seemed to minimize the relevance of ID. Staff, for example, mainly attributed negative traits (like "unpredictable," "insecure," "self-centred," "lacking in empathy") to the personality disorder and not the ID of their clients. Also, Maes and Van Puyenbroeck (2008) demonstrated that some staff members held stereotypical attitudes toward elderly patients with ID based on ageist assumptions (e.g. people should have the opportunity to slow down and be inactive), that may limit the range of opportunities that are offered to older people with ID.

Only the study by McConkey and Truesdale (2000) did not focus on cognitive aspects of public stigma but on staff's behavioral intentions. The authors found that care providers did not differ from mainstream nurses in terms of the amount of contact they had with people with ID in their personal lives, as well as their willingness to engage in social contact with people with ID.

In summary, studies concerning *public stigma* were scarce and mainly focused on the cognitive aspects of stigma (i.e. stereotypes). Evidence was found for the presence of both stereotypical and non-stereotypical views on people with ID among care providers. In addition, based on two studies, there is preliminary evidence that care providers may hold stereotypical views on people with ID based on other social identities, such

as personality disorders or being elderly. Regarding behavioral intentions, specialized ID care providers appeared not to differ from mainstream nurses.

Structural stigma

The largest number of studies ($n = 33$) provided indications of the support of structural stigma. Regarding the focus of these studies, two issues were prominent, namely community inclusion and sexuality. In addition, three studies (as presented within four articles) addressed the attitudes of care providers to processes of decision-making by people with ID and being informed and involved, and finally, one article reported on human-rights knowledge of staff (Redman et al. 2012).

First, within articles addressing community inclusion ($n = 14$), in a general sense, this inclusion was valued as important for people with ID (Doody et al. 2013, Golding and Rose 2015). For example, in the study by Golding and Rose (2015), care providers were generally positive about integration and believed that both the individual with ID and society would gain from integration. Moreover, based on outcomes from the Community Living Attitude Scale ($n = 7$), care providers showed no desire to exclude people with ID from community life (i.e. in all studies, the subscale “exclusion” received the lowest mean score) and care providers unanimously perceived people with ID as being similar to themselves (in all studies, the highest mean score). For example, Henry et al. (2004) reported on the CLAS (note: in other studies referred to as CLAS-MR or CLAS-ID [Henry et al. 1996]) (6-point scale, $Mdn = 3.5$) low scores on exclusion ($M = 1.68$) and high scores on similarity ($M = 4.81$). Similarly, on item level, there was clear consensus on items of the exclusion and similarity subscales (e.g. 95% of staff disagreed that homes/services for people with ID should be kept out of residential neighborhoods [exclusion subscale]; and 93.4% agreed that people with ID have goals for their lives just like other people [similarity subscale]) (Jones et al. 2008).

However, care providers had ambivalent attitudes (i.e. scores inclined toward the mean “not agree/not disagree”) toward sheltering (i.e. belief that people must be protected) and empowerment (i.e. support of self-advocacy and empowerment). For example, Henry et al. (2004) reported close to neutral scores on sheltering ($M = 3.43$) and empowerment ($M = 3.97$). Jones et al. (2008) showed a similar indecisiveness on item level, (e.g. 23.7% of staff disagreed with the statement that “the opinion of people with ID themselves should carry more weight than those of their family members and professionals,” in decisions affecting that person [empowerment subscale]); moreover, 48.1% agreed that sheltered workshops for people with ID are essential [sheltering subscale]). Similarly, Golding and Rose (2015) reported that care providers acknowledge being

overprotective and concluded that care providers care providers needed to find a balance between protection and empowerment.

Moreover, four of the 14 studies clearly indicated the skepticism of staff with regard to community inclusion. That is, in two Australian studies, care providers working in comparable community-based group homes in one geographical area, doubted the feasibility of the principles of community inclusion, choice, and participation for people with severe/profound ID (Bigby et al. 2009, Clement and Bigby 2009). Reasons for non-feasibility were, for example, that the implementation of such principles would make no difference for people with severe ID, that people are too different, or that they are not ready for inclusion (Bigby et al. 2009). Moreover, Venema et al. (2015, 2016) conducted two studies in the Netherlands with care providers working in a reversed integration setting (i.e., a setting in which people without an ID purposefully choose to live next to people with an ID). In these studies, conducted in one geographical area with staff working with people with high support needs, staff held relatively negative attitudes toward integration. They mentioned several perceived disadvantages of integration, such as the possibility of a decreased freedom of movement compared to residential areas. That is: “*In contrast to the residential facility, in the reversed integration setting there were “regular” traffic movements and because the clients were unfamiliar with the traffic rules, they were not allowed to go outside on their own anymore.*” Moreover, staff assumed that neighbors in a reversed integration setting held less positive social norms regarding integration than the neighbors themselves actually held (Venema et al. 2016). Similarly, Golding and Rose (2015) reported that, when specifically asked, care providers discussed potential harms to society by integrating people with ID in the community such as physical harm, or feeling intimidated and frightened. Moreover, Clement and Bigby (2009) reported that activities for people with ID guided by care providers were focused on community presence, not participation.

Thus, concerning community inclusion, care providers seem to hold a generally positive attitude. When looking for possible support of social norms and policies that restrict opportunities for people with ID (stigma), there are indications that care providers judge community inclusion to be less feasible for specific groups of people with ID (i.e. those with behavioral or psychiatric problems, and people with severe/profound ID) (Bigby et al. 2009, Venema et al. 2015). Moreover, there was a tendency for care providers to be ambivalent about whether people with ID should be protected or empowered (e.g. Golding and Rose, 2015).

Second, studies concerning possible structural stigma related to the sexuality and parenthood of people with ID ($n = 14$) focused on a large variety of aspects, such

as sexual rights, masturbation, intercourse, sexual education, marriage, relationships, homosexuality, and parenthood. Attitudes of staff were mainly discussed as being either liberal or conservative, with most results being interpreted as (moderately) liberal. For example, liberal attitudes referred to the agreement that sexuality is an important aspect of a person's life and that people with ID have sexual desires similar to those of people without ID (Parkes 2006, Christian *et al.* 2002). Nevertheless, care providers seemed to be more positive toward the sexuality of people from the general population than toward the sexuality of people with ID (Gilmore and Chambers 2010, Meaney-Tavares and Gavidia-Payne 2012). For example, Gilmore and Chambers (2010) demonstrated that, on issues related to access to sexual education, contraception and freedom of sexual expression, care providers saw more freedom as acceptable for women without ID than for women with ID. This relationship was not found for men with and without ID. Also, Christian *et al.* (2002) demonstrated that liberal attitudes do not necessarily indicate that the support of people with ID regarding sexuality is a high priority. That is, 44% of staff felt that when providing support to women with ID, there were more important priorities to focus on than sexuality (Christian *et al.* 2002).

Concerning homosexual relationships and parenthood, care providers seemed to hold more ambiguous views. Care providers expressed uncertainty about how to deal with homosexual relationships compared to heterosexual relationships (Yool *et al.* 2003) and were less positive about parenthood compared to other aspects of sexuality (Gilmore and Chambers 2010, Cuskelly and Bryde 2004). Moreover, some staff members seemed to support restrictions related to mandatory HIV testing (44% of staff agreed with mandatory testing for people with ID) (Murray *et al.* 1995). Additionally, care providers seemed to hold ambiguous attitudes toward both privacy and self-determination in terms of sexuality. For instance, about 25% of the care providers were not sure whether people with ID should be allowed to have unsupervised relationships, or whether to inform parents about their adult child's intimate relationships (Evans *et al.* 2009). Finally, intimate relationships were viewed as less acceptable for people with severe compared to mild ID (Evans *et al.* 2009, Harris and Brady 1995); moreover, care providers deemed the individual's level of understanding as relevant to the acceptability of sexual relationships, as well as involvement in decisions about the individual's own sexuality (Christian *et al.* 2002, Yool *et al.* 2003).

In summary, sexuality was a prominent theme and staff seemed to hold mostly liberal attitudes toward sexuality of people with ID, although some restrictive or ambiguous attitudes were present. Indications of possible stigmatization were found regarding

homosexuality, parenthood, the priority of sexuality in support, privacy, and self-determination concerning sexuality.

Finally, a Dutch study [(Bekkema *et al.* 2014, 2015)], an Australian (Wiese *et al.* 2013), and a British one (Crook *et al.* 2016) examined staff attitudes, as well as their behavior related to processes of decision-making and being informed and involved. It was demonstrated that agreement with certain social norms/human rights did not automatically lead to staff following-up on such rights. That is, care providers were highly likely to believe that clients' wishes should always be leading in terms of decisions about the place of end-of-life care and they believed this more so than ID physicians and general practitioners. Nevertheless, in the end, only 8% of the respondents reported the wishes of the client as an actual consideration in the decision about the place of end-of-life care (Bekkema *et al.* 2015). Similarly, although staff working with elderly people with ID felt that people with ID have the right to know about dying, clients were hardly ever engaged in this topic (Wiese *et al.* 2013). Also, clinicians feel that people with ID should not be excluded from research. Yet, a suspicion of research intentions, or not perceiving immediate or direct benefits for a client, can prevent clinicians from allowing people with ID to participate in research (Crook *et al.* 2016). Moreover, in medical decision-making, the wishes/preferences of people with mild/moderate ID were taken into account more often (27.8%) than the wishes/preferences of people with severe/profound ID (2.9%) (Bekkema *et al.* 2014).

Discussion

This scoping review was systematically conducted to identify studies that may address possible stigmatization by care providers toward people with an ID. The aim was to provide an overview of these studies in terms of general characteristics, methodology used, moderators of stigma, and indications concerning the nature of the stigmatization.

Given the ubiquity of stigmatization, it seems especially relevant to address stigmatization in relation to care providers who have direct client contact. Obtained knowledge may help care providers to enact their key role in the lives of people with ID. Stigmatization was conceptualized as either public stigma (i.e. stereotypes, prejudice, and discrimination) or support of structural stigma (i.e. social norms and policies that restrict opportunities for people with ID). Due to the lack of research on stigma in the field of ID, our exploration of possible stigmatization by care providers included the more prevalent literature on "attitudes" and related concepts (e.g. beliefs). However, because these studies did not explicitly aim to address stigmatization, any

interpretations regarding possible stigmatization of staff should be made with caution.

The 40 studies included in the review were mainly conducted in Western countries, with care providers working either in unspecified ID settings or a variety of different settings (e.g. day care, residential). A minority of studies considered care providers other than support staff (e.g. therapists, nurses, or social workers), the majority of studies focused on support staff. Studies mostly did not differentiate between varying levels of ID. Most studies used self-report Likert-type measures of explicit attitudes; this has been reported before by, for example, Antonak and Livneh (2000). Several studies were conducted in a forensic setting, which might have colored the experiences and perceptions of staff working in these specialized institutions. For example, staff's perceptions may have been influenced by clients' criminal behavior and the environmental/procedural restraints of the secure setting, as well as their ID.

Studies related to public stigma were scarce. Two studies showed that care providers may stigmatize people with ID based on other social identities (e.g. in case of comorbidity, a person's personality disorder was found to be more strongly stigmatized than the person's ID). This issue of intersecting identities may need further research, especially considering the fact that an ID is often viewed as a dominant social identity (e.g. Beart et al. 2005, Logeswaran et al., 2019). Concerning the presence of stereotypical perceptions of people with ID, both the presence and absence of stereotypes were demonstrated. All studies (except for one on behavior/behavioral intentions) focused on cognitive aspects of public stigma. Studies on the possible support of structural stigma mainly focused on aspects of community inclusion, sexuality, and parenthood. Of note, some alternative, current, and relevant themes were scarce (e.g. decision-making, or being informed) or even missing (e.g. employment and social networks).

There was skepticism regarding the feasibility of community inclusion for clients with high support needs. Care providers tended to be ambivalent about whether people with ID should be protected or empowered. This finding is specifically relevant, given the fact that people with an ID have reported experiences of over-protection, lack of recognition, and dependence on support as important expressions of stigmatizing treatment (e.g. Jahoda and Markova 2004, Jahoda et al. 2010, Giesbers et al. 2019). Possible indications of stigmatization regarding sexuality were found on issues related to parenthood, homosexual relationships, priority of supporting sexuality, sexuality-related privacy, and self-determination; these issues may warrant more research into possible support of structural stigma. Furthermore, stigmatization seemed to be related to subgroups of people with ID and appeared to be the strongest for people with severe/profound ID, and

people with high support needs (including people with challenging behavior, or comorbid psychiatric diagnoses). Finally, agreement of staff with certain rights, such as (informed) decision-making, did not necessarily lead to staff acting in accordance with such rights.

Implications for clinical practice

Due to the key role of care providers, their continuous training and coaching in maintaining high-quality levels of support is essential. Based on the present results, attention for the potential presence and influence of stigmatizing attitudes on the quality of care providers' support seems needed. The tendency to include care providers' attitudes in the content of staff training programs is however, still limited in the field of ID (Hastings 2010, Smidt et al. 2009, Van Oorsouw et al. 2013). Comparably, in the field of mental illness, interventions that address stigmatization by mental health professionals are also uncommon (Thornicroft et al. 2016). The few interventions that were found in the field of mental illness, concerned information-based approaches that resulted in short-term improvements in knowledge and behavior (Thornicroft et al. 2016). Therefore, a first step may be to raise awareness concerning the relevance of stigmatization and attitudes in the context of services that are provided to people with ID (Embregts 2011, Pijnenborg et al. 2016, United Nations 2006).

There is, however, limited evidence concerning what might follow this first step to raise awareness. In all healthcare fields, the question what might constitute effective elements of training that can reduce stigmatization of care providers are hardly explored. Yet, leads for future development of interventions can, for example, be derived from the general reference point that stigmatization can only exist in a context of power difference (Goffman 1963, Link and Phelan 2001). Given the inevitable power difference that does exist in the relationship between care provider and service user (client), it seems important that care providers are willing to share their power (e.g. by shared-decision making) and to listen carefully to clients and their families/network (Douglas and Bigby 2018, Pijnenborg et al. 2016). This may reduce the demonstrated risk on over-protection and limited involvement in decision-making for people with ID. For this purpose, out of many possibilities, the approach of experience-based co-design might, for example, be useful (e.g. Bate and Robert 2006), because it facilitates the exchange of experiences between service users and care providers with the aim to improve the quality of services. Also, working together with experts-by-experience in individual support questions of service users toward more independence, may prove specifically helpful because of its empowering function (Pijnenborg et al. 2016).

A second lead for future development of interventions, concerns the potential risk on diagnostic

overshadowing which is often related to stigmatization (e.g. Evans-lacko et al., 2010). Diagnostic overshadowing concerns a tendency to overlook symptoms of mental health or physical problems and attribute them to being part of “having an intellectual disability” (Mason and Scior, 2004, Werner et al., 2013). Care providers (e.g. support staff) in the field of ID often have a signaling function of mental and physical health symptoms toward health professionals and may therefore contribute to diagnostic overshadowing by overlooking relevant symptoms. In staff coaching, the advices regarding diagnostics in relation to stigmatization as made by Pijnenborg *et al.* (2016) may prove relevant: (1) try to place symptoms in a normalizing framework, (2) do not insist on people accepting the diagnosis (of ID/personality disorder), but validate emotions and symptoms, (3), do not stress biomedical factors in discussing a client’s diagnosis but stress the potential to improve and learn.

A final implication concerning what support staff may need to maintain high quality levels of support, was found within studies concerning attitudes toward community inclusion. Two of these studies demonstrated that support staff struggle to interpret the meaning of broad and often not specifically defined policy principles (e.g. community inclusion) or display uncertainty in terms of how to apply such principles to specific groups of people (e.g. people with severe ID) (Bigby *et al.* 2009, Clement and Bigby 2009). Therefore, staff may need explicit, practical information regarding policy principles concerning human rights, possibly in combination with on-the-job coaching to convey latest knowledge to the daily support of individual clients (Van Oorsouw *et al.* 2009).

Implications for research

Concerning future research, studies on staff’s expression of public stigma are currently limited in both number and scope. Addressing not only cognitions, but also emotions and behavior of staff, may provide directions for staff training. Moreover, studies on staff’s support of structural stigma have mainly focused on sexuality and community inclusion, while other issues are scarcely represented. For example, Stevens and Harris (2017) indicate that attitudes of care providers are pivotal in creating a positive (or negative) climate when supporting people to get and keep jobs (Stevens and Harris 2017). Future research into staff’s possible support of restrictive social norms regarding employment may prove to be a fruitful effort to improve an individual’s opportunity for employment. Additionally, several other issues, such as friendships, social networks, self-determination, valued leisure activities, or physical health, may also benefit from this focus (e.g. Wong and Wong 2008).

Related to methodology, mostly Likert-type self-report studies or qualitative thematic studies into explicit attitudes were employed. Future observation studies or proxy reports can have the additional potential to address behavioral presentations of stigma that care providers may not be aware of or either may not be willing to report. Moreover, given the complex nature of the process of stigmatization, it seems meager that only Likert scales are used to assess internal processes. Numerous alternatives to Likert-type scales have been described (e.g. q-methodology, adjective checklists, rankings, socio-metrics, qualitative methods) that may increase the validity of the conclusions drawn from existing studies (Antonak and Livneh 2000, Haddock and Zanna 1998). Moreover, to obviate the threats of validity inherent to explicit measures of stigma/attitudes (e.g. social desirability bias, generosity effect), implicit methods such as the quantitative implicit association test, qualitative causal layered analysis, may prove valuable (Antonak and Livneh 2000, Dorozenko *et al.* 2015). Finally, most studies did not differentiate between subgroups of people with ID. Given the large diversity within the total group of people with ID, and the indications that stigma might vary for different subgroups of people with ID, future studies might benefit from using vignettes or examining real-life situations to explore the impact of (for example) the concealability of ID, or the amount of deviant behavior on stigmatization by care providers.

The present study has some limitations. The exclusion of gray literature and studies published in languages other than English may have caused a bias toward significant results and information from specific regions of the world. Also, as this review covers research from around the world the recommendations are generic. Therefore, some issues may be of local concern rather than a widespread issue and might need further exploration in local conditions. Finally, this study focused on care providers as participants of studies. Future review study might focus on the reports of clients and relatives about their care providers’ attitudes to complete the picture.

Conclusion

Care providers are key agents in supporting people with ID to achieve valuable life goals. To provide high-quality support, staff should receive training not only to improve the level of their knowledge and skills, but also to address the possible presence of stigmatization. It is of foremost importance to raise awareness of the relevance of stigmatization in the context of services provided to people with ID. Moreover, care providers should be encouraged to share power with people with ID and their families, for example, in working together with experts-by-experience. Also, the accurate use of diagnostic information is relevant to prevent diagnostic

overshadowing. More studies on public stigma may provide new directions for staff training regarding stereotypes, prejudice, and discrimination. Preferably, future studies into support of structural stigma among care providers, should address a wider range of life domains (e.g. employment).


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