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published in

British Journal of Learning Disabilities
2020

DOI (link to publisher)

[10.1111/bld.12294](https://doi.org/10.1111/bld.12294)

document version

Publisher's PDF, also known as Version of record

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citation for published version (APA)

Chien, T., Sterkenburg, P. S., Prah, C., Anderson, N., & Bos, A. (2020). Self-concept and facial appearance of individuals with an intellectual disability: A scoping review. *British Journal of Learning Disabilities*, 48(2), 84-97. <https://doi.org/10.1111/bld.12294>

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ORIGINAL ARTICLE



Self-concept and facial appearance of individuals with an intellectual disability: A scoping review

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Accessible Summary

- This paper looks at how self-concept is related to facial appearance.
- Very little information can be found on how persons with intellectual disabilities think and feel about their own facial appearance.
- In this review 19 articles on subject of self-concept in people with intellectual disabilities were included.
- Results show that self-concept of individuals with intellectual disabilities is affected by the relationships they have (positively and negatively).
- The perceptions of caregivers, peers and their awareness of stigma effects self-concept.
- How facial appearance affects the self-concept of persons with intellectual disabilities remains unclear and should be a focus of research in future.

Abstract

Background: The mental health and well-being of individuals can be positively affected by improving facial appearance through orthodontic treatment. However, research is limited on the relationship between facial appearance and self-concept of individuals with intellectual disabilities.

Materials and methods: This scoping review includes 19 articles and is aimed to examine the self-concept of individuals with intellectual disabilities and determine how the self-concept might be impacted by facial appearance. Furthermore, this review is exploratory in the way that an attempt was made to extract constructs that contribute to the self-concept of persons with intellectual disabilities.

Results: Unfortunately, no articles were found on how individuals with intellectual disabilities think about their own facial appearance. However, the articles on self-concept in persons with intellectual disabilities do mention some interesting facts: social comparisons lead to social stigma that can contribute negatively to the self-concept of individuals with intellectual disabilities. Also, the ability to communicate and express oneself can contribute to one's self-esteem. Furthermore, parents/caregivers often influence the concept of oneself. Moreover, an individual's relationship with their social environment defines their self-concept.

Conclusion: It is currently unknown how individuals with intellectual disabilities view their own facial appearance and whether their self-concept is influenced by their

Chien and Sterkenburg contributed equally to this study.

appearance. Questionnaires which address attitudes on facial appearance could provide a deeper understanding of the self-concept of individuals with intellectual disabilities and possibly make way for orthodontic treatment. However, caution is needed concerning changing the physical appearance of persons with intellectual disabilities. One should also battle stigma by encouraging the social inclusion of persons with intellectual disability.

KEYWORDS

aesthetics, facial appearance, intellectual disability, self-concept, self-esteem, social stigma

1 | INTRODUCTION

Facial appearance and expressions play crucial roles in communicating with one's social environment. Previous research has shown that more attractive people are often seen as more intelligent and successful, have greater opportunities for mate selection and have a higher quality of life compared to less attractive people (Dion, Berscheid, & Walster, 1972; Lorenzo, Biesanz, & Human, 2010). The social challenges encountered by individuals with facial disfigurements or craniofacial anomalies can be psychologically damaging (Kiyak, 2008). A cleft lip or cleft lip and palate are among the most common congenital facial deformities (prevalence: 1/700 live births worldwide). Many individuals with those deformities face problems with self-esteem and difficulties forming relationships with others (Sousa, Devare, & Ghanshani, 2009). Qualitative studies on individuals with cleft lip/palate have reported higher incidences of being subjected to teasing and social isolation, which have led to a decline in social behaviour and, overall, a reduced quality of life (Bemmels et al., 2013; Chetpakdeechit, Hallberg, Hagberg, & Mohlin, 2009). A study that investigated Norwegian adults showed that individuals with complete cleft lip and palate (CLP) experienced twice as much anxiety, depression and palpitations, as those without CLP (Ramstad, Ottem, & Shaw, 1995). Other congenital craniofacial anomalies are expected to have similar impacts on psychological, emotional and social functions. Consequently, it is understandable why children, adolescents and adults often seek medical and dental services to correct facial deformities to improve their appearance. The smile is one of the most important contributors to facial attractiveness. This is a key tenet in the field of orthodontics (Chang et al., 2011). An orthodontist is a dentist with specialty training for treating facial and dental irregularities. During the period when the orthodontic specialty was developed, the recognised benefits of treatment were primarily focused on health; thus, most treatments involved correcting malocclusions and dental abnormalities that had a causal association with periodontal disease and caries (Shaw, Addy, & Ray, 1980). However, the need for orthodontics is complicated. Although empirical studies have shown that orthodontic treatments increase patient quality of life, when investigated more rigorously, the strength of the association was described as modest, at best. A systematic review conducted in the UK (Javidi, Vettore, & Benson, 2017) that included

13 studies examined the evidence for changes in oral health-related quality of life (OHRQoL) and compared improvements in OHRQoL before and after orthodontic treatments, for individuals under the age of 18 ($n = 243$). The evidence that OHRQoL increased after orthodontic treatment was moderate, and the evidence was low and moderate in quality.

The same complications existed when considering the need for orthodontic treatments among individuals with intellectual disabilities. According to the Diagnostic and Statistical Manual of Mental Disorders, Version Five (DSM-5), the characteristics of intellectual disability disorder include impairments of general cognitive abilities, which impact three domains: conceptual (language, reasoning, memory), social (interpersonal skills, empathy) and practical (self-management, employment, financial, recreational) (American Psychiatric Association, 2013). No reference was made to intellectual disability in the review reported by Javidi et al. (2017). Nevertheless, the perceived need for orthodontics may be considerably different in this population compared to the general population. First, individuals with severe intellectual disabilities generally have a higher prevalence of dental disease, such as periodontal disease and untreated caries, compared to the general public (Anders & Davis, 2010). Additionally, individuals with intellectual disabilities also experience injuries from bruxism (i.e. jaw clenching or excessive teeth grinding) much more frequently than individuals without intellectual disabilities (DeMattei, Cuvo, & Maurizio, 2007). By correcting tooth movements and improving occlusion, orthodontic treatment can potentially reduce the incidence of caries and the risk of damage due to periodontal diseases and bruxism (Gkantidis, Christou, & Topouzelis, 2010). Consequently, in this population, the need to improve aesthetics with orthodontic treatment may not be as important as the need to address active dental disease. However, evidence in support of this hypothesis is lacking; thus, further investigation is needed on this topic by means of an exploratory review.

2 | METHODS

In this review, the Arksey and O'Malley (2005) methodological framework for conducting a scoping review was used. This framework consists out of the following six stages: (a) identifying the research question; (b) identifying relevant studies; (c) selecting

relevant studies; (d) charting the data; (e) collecting, summarising and reporting the results; and (f) consulting with stakeholders to inform or validate study findings (optional) (Arksey & O'Malley, 2005; Levac, Colquhoun, & O'Brien, 2010).

2.1 | Identifying the research question

In the present review, the aim is to gain insight into the self-concept of individuals with intellectual disabilities across the spectrum and more precise: determine how facial appearance is related to their self-concept. The purpose of using the scoping approach was to outline what is already known on the topic and to explore possible research gaps in the existing literature. The review questions are as follows: "Is the self-concept of persons with IDs related to the experience of their facial appearance?" and also: "What constructs are related to the self-concept of persons with IDs?"

2.2 | Identifying relevant studies

In line with the scoping review approach and due to the lack of literature in the field of intellectual disability and self-concept in relation to facial appearance, quantitative, qualitative, mixed-methods and grey literature (blog) studies were included that explore the relationship between intellectual disability, facial appearance and self-concept. Four databases were consulted for papers written in English: MEDLINE/PubMed, PsycINFO, Web of Science and ERIC.

The search terms were related to three categories: disability, aesthetics and patient attitudes. The search terms were as follows: disabilities (Intellectual, Developmental, Disabilities, Neurodevelopmental, Mental, Retardation, ADHD, Autism, Visual impairments, Deafness, Cerebral palsy, Motor disorder, Blindness); Aesthetics (Aesthetics, Physical appearance, Body image, Facial, Self image); and Attitude of Patient (Attitude to health, Surveys and Questionnaires, Self report, Satisfaction, Expectation). These terms

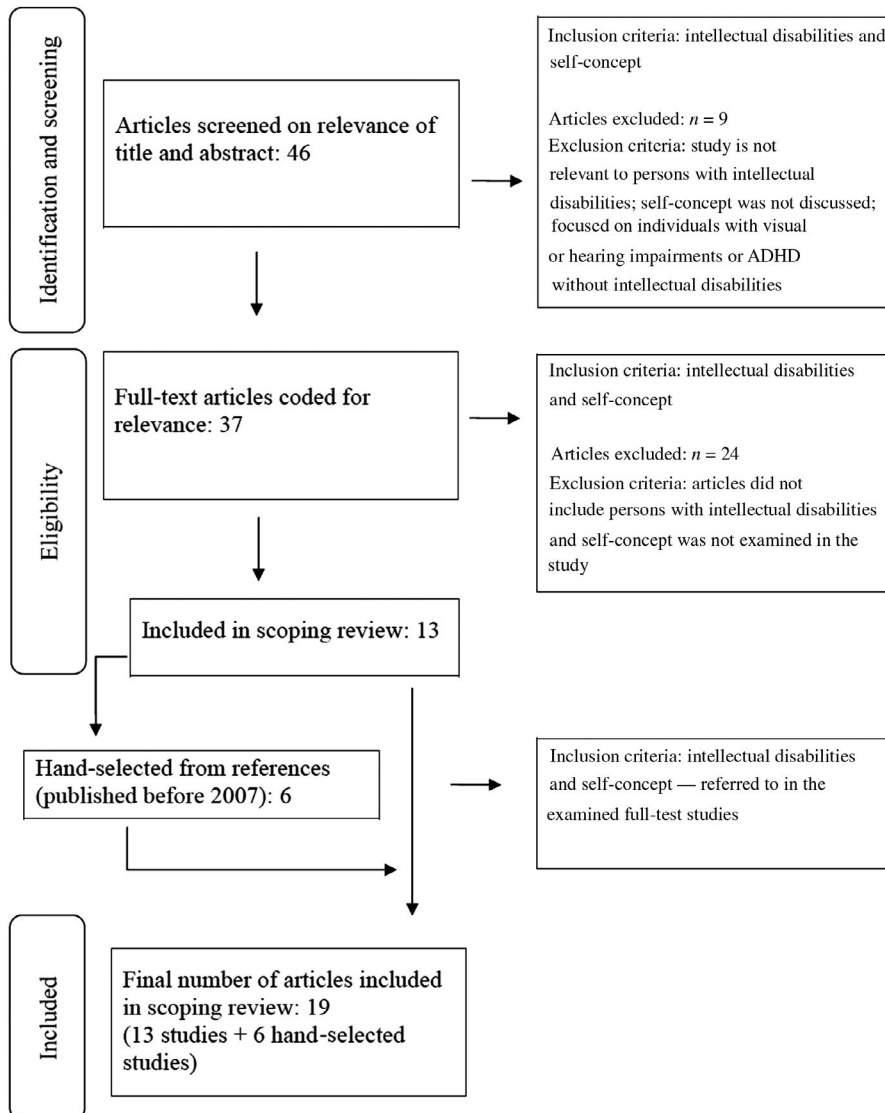


FIGURE 1 Diagram of the process of selection of literature for the scoping review

were used together; thus, the results always included studies that involved all three subjects. The search was narrowed by selecting articles that were published over a 10-year period, between 2007 and 2017, for analysis. A 10-year period was used as orthodontic care may have changed a lot over time and is expected to be quite different more than 10 years ago compared to more recent times.

2.3 | Selecting relevant studies

Abstracts from 46 articles were retrieved. Two evaluators (TC and PS) scored the titles and abstracts individually, based on relevance to the specific themes. Our goal was to learn about individuals with intellectual disability and their self-concept in relation to facial appearance. Consequently, it was vital to select studies that addressed those two ideas. Accordingly, abstracts were included when they scored positive on the following subject matters: intellectual disability, self-concept, self-perception and body image.

Abstracts that did not clearly examine the subject received a score of 0; those that clearly included the themes received a score of 1; those that were ambiguous received a score of 2; and those that could not be scored received a score of 3 (Figure 1). Studies that did not specifically discuss individuals with intellectual disabilities or self-concept were excluded, even when they discussed self-perception and body image. Studies were also excluded when they examined individuals with visual or hearing impairments in addition to ADHD, because those conditions did not encompass intellectual disability. Calculated, using SPSS, the inter-rater reliability for inclusion of articles showed a Cronbach's alpha of .70.

Articles with abstracts that received an overall score of either 1 or 2 from both evaluators were selected for full review. The evaluators disagreed on five abstracts; thus, these required discussion between the evaluators. Of the five abstracts, two were included and three were excluded: two that focused on ADHD, not intellectual disability, and one that did not focus on self-concept. Of the 46 articles retrieved, 9 articles were excluded; thus, 37 were subjected to a full-text review (Figure 1).

2.4 | Charting the data

Out of the 37 full texts screened for relevance to intellectual disability and self-concept, 15 were selected for the final analysis. The screening process for these full texts was similar to that conducted for the abstracts. The two evaluators read all articles separately, and scores were compared. The Cronbach's alpha for inter-rater agreement on the full-text articles was 0.94. For two articles, the two evaluators assigned different scores on the inclusion of self-concept. After discussion and review, they reached a consensus. Among the references in the full-text papers selected, we identified five relevant articles that had not been included in our electronic search. These hand-picked articles were selected because the subject matter focused heavily on self-concept in individuals with intellectual disability and were cited in almost every study we found; therefore, these six hand-selected studies published before 2007 were also

included in the review. None of these focused on orthodontic care or facial appearance. In Figure 1, the flow chart visualises the selection process for the final set of articles.

The two evaluators and another investigator (the first, second and last authors) read all 18 full-text articles and one blog. They independently selected themes and reached a consensus on four themes (presented in the Section 3). A total of 18 articles and one blog ($n = 19$) were included in the review. An overview of the studies is provided in Table 1. The charted information included the country, the study design, sample size and gender, IQ (if known), instruments, main findings and limitations. Reporting in Table 1 was done by the first author and checked by the independent researcher. Furthermore, to get an impression on the methodological quality of the studies, the Mixed Methods Appraisal Tool (MMAT; Hong et al., 2018) was used. With the MMAT, studies are methodologically judged on seven criteria. The advantage of this tool is that it is suitable for qualitative, as well as quantitative and mixed-methods studies. First, the second author and an independent researcher independently coded three randomly selected articles, discussed the scores and reached consensus. Then, the independent researcher scored the other articles, where she consulted the second author when in doubt—together, they reached consensus.

3 | RESULTS

3.1 | Collecting, summarising and reporting the results

In total, 18 articles and one blog ($n = 19$) were included in the analysis. Seven studies reported results based on a qualitative study design, where data were collected mostly through questionnaires and interviews. Among the qualitative studies, three were comparative, where results from individuals with intellectual disability were compared with results from their caregivers or that of other individuals. Other qualitative studies reported longitudinal, narrative, cross-sectional or participatory observational data. Quantitative studies that employed validated instruments were also included, such as the Rosenberg Self-Esteem Scale and the Pictorial Scale of Perceived Competence and Social Acceptance ($n = 7$). Furthermore, there were three studies included with mixed designs (qualitative and quantitative methods combined). Finally, we included one review article and one blog/case description. Although the methodological soundness of the blog/case description was low, it improved the social validation of this review because it is written by a parent of a child with disabilities; it was therefore included in this scoping review.

Unfortunately, no articles were found that reported on how individuals with intellectual disability experience their own facial appearance. Thus, the remaining articles focusing on self-concept of people with intellectual disabilities were analysed. This was done to explore and learn whether and how these topics are related to the hypothetical connection between self-concept and facial appearance, for the purpose of setting up future studies. Based on the

TABLE 1 Summary of the articles indicating sample, design, characteristics, intervention, main findings and limitations

Study and country	Design	Sample	IQ	Instruments	Main findings	Limitations	MMAT ^a
Theme 1: Self-concept and social comparison (n = 8)							
Cunningham and Glenn (2004) ^f UK	Mixed; Comparative Design	77 young adults with Down syndrome and 78 parents; 45 men and 32 women; M age: 19 years and 11 months; SD = 22 months Recruited from Manchester Down Syndrome Cohort	Mean verbal mental age: 6 years 4 months SD = 25.9 months	For young adults, British Picture Vocabulary Scale II was administered followed by open-ended interviews. Semi-structured interviews with the parents	Self-descriptions of young people with Down syndrome followed the typical developmental path Aspirations were age-appropriate but their understanding was limited by cognitive level Participants tend to maintain self-esteem by making downward comparisons	Structured questions limited exploration of other issues	S1: yes S2: yes S1: yes S2: yes 5.1: yes 5.2: yes 5.3: yes 5.4: yes 5.5: yes
Gibbons (1985)	Mixed	63 men; 60 women; Mean age: 31 years No visible physical abnormalities, not married and having "typical" access to the community	IQ = 40 -70; mean = 61	Interviews. Participants were presented pictures of a person with different labels and attributes. Participants were asked to answer questions about the person in the picture. Participants were then asked questions to determine whether they maintained similar opinions about their own social behaviour	There are negative perceptions of social behaviours of people in institutions and community facilities. Women are especially critical in evaluations of male peers. This has been termed "downward comparison." There is also evidence of low self-esteem among institutionalised persons with intellectual disability	Not mentioned	S1: yes S2: yes 5.1: no 5.2: yes 5.3: yes 5.4: yes 5.5: yes
Glenn and Cunningham (2004) UK	Mixed; Comparative Design	77 young adults with Down syndrome and 78 parents; 45 men and 32 women; M age: 19 years and 11 months; SD = 22 months Recruited from Manchester Down Syndrome Cohort	Mean verbal mental age: 6 years 4 months SD = 25.9 months	For young adults, British Picture Vocabulary Scale II was administered followed by open-ended interviews. Semi-structured interviews with the parents	Few felt that their disability was particularly important People with Down syndrome typically follow the sequence of social-cognitive development. High self-esteem was maintained, and awareness of Down syndrome or disability did not appear to be a major problem Awareness of disability was associated with IQ	Structured questions limited exploration of other issues	S1: yes S2: yes 5.1: ? 5.2: yes 5.3: yes 5.4: yes 5.5: yes
Huck et al. (2010) Sydney, Australia	Quantitative	17 children; 11 boys; 6 girls Mean age: 9 years	11 moderate (IQ 30-54) 6 mild (IQ 55-70)	Perceived cognitive and physical competence and peer maternal acceptance were measured using (PSPCSA ⁷). Also measured academic performance and social status	Most children were positive in their perception of competence and acceptance. However, self-concept is likely to be negatively impacted when comparisons are made with higher functioning peers	Small sample size. Failure to collect inter-rater reliability data on the scoring of the PSPCSA	S1: yes S2: yes 4.1: yes 4.2: yes 4.3: yes 4.4: no 4.5: yes
Jahoda et al. (1988) ^f Scotland	Mixed	12 adults living in the community and attending training centres. 5 men and 7 women (21-40 years) as well as their mothers and members of the staff. Exclusion criteria: severe speech impediments	Mild intellectual disability; IQ = 40-70	Semi-structured interviews.	Participants were aware of the stigma, but a majority considered themselves the same as other people Participants' self-concepts were not related to the way they were perceived by mothers and staff.	Small sample.	S1: yes S2: yes 1.1: yes 1.2: yes 1.3: ? 1.4: yes 1.5: yes
Johnson (2012) UK	Quantitative, cross-sectional Design	44 adults; Mean: 35.6 years; SD 11.6 years Staying in a forensic hospital for people with intellectual disability	Intellectual disability: IQ range 60-77	Rosenberg Self-Esteem Scale Adapted Evaluative Beliefs Scale	Compare themselves with their peer group, not to staff, when scoring their self-esteem. Majority scored moderate or high self-esteem. Statistically positive correlation between the two scales	Key researcher had met 70% of the population before the study. No control	S1: yes S2: yes 4.1: yes 4.2: yes 4.3: yes 4.4: yes 4.5: yes

(Continues)

TABLE 1 (Continued)

Study and country	Design	Sample	IQ	Instruments	Main findings	Limitations	MMAT ^a
Nader-Grosbois (2014) Belgium	Quantitative; Comparative Design	28 children without intellectual disability: 7–8 years 32 children or adolescents with mild to moderate intellectual disability: 11–16 years	Children without intellectual disability: mean 105.67 (SD 11.64 years) Children with intellectual disability: mean 61.51 (SD 14.10 years)	WISC-IV ^b assessing verbal and nonverbal intelligence. SPPLD ^c questionnaire measuring self-reported overall self-perception and self-perceived competencies in nine domains: intellectual or cognitive ability, reading, spelling, writing, mathematics, social acceptance, athletic competence, behavioural conduct and physical appearance, spatial and temporal problem-solving exercises	Self-perception perceived by domains does not differ in adolescents with and without intellectual disability. Intellectual disability adolescents attribute more importance to social acceptance than children without intellectual disability	Performance was measured in the context of complex problem-solving, requiring several prerequisites. Perception of competencies from teachers and parents was not taken into account	7/7 S1: yes S2: yes 3.1: yes 3.2: yes 3.3: yes 3.4: yes 3.5: yes
Paterson et al. (2012) UK	Quantitative; Cross-sectional Design	43 adults recruited from a day centre; 25 women, 18 men, group's mean age was 40 years old (SD = 12.7) Living in the community	Intellectual disability: Mean British Picture Vocabulary Scale raw score of 87.1 (SD = 26.9)	Stigma Perception Questionnaire; adapted social comparison scale; Adapted Rosenberg Self-Esteem Scale	Greater perception of stigma related to lower self-esteem. People with intellectual disability have higher esteem when they consider themselves as more able compared to the majority of the group. Positive contributions to the community can boost self-esteem	Small sample size. Visual stigma was not investigated	7/7 S1: yes S2: yes 4.1: yes 4.2: yes 4.3: yes 4.4: yes 4.5: yes
Theme 2: Self-esteem and the ability to communicate to others (n = 3)							
Jackson et al. (2014) UK	Qualitative; Comparative design	12 adults with Down syndrome 5 men, 7 women 18–34 years and their mothers	Intellectual disability: Not specified	Semi-structured interview	Low self-esteem seems to be worsened by poor communication skills; difficulties in communication can also lead to decrease in self-esteem	Participants could communicate in their preferred modes of communication	7/7 S1: yes S2: yes 1.1: yes 1.2: yes 1.3: yes 1.4: yes 1.5: yes
Monteleone and Forrester-Jones (2017) UK	Qualitative	15 adults in an adult day service; 10 men, 5 women	Intellectual disability: Not specified	Open-ended interviews.	Participants felt feelings of otherness and sought out ways to "appear normal." Participants who showed downward social comparisons seemed to have high self-esteem. Participants associated their identity with how they are perceived by their peers. Participants had difficulty with self-reflection and expressing their feelings about disability	All participants were recruited from the same service, providing a limited perspective.	7/7 S1: yes S2: yes 5.1: yes 5.2: yes 5.3: yes 5.4: yes 5.5: yes
Todd (2000)	Participatory observational study	21 adolescents attending an outreach unit	Intellectual disability: Severe	Observation and interviews	Generally unaware of their stigmatised status Information concerning their disability was withheld from them Adolescents did not "feel stigma" as otherness was not discussed	Study done in one outreach unit; therefore, the results may not be generalisable	6/7 ^b S1: yes S2: yes 1.1: yes 1.2: yes 1.3: ? 1.4: yes 1.5: yes
Theme 3: Self-concept and its relationship to the views of others (n = 8)							

(Continues)



TABLE 1 (Continued)

Study and country	Design	Sample	IQ	Instruments	Main findings	Limitations	MMAT ^a
Cunningham and Glenn (2004) ^f UK	Mixed; Comparative Design	77 young adults with Down syndrome (DS) and 78 parents; 45 men and 32 women; M age: 19.11 years; SD = 22 months Recruited from Manchester Down Syndrome Cohort	Mean verbal mental age: 6.4 years, SD = 25.9 months	For young adults, British Picture Vocabulary Scale II was administered followed by open-ended interviews. Semi-structured interviews with the parents	Self-descriptions of young people with DS followed the typical developmental path Few felt that their disability was particularly important High self-esteem was maintained. Awareness of Down syndrome or disability did not appear to be a major problem. Awareness of disability was associated with IQ	Structured questions limited exploration of other issues	7/7 S1: yes S2: yes 5.1: yes 5.2: yes 5.3: yes 5.4: yes 5.5: yes
Dunn et al. (2009) Australia	Quantitative; comparative design	30 children with cerebral palsy; 14 girls, 16 boys; Mean: 11.5 years	Mild intellectual disability; IQ = 40–70	Self-perception profile was used to measure self-concept of the child Parent Rating Scale was used to measure parent perception of child's abilities	Parents rated abilities and attributes of their child differently than the child. Children had a positive view of their self-concept. Parents rated their child's athletic competence significantly lower than the child's rating. Parents rated their child significantly higher on physical appearance to the child's rating. Degree of disability has an impact on parental rating of their child's physical appearance	Study was conducted on children with mild disability therefore cannot be generalised to moderate intellectual disability Did not include parent rating of global self-worth	6/7 ^g S1: yes S2: yes 4.1: yes 4.2: ? 4.3: yes 4.4: yes 4.5: yes
Goleniowska (2014)	Blog/case description			Personal anecdote	Author explored techniques to increase self-esteem and confidence for parents with children with learning disabilities. For example, accepting child, adopting a positivity outlook, bonding with child, creating friendships	Not generalisable	3/7 S1: yes S2: yes 1.1: yes 1.2: no 1.3: no 1.4: no 1.5: no
Jahoda et al. (1988) ^f Scotland	Qualitative	12 adults living in the community and attending training centres. 5 men and 7 women (21–40 years) as well as their mothers and members of the staff. Exclusion criteria: severe speech impediments	Mild intellectual disability; IQ = 40–70	Semi-structured interviews	Parents viewed their child as different from other people. The participant's self-concept is not determined by the perception of mothers and staff	Small sample	6/7 ^g S1: yes S2: yes 1.1: yes 1.2: yes 1.3: ? 1.4: yes 1.5: yes
Salaun et al. (2014) France	Quantitative; nonran- domised	23 adolescents, 9 boys, 13 girls; mean: 15.13 years Participate in the Adapted Physical Activity Program	Mild intellectual disability; IQ = 40–70	PSI-VSF-ID ^d EUROFIT test battery and other physiological measures, for example body mass index A nine-drawing body silhouette scale	An inclination towards positive illusory bias in physical-sport competence appears to be correlated to higher scores on global self-esteem and self-perception	Participants lived in a sheltered environment. They made comparisons only with their peers and not with adolescents without intellectual disability	6/7 ^g S1: yes S2: yes 3.1: yes 3.2: yes 3.3: yes 3.4: yes 3.5: ?

(Continues)

TABLE 1 (Continued)

Study and country	Design	Sample	IQ	Instruments	Main findings	Limitations	MMAT ^a
Schiaviti et al. (2014) Canada	Qualitative; comparative design	10 children with cerebral palsy and their caregivers; 8 boys, 2 girls; mean 12.5 years 12 caregivers of children not self-reporting; mean 8.11 years; 8 boys, 4 girls	Intellectual disability was reported for 6 participants; not specified	Semi-structured interviews	Children and caregivers have different perspectives on disability. Children had a positive view of their abilities and described their strengths and facilitating factors; caregivers expressed a number of hindering factors. Caregivers seem preoccupied by the future while the child was more focused on the present. Children demonstrated acceptance of their condition	Findings may not represent the perspectives of the international cerebral palsy community Did not compare any findings based on sex	7/7 S1: yes S2: yes 1.1: yes 1.2: yes 1.3: yes 1.4: yes 1.5: yes
Shields et al. (2007)	Quantitative; Comparative design; comparative design	47 children; 24 boys and 23 girls; mean 11.8 years, SD = 2.6 years diagnosed with spastic diplegia or hemiplegia; classified as Gross Motor Function Classification System 12 Level I, II or III; sufficient language comprehension	Intellectual disability; 2 participants attended specialised schools. Not specified	Self-perception profile measured six domains of self-concept: global self-worth, scholastic competence, social acceptance, athletic competence, behavioural conduct and physical appearance	Children with cerebral palsy had a positive self-concept for all domains except athletic competence. No difference was found for global self-worth, physical appearance or behavioural conduct. A diagnosis of cerebral palsy does not lead to lower self-concept	Study was restricted to children with cerebral palsy who had a mild to moderate disability; results cannot be generalised to children with more severe disability	6/7 S1: yes S2: yes 3.1: ? 3.2: yes 3.3: yes 3.4: yes 3.5: yes
Taylor (2000)	Longitudinal study; Narratives	1 family, its kin and friends Low SES family	Intellectual disability; not specified Multiple disabilities, for example medical, language, physical	Participatory observational study	The family does not perceive disability as stigmatising	Not representative. Results are not generalisable	7/7 S1: yes S2: yes 1.1: yes 1.2: yes 1.3: yes 1.4: yes 1.5: yes
Theme 4: Self-concept, stigma and well-being (n = 2)							
Ali, Hassiotis, Strydom, & King (2012) UK	Review	37 articles		Studies covering the period from January 1990 to February 2012 Structured Questionnaire was used to extract information about the studies	Awareness of stigma in people with intellectual disability seems to be related to the extent to which individuals internalise the label of intellectual disability	Excluded: non-English studies	7/7 S1: yes S2: yes 1.1: yes 1.2: yes 1.3: yes 1.4: yes 1.5: yes
Rubbert et al. (2012) UK	Qualitative; body awareness group	4 adults, 2 men, 2 women; 35–48 years Participate in the Body Awareness Program; "Health at Every Size Model" ^h	Mild intellectual disability: IQ = 40–70	Adapted version of Rosenberg's Self-Esteem Scale for persons with a learning disability	Self-esteem played a significant role in weight loss	Small sample. The group had a significant social function No follow-up	7/7 S1: yes S2: yes 1.1: yes 1.2: yes 1.3: yes 1.4: yes 1.5: yes

^aPictorial Scale of Perceived Competence and Social Acceptance for Young Children (PSPCSA).

^bThe Wechsler Intelligence Scale for Children (WISC).

^cSelf-Perception Profile for Learning Disabled Students (SPPSD).

^dVery Short Form of the Physical Self-Inventory for adolescents with intellectual disability (PSI-VSF-ID).

^eMixed Methods Appraisal Tool.

^fReported for Themes 1 and 3.

^gOne or two methodological quality criterion/criteria could not be evaluated and was therefore scored as 0.



full-text articles, we identified four themes: theme 1: self-concept and social comparison ($n = 8$); theme 2: self-esteem and the ability to communicate with others ($n = 3$); theme 3: self-concept and its relationship to the views of others ($n = 8$); and theme 4: self-concept, stigma and well-being ($n = 2$) (see also Table 1). The articles by Jahoda, Markova, and Cattermole (1988) and Cunningham and Glenn (2004) covered theme 1 and theme 3.

3.2 | Theme 1: Articles about self-concept and social comparison ($n = 8$)

The first theme features the impact of social comparison on self-concept in individuals with an intellectual disability. Eight articles illustrated this theme. According to Cunningham and Glenn (2004), the development of a global self-concept emerges when children are approximately 7 and 8 years old; until then, children lack the cognitive capacity to integrate evaluations of different competencies into an overall view of the self. At ages 7 and 8 years, children undergo a key developmental transition, because they begin making social comparisons. Children over 8 years old with an intellectual disability that made downward social comparisons—the practice of making comparisons to individuals inferior to oneself—showed higher self-esteem. Conversely, those that compared themselves to individuals without disabilities (Huck, Kemp, & Carter, 2010; Nader-Grosbois, 2014) or individuals from another gender (Gibbons, 1985) reported lower self-esteem.

Another study, conducted with adults with intellectual disabilities in a forensic hospital in the UK, found that these individuals compared themselves to their peer group, not to the staff (Johnson, 2012). That study evaluated 44 males with the Self-Esteem Scale and an adapted Evaluative Beliefs Scale. On both scales, the self-esteem levels were moderate to high.

In addition to individuals with intellectual disabilities comparing themselves to others, they also experienced how others compared individuals with intellectual disabilities to themselves. The results showed that many individuals with intellectual disabilities experienced stigmatisation. Individuals with Down syndrome (DS) that compared themselves to peers in mainstream settings showed an increased likelihood of realising their inherent differences and feeling stigmatised (Glenn & Cunningham, 2004).

There seems to be a relationship between the extent of stigma one feels and one's self-esteem. Paterson, McKenzie, and Lindsay (2012) studied participants recruited from Adult Resource Centers of a local health board in central Scotland. They found that participants with the greatest perceptions of stigma had the lowest self-esteem. It was predicted that those individuals often incorporated negative social attributions into their definition of self. Although individuals with intellectual disabilities often have low self-esteem, some studies have indicated that many do not necessarily believe disability is a negative attribute. Jahoda et al. (1988) examined participants with intellectual disabilities, including DS and brain damage. They investigated how the participants coped with the stigma of having an intellectual disability. They found that the majority of

those participants did not believe that the stigma made them less worthy people.

Summarising this theme: (a) social comparisons seem to influence the self-esteem of persons with intellectual disability; (b) many persons with intellectual disabilities feel stigmatised, which can lower their self-esteem and (c) self-esteem is possibly related to, but a different construct than self-concept: as low self-esteem does not necessarily coincide with feeling less worthy.

3.3 | Theme 2: Articles about self-esteem and the ability to communicate with others ($n = 3$)

The second theme enholds the aspects of an individual's self-concept that involved self-esteem and communication capacity. Three studies supported the notion that the self-concept of individuals with intellectual disabilities was greatly influenced by self-esteem and the ability to communicate with others.

Individuals with intellectual disabilities often have difficulties in communication, particularly when they experience delays in speech and language use. Jackson, Cavenagh, and Clibbens (2014) explored the relationship between communication and self-esteem in adults with DS ($N = 12$) with semi-structured interviews. Participants described negative experiences, like bullying or teasing, which impaired their ability to communicate. The study found a link between low self-esteem and reduced communicative ability: low self-esteem increased difficulties in communication and in turn, difficulties with communication often compelled individuals to withdraw from social environments, which exacerbated their low self-esteem. Furthermore, mood was related to communication. Difficulties in communication led to feelings of anger and frustration, which also contributed to greater communication difficulties.

Monteleone and Forrester-Jones (2017) interviewed 15 adults with intellectual disability in the UK and found that participants were almost universally uncomfortable discussing disability. While responses conveyed feelings of isolation and adverse experiences involving their disability, many were unable to articulate meaning or grasp an understanding of the terminology presented. One participant, not familiar with the terms, asked for clarification: "Special needs? What is that?" Adolescents with severe intellectual disabilities appeared generally unaware of their stigmatised status. When interviewed, many did not acknowledge their disability and talked about further similarities to individuals without disabilities (Todd, 2000). Todd (2000) found that caregivers did not discuss with adolescents the fact that they were different from other individuals or that they had different needs. The findings in this theme demonstrate the relationship between the ability to communicate and self-esteem (and therefore possibly self-concept) in people with intellectual disabilities.

3.4 | Theme 3: Articles about self-concept and its relationship to the views of others ($n = 8$)

This theme provided an exploration of how the parent's perspective on facial appearance can play a role in shaping self-concept.

Self-concept is an integral part of a child's understanding of him/herself, and it is often impacted by the views of the people close to them. Eight studies investigated the ability of parents to provide insight into their child's needs.

Jahoda et al. (1988) performed a qualitative study that included 36 participants with mild intellectual disabilities. They found that self-concept was not determined by the perspective of the mother or the staff. A similar result was found in a study by Cunningham and Glenn (2004), who interviewed 77 people with DS and their parents. They found that other people's awareness of DS did not correspond to parent perspectives. In general, most of the individuals with DS had high levels of self-esteem. However, one young woman wanted to learn more about DS, but could not, because her parents did not want to discuss it. Additionally, one of the major findings of Dunn, Shields, Taylor, and Dodd (2009) was that parents did not accurately evaluate the abilities and attributes of their child. They found poor agreement among the five self-concepts assessed: scholastic, social, physical, behavioural and athletic. A parent's views can challenge a person's sense of self and cause psychological distress, because the parent's perception of their child's competencies can greatly impact how their child feels about him/herself. Anecdotal examples from Goleniowska (2014) highlight how important it is for parents to play a role in supporting feelings of self-esteem and self-worth in their child. Based on the author Goleniowska (2014), either by giving praise or by adopting a positive outlook, parents have the potential to be positive role models, and they can make a child with a disability feel truly valued as a member of the community.

Additionally, Schiariti et al. (2014) found that, although children with cerebral palsy (CP) exhibited issues in mobility and self-care, they were generally positive and frequently discussed their strengths and functional abilities. On the other hand, parents mostly focused on the limitations and challenges their child faced and their concerns for the child's future. This discordance was perhaps influenced by the experience of a child growing up with a disability and accepting it. Many children interviewed stated that they did not view themselves as different from other children; they were born with CP and made the necessary adjustments in their lives to cope. Another study on children with CP (Shields, Loy, Murdoch, Taylor, & Dodd, 2007) analysed how these children compared themselves to children without impairments. The results were similar, indicating that children with CP did not have a lower overall self-concept compared to children without impairments.

The relationship between self-perception variables and morphological variables was examined by Salaun, Reynes, and Berthouze-Aranda (2014). They found that global self-esteem and self-perception could predict the inclination towards a positive illusory bias, among adolescents ($n = 23$) with obesity and intellectual disabilities that were scheduled to receive an intervention. They reported that our self-concept (self-competence) was based on how others looked at our competences and, thus, on our perception of how others see us.

Taylor (2000) conducted a longitudinal study of a family that included several members with intellectual disabilities. That study showed that the family did not perceive disability as stigmatising.

The explanation for the lack of stigmatisation was that the family was embedded in their own world, where having a disability was more common than not having a disability. In that "culture," positive identities were maintained, because the disability was not the "master status" that determined interactions with others. For example, a niece with "spina bifida" was described as "crippled, just like Kathy" (Taylor, 2000: p.86). Thus, she was described as a person, not as a "condition."

In summary, a child's self-concept is not developed in isolation from his or her surroundings: parents can play a critical role in shaping a child's idea of who and what the self is. From these results, it is clear that three important factors contribute to the self-concept of an individual with intellectual disability: social relationships, self-esteem and caregiver attitudes.

3.5 | Theme 4: Articles about self-concept, stigma and well-being ($n = 2$)

The awareness of stigma from physical appearances was investigated by Ali et al. (2012) in a review. They found that the awareness of stigma in individuals with intellectual disabilities seemed to be related to the extent to which individuals internalised the "label" of intellectual disability. Furthermore, they found that an internalisation of the stigma associated with the "intellectual disability" label was associated with lower self-esteem, negative self-evaluations, negative self-comparison and psychiatric symptoms. Consequently, this internalisation affected the general well-being of individuals with intellectual disabilities. On the other hand, Rubbert, Bisnauth, and Offen (2012) mentioned that it was not the stigma, but the self-esteem that affected well-being. They focused on body awareness among individuals with learning difficulties ($n = 4$) and found that self-esteem played a significant role in weight loss, because self-esteem determined the individual's own belief in the ability to change.

4 | CONCLUSION AND DISCUSSION

This review addressed the question of how the self-concept of individuals with intellectual disabilities is related to the facial appearance. Furthermore, constructs were explored that contribute to the self-concept of persons with intellectual disabilities. Unfortunately, no studies were found that directly evaluated how facial appearances were perceived by individuals with intellectual disabilities. It seems there is a lack of knowledge which needs to be addressed in the future as awareness on the importance of facial appearance may contribute to improve quality of life for individuals with an intellectual disability. Our results reinforced findings from previous studies that showed that self-concept was influenced by personal and environmental factors. We found that there was no clear consensus on what exactly shaped the self-concept of individuals with intellectual disabilities. Some studies have suggested that individuals with intellectual disabilities experienced stigmatisation, which negatively impacted their self-concept (Jahoda et al., 1988; Paterson et al., 2012).



Other studies have suggested that the perceptions of stigma and disability had little influence on psychological well-being (Schariti et al., 2014). A study that evaluated the self-concept of individuals with CP found that, often, children with CP did not perceive deficits in their level of physical functioning (Dunn et al., 2009). This suggested that physical functioning was of limited importance to their self-concept. Crocker and Major (1989) and Taylor (2000) reported that the extent of stigma one feels is often related to how different one feels from others in a group. Additionally, individuals with the least perception of stigma experienced the greatest self-esteem (Abraham, Gregory, Wolf, & Pemberton, 2002).

While this was not part of our original aim, this review of studies on self-concept and intellectual disabilities revealed that social and parental relationships affected the self-concept of individuals with intellectual disabilities. Concerning theme 1 "Self-concept and social comparison," the study indicates that not the "intellectual disability" label, but rather, the social comparisons contribute to lower self-esteem. This notion was supported by the social comparison theory (Festinger, 1954), which holds that individuals are compelled to evaluate themselves, through either objective measures or subjective measures established by peers. An individual's self-concept is multi-dimensional; it is influenced by personal and environmental factors and by the experience of intellectual inadequacy or social stigmatisation.

In theme 2 "Self-esteem and ability to communicate with others," the self-concept of individuals with intellectual disability is greatly influenced by feeling engaged with others. In Down syndrome (DS), Cunningham and Glenn (2004) showed that the feeling of self-esteem was influenced by the feeling of belonging to a group and feeling supported by others in the environment. Also, Schariti et al. (2014) found that children with CP did not necessarily see themselves as different from other children. Clinicians need to take this into account when planning treatment; moreover, clinicians might need to educate parents and caregivers to ensure that they understand that disability and its associated lack of socially normative physical and maybe even facial traits will not necessarily lead to a low self-concept. However, this needs to be examined especially among persons with DS for whom the facial appearance related to the syndrome is highly visible.

Theme 3 "Self-concept to the views of others" indicates that it is important to consider that individuals with intellectual disability seldom have opportunities to discuss their self-concept, communicate socially about or explore the meaning of self-concept. Currently, without a clear comprehension of disability or the confidence to communicate, individuals with intellectual disabilities are obliged to develop notions of disability based upon prior interactions with others and prejudice present in society. This condition has broad implications for clinical practice, because it reveals the need to develop more interventions that can assist individuals with intellectual disabilities in communicating with others. This type of intervention could help reduce feelings of isolation in these individuals and encourage them to establish meaningful relationships in their social environment.

With regard to the 4th theme, "Self-concept, stigma and well-being," the awareness of stigma or self-esteem affected the well-being of individuals with intellectual disability. However, we found a lack of studies that specifically explore how facial appearance contributes to the self-concept and well-being.

4.1 | Limitations of the current review

The main limitation of this review was that it did not include dissertations or studies that were published in languages other than English. Also, a potential limitation could be that because literature published before 2007 was excluded from the review, valuable information could have been missed out on. Moreover, no MESH terms were used when searching for articles; therefore, relevant articles might have been overlooked. Furthermore, very few studies published the estimated levels of intellectual (and social-emotional) functioning of the participants (although all subjects were considered to have an intellectual disability). Therefore, it is more difficult to compare the outcomes of the various studies. Although most studies included in the review were of strong methodological construct, the blog/case description by Goleniowska (2014) can be considered as weak and conclusions from this report should be interpreted with caution.

4.2 | Other literature on cosmetic enhancement in people with intellectual disabilities

The urge to change the appearance of persons with facial disfigurement due to a syndrome was initiated decades ago, with the uprise of plastic surgery. As Rozner (1983) stated in an article published in *The Lancet* 36 years ago about facial plastic surgery for people with DS, surgery to the "relief of Down stigmata" (diminishing the size of the tongue and other facial plastic surgery) "generated enormous debate." While performing facial plastic surgery, persistent first dentition and carious teeth were removed and orthodontics ("as in the normal child") was performed. Rozner (1983) reported quick improvement in speech and claimed improved mood and self-confidence in the children. However, peer and community acceptance were still deemed unknown (Rozner, 1983). Furthermore, Strauss, Mintzker, Feuerstein, Wexler, and Rand (1988) found peer social perceptions were improved upon facial plastic surgery of adolescents with DS. Peers believed the children with DS were more attractive, intelligent, good-hearted and socially appealing. Next, Hems and Godfrey (1990) gave a case report on cosmetic surgery and hair removal of a person with Cornelia de Lange syndrome. Results were positive: "a significant improvement in the patient's willingness to interact socially was noted over the period of treatment" and the authors claimed that this kind of cosmetic surgery will possibly improve body image and facilitate social integration. Wexler, Peled, Rand, Mintzker, and Feuerstein (1986) also described similar facial plastic surgery being performed upon children with DS and reported an increase in confidence, especially in older children.

However, Kravetz, Weller, Tennenbaum, Tzuril, and Mintzker (1992) repeated the study of Wexler et al. (1986) while including a

control group and found no increase in parents' perceptions of the physical, personal and social functioning of their child after cosmetic surgery. Besides the reasonable doubt whether changing the appearance of a child with DS (or intellectual disability) changes his/her self-concept, Aylott (1999) and Suziedelis (2006) call our attention to some ethical concerns on the topic. Rozner (1983) suggests to operate on children between the ages of 4 and 17, but Aylott questions whether it is ethically sound to "subject a child to cosmetic surgery when he/she does not understand what is happening to him/her." Every procedure has risks and downsides (among others: anxiety, pain and side effects). Suziedelis (2006) therefore calls our attention to the ethical problem that a young child is too young to give his/her consent.

Who defines what beauty is? Are crooked teeth always ugly? Cultural images possibly influence our general opinion on this subject. Also, perceptions of beauty or ugliness are not self-contained: our expectations influence our perceptions (Butz & Kutter, 2017). One could argue that when prejudice about people with intellectual disabilities is reduced and contact between people with and without intellectual disabilities is encouraged, perhaps appearance does matter less. Likewise, Aylott (1999) states that "there have been changes in challenging discriminatory attitudes towards people with a disability in society. This, however, is the result of the public coming into contact and building relationships with people with disabilities in the wider community and not cosmetic surgery." Suziedelis (2006) argues for a more "tolerant society" instead of changing the appearance of children with DS. However, orthodontics is not as great a risk as plastic surgery and perhaps a relatively "easy," low-risk treatment will improve the quality of life of people with intellectual disabilities. It is therefore crucial to know what persons with intellectual disabilities and their parents think of this subject: Is there a wish for correcting the position of the teeth?

4.3 | Recommendations for further exploration

The novelty of the present review lies in its discovery of how individuals with intellectual disability evaluate their self-concept. There is an urgent need for more knowledge on the relationship between facial features and the perception of self-concept among individuals with intellectual disability. A reliable, validated questionnaire that addresses attitudes on facial appearance could provide a deeper understanding of the self-concept of individuals with intellectual disabilities.

Therefore, we propose a qualitative study with a questionnaire for individuals with intellectual disability, which includes direct, multiple-choice questions about their satisfaction with their own facial features and whether they desire orthodontic treatment. As evidenced by our third theme (self-concept and the effects of views of others), we found that sometimes, young individuals with intellectual disabilities and their parents held competing perspectives. Therefore, we would extend our proposal to include two questionnaires: one for parents and one for individuals with intellectual disability. These questionnaires would include pointed

questions for both the parent and the person with an intellectual disability to understand what aspects of facial appearance are most important to them. It would be of interest to know whether facial appearance, and which of its aspects, might predict improvements in general well-being and self-concept for individuals with intellectual disabilities.

Future studies could have broad implications for orthodontists, craniofacial orthopaedic specialists and other medical professionals that treat individuals with intellectual disability. If they wish, people with intellectual disabilities have as much right as any other person to undergo orthodontic treatment and effort should be done to create the circumstances to make this possible.

ACKNOWLEDGEMENTS

The authors thank Carol Mita, research service librarian from Countway Library of Medicine in Boston, MA, USA, and Anke de Jong, the librarian of Bartiméus The Netherlands, for their support. Our acknowledgements also go to Paula Dekkers-Verbon, scientist-practitioner at the "Social relations and attachment" research laboratory of Bartiméus—Vrije Universiteit Amsterdam, for her contributions as independent researcher.

CONFLICT OF INTEREST

The authors declare that they have no conflict of interest.

AUTHOR CONTRIBUTIONS

TC and PS conducted the study. TC wrote the first draft of this manuscript. PS and AB actively participated in the writing process. AB commented on the manuscript throughout the writing process. CP and NA commented on the semi-final and final manuscripts. PS finalised the manuscript.

ETHICAL APPROVAL

The authors did not perform any procedures with human participants or animals for this study.

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How to cite this article: Chien T, Sterkenburg PS, Prah C, Anderson N, Bos A. Self-concept and facial appearance of individuals with an intellectual disability: A scoping review. *Br J Learn Disabil*. 2020;48:84–97. <https://doi.org/10.1111/bld.12294>