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Title: Parental perceptions of facilitators and barriers to physical activity for children with intellectual disabilities: A mixed methods systematic review

Abstract

Background: There is a need increase our understanding of what factors affect physical activity participation in children with intellectual disabilities (ID) and develop effective methods to overcome barriers and increase activity levels.

Aim: This study aimed to systematically review parental perceptions of facilitators and barriers to physical activity for children with ID.

Methods: A systematic search of Embase, Medline, ERIC, Web of Science, and PsycINFO was conducted (up to and including August, 2017) to identify relevant papers. A meta-ethnography approach was used to synthesise qualitative and quantitative results through the generation of third-order themes and a theoretical model.

Results: Ten studies were included, which ranged from weak to strong quality. Seventy-one second-order themes and 12 quantitative results were extracted. Five third-order themes were developed: family, child factors, inclusive programmes and facilities, social motivation, and child's experiences of physical activity. It is theorised that these factors can be facilitators or barriers to physical activity, depending on the information and education of relevant others, e.g. parents and coaches.

Conclusions: Parents have an important role in supporting activity in children with ID. Increasing the information and education given to relevant others could be an important method of turning barriers into facilitators.

What this paper adds?

This study is the first to systematically review parental perceptions of facilitators and barriers to physical activity for children with ID. Through a structured search and synthesis of data, relevant factors which affect physical activity in children with ID have been identified. The development of a conceptual and theoretical understanding of the

relationships between these factors highlights the complexity of supporting physical activity for children with ID. The importance of information and education was identified, which could provide an effective method of turning barriers to activity into facilitators. These findings highlight specific factors which need further investigation in future research and contributes valuable information to the limited knowledgebase on physical activity in children with ID.

Highlights

- Children with ID face many complex barriers to physical activity
- Information and education are important for turning barriers into facilitators
- Children with ID are not getting the support required to enable physical activity

Keywords

Physical activity; children; intellectual disabilities; facilitators; barriers; systematic review; meta-ethnography.

1 **1. Introduction**

2 Physical activity has numerous physical and mental health benefits for children (Ahn &
3 Fedewa, 2011; Biddle & Asare, 2011; Janssen & LeBlanc, 2010). To gain clinically meaningful
4 health benefits from physical activity, it is recommended that children participate in at least
5 60 minutes of moderate to vigorous physical activity per day (Chief Medical Officers, 2011).
6 However, recent studies have shown that children with ID do not participate in sufficient
7 activity to gain meaningful health benefits (Boddy, Downs, Knowles, & Fairclough, 2015;
8 Einarsson et al., 2015). This is concerning as children with ID experience various negative
9 health outcomes and chronic health conditions, such as anxiety disorders, obesity, and
10 reduced cardiorespiratory and muscular function (Maiano, 2010; Oeseburg, Dijkstra,
11 Groothoff, Reijneveld, & Jansen, 2011). Increasing levels of physical activity could therefore
12 be an effective method of improving relevant health outcomes for this population (Johnson,
13 2009). However, it is necessary to first increase our understanding of why children with ID
14 are, in general, inactive.

15 These low activity levels could be due to factors associated with ID or could be attributed to
16 various socio-ecological factors which limit opportunities for physical activity
17 (Bronfenbrenner, 1979). Previous research has demonstrated that children with ID have
18 different experiences relating to participation and inclusion compared to their typically
19 developing peers, such as participating in less social and recreational activities, preferring
20 solitary and passive activities, and having fewer friends (Buttimer & Tierney, 2005; Solish,
21 Perry, & Minnes, 2010). Disability effects, societal attitudes to disability, accessible facilities,
22 and staff information have also been reported to affect physical activity in children with
23 disabilities (Shields, Synnot, & Barr, 2012). Furthermore, cognitive factors associated with
24 developmental disabilities, such as a reduced ability to judge safety and understand rules
25 and concepts within play, also limits participation (Serman et al., 2016).

26 Another important factor affecting the participation of children with ID in physical activity is
27 parents (Shields et al., 2012; Serman et al., 2016). Parental beliefs and behaviours
28 regarding activity are significant correlates of physical activity in children with ID (George,
29 Shacter, & Johnson, 2011; Pitchford, Siebert, Hamm, & Yun, 2016). This is in line with
30 research in typically developing children which has highlighted the “gatekeeper” role that

31 parents play in the promotion of physical activity (Bois, Sarrazin, Brustad, Trouilloud, & Cury,
32 2005; Trost et al., 2003; Welk, Wood, & Morss, 2003). However, children with disabilities are
33 more reliant on support from others, in particular parents, to be active, which highlights the
34 key role that parents have in promoting activity for their children with ID (Downs, Boddy,
35 Knowles, Fairclough, & Stratton, 2013; Martin & Choi, 2009). Therefore, understanding
36 physical activity in children with ID from the perspective of parents, and investigating
37 factors that parents view as facilitators and barriers to physical activity, will help inform the
38 development of relevant interventions to increase the activity levels of children with ID.

39 Numerous studies have investigated parental perceptions of facilitators and barriers to
40 physical activity for children with ID. However, due to the wide scope of research in this
41 field, it is currently not possible to draw definitive conclusions. Therefore, the aim of this
42 study is to conduct a mixed-methods systematic review to investigate parental perceptions
43 of facilitators and barriers which affect the physical activity participation of their children
44 with ID.

45 **2. Method**

46 This study was conducted in accordance with the Preferred Reporting Items for Systematic
47 Reviews and Meta-Analyses (PRISMA) guidelines (Moher, Liberati, Tetzlaff, & Altman, 2009).

48 *2.1 Search strategy*

49 Relevant studies were identified through a systematic search to prevent the “berry-picking
50 model” which is often a limitation of reviews including qualitative papers (Barroso et al.,
51 2003). Five electronic databases relating to various fields, including psychology, education,
52 and health (Embase, Medline, ERIC, Web of Science, and PsycINFO), were searched from
53 database inception (range: 1946-1996) up to and including August, 2017 to enable the
54 identification of studies which are relevant to the aims of this review, regardless of the
55 scientific field or date of publication. This search was focussed on truncated physical
56 activity, ID, and parental terms, and was broad to ensure all study designs were captured;
57 the Embase search strategy, which was adapted for the other databases, is presented in
58 Figure 1. A reference list search of included studies was also conducted.

59 INSERT FIGURE 1 HERE

60 *2.2 Eligibility criteria*

61 To be eligible for this review, studies had to include qualitative or quantitative data from
62 parents relating to factors they perceive to be facilitators and/or barriers to physical activity
63 in their child with ID. To ensure the data were representative of the intended population,
64 studies were excluded if <50% of the sample of parents had children with ID aged <18 years.
65 Parental data that was study-specific, e.g. parents' views relating to an intervention, were
66 also excluded. If the data presented in the primary studies did not enable eligibility to be
67 assessed, corresponding authors were contacted and asked to provide additional
68 data/clarification; only one author who was contacted did not provide the required data,
69 which resulted in exclusion of the study.

70 *2.3 Study selection*

71 Title and abstract screening and full-text screening were independently conducted by two
72 researchers (AMMcG & CAM), with any discrepancies discussed to reach a consensus.
73 Reliability for the title and abstract screening and full-text screening was investigated using
74 Cohen's kappa scores (κ), which demonstrated substantial agreement for both screening
75 phases ($\kappa = .65$ and $\kappa = .64$, respectively; Landis & Koch, 1977).

76 *2.4 Quality assessment*

77 The Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a
78 Variety of Fields is a reliable tool for quality assessment that was specifically designed for
79 use in systematic reviews (Kmet, Lee, & Cook, 2004). This tool, which has been summarised
80 in Appendix 1, enables quantitative and qualitative studies to be assessed using design-
81 specific criteria. Quality assessment was conducted for descriptive purposes and did not
82 determine whether studies were included in the review. The aim of the quality assessment
83 was to investigate if the research design and methods were appropriate for the research
84 questions posed. Two researchers (AMMcG & CAM) independently scored studies based on
85 whether the assessment criteria were fully, partially, or not met. Quality was scored as a
86 percentage of the relevant criteria met, thus enabling comparison on quality between all
87 included studies. Scores of <55%, 55-75%, and >75% were interpreted as weak, moderate,
88 or strong quality, respectively (Eddens, van Someren, & Howatson, 2017). There was an

89 almost perfect inter-rater reliability ($\kappa = .83$; Landis & Koch, 1977), with discrepancies
90 discussed until a consensus was met.

91 *2.5 Data extraction*

92 Prior to extracting data for synthesis, the reviewers (AMMcG & CAM) immersed themselves
93 in the data by reading each study multiple times to ensure a high level of familiarity and
94 understanding (Noblit & Hare, 1988). A data extraction form was developed using Excel and
95 piloted by both reviewers.

96 Descriptive data (e.g. methods and context of study) were extracted for all studies and
97 quantitative results (e.g. percentage scores) extracted from relevant papers. Qualitative
98 data were extracted based on the first- and second-order themes from the primary studies.
99 As described by Schultz (1962), first-order themes relate to participant's own views and
100 beliefs, i.e. interview extractions, with second-order themes being the primary study
101 authors' interpretation of these. For studies that included various participant groups, e.g.
102 parents and recreation staff, only data from parents were extracted.

103 *2.6 Analysis and synthesis*

104 Qualitative studies were synthesised using a meta-ethnography approach, with quantitative
105 findings additionally synthesised into the themes generated by the meta-ethnography.
106 Meta-ethnography is an inductive and interpretive technique used to systematically
107 synthesise qualitative research (Noblit & Hare, 1988). The approach used in this review was
108 based on the seven-step process described by Noblit & Hare (1988), which has been
109 summarised in Table 1; phases 1-3 have been described within the previous method sub-
110 sections.

111 Specific to a meta-ethnography, the term "synthesis" refers to reconceptualization across
112 numerous studies which contributes to human discourse (Doyle, 2003). Therefore, a meta-
113 ethnography goes beyond a single account and systematically identifies analogies between
114 accounts. Through the selection of important themes, the "senses" of multiple accounts can
115 be translated into one another, while preserving the meanings of the original texts (Noblit &
116 Hare, 1988). This enables a more formalised knowledge to be generated, which is based on
117 third-order themes (through the synthesis of second-order themes), and the development

118 of a mid-level theory or theoretical framework, thus advancing this field of research
119 (Zimmer, 2006). Third-order themes refers to the synthesis of second-order themes, and is
120 based on the synthesising researchers' views and interpretations of these themes (Schultz,
121 1962). Two researchers were involved in the analysis and synthesis processes (AMMcG and
122 CAM). AMMcG (Ph.D.) and CAM (M.D.) have extensive experience of physical activity
123 research in children with ID, utilising both quantitative and qualitative methods.

124 INSERT TABLE 1 HERE

125 **2.6.1 Determining how the studies are related (phase 4)**

126 This phase involves investigating relationships between second-order themes arising from
127 each study. The second-order themes extracted were put on separate pieces of paper with a
128 summary explanation to ensure the integrity of the original meanings remained. Similar
129 themes were then grouped together to enable a description of how these studies are
130 related; this process was completed separately for the facilitators and barriers themes. This
131 phase was conducted by one researcher (AMMcG).

132 **2.6.2 Translating the studies into one another (phase 5)**

133 Based on the findings from phase four, which demonstrated similar findings between the
134 studies, two separate reciprocal translations were carried out for the facilitators and
135 barriers themes. In keeping with the meta-ethnography approach, the aim of this phase was
136 to compare and match concepts across the papers by translating one paper into another.
137 Studies were translated chronologically by investigating how the first paper related to the
138 second, and how these combined findings related to the third paper, and so on. In line with
139 the methodology used by Britten et al. (2002), a grid was developed in which the key
140 themes identified in the previous phase were inserted as rows and each study was inserted
141 as a column. This enabled similar themes from across the studies to be identified and
142 categorised together, with first-order themes and primary authors' narratives used to
143 ensure themes were accurately grouped together. At this phase, the extracted quantitative
144 results were translated into the grouping categories developed. This process with initially
145 conducted by one researcher (AMMcG), with a second researcher (CAM) reading and
146 validating the translations. From this process, it was possible for key themes to be matched

147 and grouped across studies and an organisational grouping framework developed for
148 facilitators and barriers, which have been summarised in Appendices 2 and 3.

149 **2.6.3 Synthesising translations (phase 6)**

150 The previous phases of this synthesis were conducted independently for facilitators and
151 barrier. However, the groupings from the previous phase were primarily reversals of one
152 another, e.g. children’s positive experiences is a facilitator whereas children’s negative
153 experiences is a barrier. Therefore, these facilitator and barrier groupings were combined to
154 generate third-order concepts and a line of argument synthesis of relevant facilitators and
155 barriers that influence physical activity in children with ID.

156 Third order themes were initially generated from the grouping themes developed. This was
157 conducted by one researcher (AMMcG) and validated by another researcher (CAM). The
158 development of an overarching line of argument explaining the interactions of the third-
159 order themes developed was conducted by both researchers.

160 **3. Results**

161 *3.1 Literature search*

162 The database searches identified 2525 records to be screened, with ten studies meeting the
163 criteria for inclusion; the full screening process is presented in Figure 2.

164 *3.2 Description of studies*

165 Qualitative data were extracted from nine studies (Alesi & Pepi, 2015; An & Hodge, 2013;
166 Barr & Shields, 2011; Fidler, Lawson, & Hodapp, 2003; Grandisson, Tétreault, & Freeman,
167 2012; Mactavish & Schleien, 2004; Melbøe & Ytterhus (2017); Menear, 2007; Njelesani,
168 Leckie, Drummond, & Cameron, 2015) and quantitative data extracted from two studies
169 (Levinson & Reid, 1991; Fidler et al., 2003). Mactavish & Schleien (2004) also included
170 quantitative data relating to the family, but data specific to children with ID could not be
171 independently extracted, therefore quantitative data from this paper was not included.

172 Studies were conducted in Australia (Barr & Shields, 2011), Canada (Grandisson et al., 2012;
173 Levinson & Reid, 1991), Italy (Alesi & Pepi, 2015), Norway (Melbøe & Ytterhus (2017),
174 Trinidad and Tobago (Njelesani et al., 2015), and the USA (An & Hodge, 2013; Fidler et al.,

175 2003; Mactavish & Schleien, 2004; Meneer, 2007). Quality assessment scores and a full
176 summary of each study is presented in Table 2.

177 INSERT FIGURE 2 HERE

178 *3.3 Third-order themes*

179 A total of 71 second-order themes were extracted for inclusion in this synthesis. More
180 second-order themes were extracted for barriers (n = 41) than facilitators (n = 30). Twelve
181 quantitative results were extracted and included for barriers (n = 6) and facilitators (n = 6).
182 From the second-order themes and quantitative results, five third-order themes were
183 developed: family, child factors, child's experiences of physical activity, social motivation,
184 and inclusive programmes and facilities. The third-order themes were developed based on
185 the organisational groupings developed from the reciprocal translation and synthesis (Table
186 3 describes how the third-order themes were formed from the organisational groupings). In
187 accordance with the aims of a meta-ethnography, this study has went beyond a description
188 of these synthesised themes (Noblit & Hare, 1988). The interactions between the third-
189 order themes were developed into a hierarchal model (Figure 3) and the theorised effects
190 discussed as part of the line of argument synthesis.

191 The following sections will report specific results for each third-order theme, with first- and
192 second-order themes used to provide support and context for these findings.

193 INSERT TABLE 2 HERE

194 **3.3.1 Family**

195 Six studies reported family as a facilitator and seven reported the family to be a barrier to
196 children with ID being active.

197 The importance of the family, both parents and siblings, in facilitating physical activity was
198 identified. Parents recognised their responsibility to provide opportunities by ensuring
199 family time for activity, both through home-based activity and family outings, and utilising
200 additional support where appropriate, e.g. personal care assistants (Mactavish & Schleien,
201 2004). This was seen as important due to the fewer opportunities children with ID have,
202 therefore, resulting in an increased focus on parent-child activities (Mactavish & Schleien,

203 2004). Yet, parents identified a lack of information on how to conduct home-based activities
204 (Menear, 2007).

205 *“I play an important role in organizing out home activities and determining how much*
206 *physical activity my child gets (Mother, age 41)” (Alesi & Pepi, 2015, pg. 6)*

207 *“My daughter will walk away from the television if you tell her that her brother is going to*
208 *take her outside to jump on the trampoline.” (Menear, 2007, pg. 63)*

209 In addition to providing opportunities, parents also viewed themselves as facilitating activity
210 out with the family structure through networking and communicating with physical
211 education teachers (An & Hodge, 2013), coaches (Barr & Shields, 2011), and typically
212 developing children (Melbøe & Ytterhus (2017). This advocacy role of parents was important
213 to educate others on their child’s abilities, provide support to others, seek out additional
214 opportunities for activity, and help ensure the inclusion of their child in physical activity.

215 *“Since Matt isn’t big enough or articulates [well] enough at this point to speak for himself,*
216 *that’s my job to be his advocate” (Mother, 8yo child; An & Hodge, 2013, pg. 155)*

217 Two studies identified the activity levels and beliefs of the family (both siblings and parents)
218 as important, in terms of being role models for activity (Barr & Shields, 2011; Grandisson et
219 al., 2012). Furthermore, descriptive data shows that 73% of parents and siblings of children
220 with ID who were involved in sport were active themselves, with only 22% of parents and
221 siblings of children with ID not involved in sport were active themselves (Grandisson et al.,
222 2012). This was not a consistent finding though as one study concluded that parents did not
223 view their engagement in physical activity as having an effect on the physical activity levels
224 of their child with ID (Alesi & Pepi, 2015).

225 The family structure was also a barrier to children with ID being physically active. A theme
226 identified across numerous studies was the time demands required to create opportunities
227 for activity. Due to parents’ competing interests and the need for one-to-one support for
228 children with ID to enable activity, physical activity was not regarded by all parents as a
229 priority (Barr & Shields, 2011; Levinson & Reid, 1991; Njelesani et al., 2015). Instead, due to
230 time restraints, parents reported promoting sedentary activities (Barr & Shields, 2011;
231 Menear, 2007). Furthermore, the additional planning demands required to take children

232 with ID to clubs and ensure suitable facilities were available, e.g. bathrooms, was an
233 additional restriction on parents' time (Mactavish & Schleien, 2004).

234 *"If we're going to do a physical activity, then I'm going to have to supervise it, and I can't*
235 *abandon everyone else and their needs...So, I give him a book or put him at the computer or*
236 *the television."* (Menear, 2007, pg. 63)

237 The cost and travel requirements were also a barrier, with 82% of parents of children with
238 ID involved in sport employed, but only 44% of parents without a job had children with ID
239 involved in sport (Grandisson et al., 2012).

240 Parental over-protection and worries that their child's ID would make them vulnerable in
241 structured sport settings was an additional barrier for activity (Alesi & Pepi, 2015; Barr &
242 Shields, 2011).

243 *"I don't want him to get disappointed or hurt. . . that is probably my weakness, I am*
244 *protecting him too much. – Hannah (mother of a 10-year-old boy)"*
245 (Barr & Shields, 2011, pg. 1028)

246 **3.3.2 Child factors**

247 Three studies noted child factors as a facilitator and six noted this as a barrier. Child factors
248 were described in relation to cognitive abilities, psychological factors, behavioural problems,
249 and physical characteristics, including those specifically related to Down syndrome (Alesi &
250 Pepi, 2015; Barr & Shields, 2011). Parents of children with Down syndrome noted that the
251 physical effects associated with Down syndrome were a greater barrier to activity than the
252 general limitations associated with ID (Barr & Shields, 2011).

253 *"Her whole build – she has flat feet, short arms, short legs . . . all those sorts of things are*
254 *barriers. – Katie (mother of a 16-year-old girl)"* (Barr & Shields, 2011, pg. 1028)

255 However, participation in activity was found to help children overcome some of the
256 psychological barriers identified, such as self-image (Alesi & Pepi, 2015).

257 *"My child has developed a more positive self-image through skill acquisition and rewarding*
258 *experiences"* (Mother, age 49; Alesi & Pepi, 2015, pg. 7)

259 Age was also identified as a moderator for disability effects, with the reduced behavioural
260 and physical abilities between children with Down syndrome and typically developing
261 children having more of an effect on physical activity as children got older and the ability
262 gap between these groups widened (Barr & Shields, 2011).

263 *“All the kids can ride their bicycles and he can’t . . . he is getting frustrated that he can’t keep*
264 *up with the other kids and some of them are even younger than him. – Hannah (mother of a*
265 *10-year-old boy)” (Barr & Shields, 2011, pg. 1029)*

266 Children with Down syndrome who played in a team matched to their developmental age
267 were physically too strong compared to their teammates, and therefore could not be placed
268 within a team (Menear, 2007). However, playing individual sports at a young age was found
269 to be effective in reducing the influence of age.

270 *“my child is so strong, so agile, and so able to play with kids his age physically and too*
271 *strong for kids that are his age mentally, so there’s no fit for him in an organised team*
272 *activity” (Menear, 2007, pg. 64)*

273 In contrast, Levinson & Reid (1991) found that 89% of parents of children with ID aged 4-10
274 years perceived that their child lacked the necessary skills to be active, with 75% of parents
275 of children with ID aged 11-21 years noting this. Therefore, the effect of age may be more
276 specific to Down syndrome.

277 Disability effects also impacts on others and their perceptions of children with ID, such as
278 typically developing children excluding children with ID from activities and games (Melbøe &
279 Ytterhus (2017). Parents also find it difficult to organise family recreation activities due to
280 the lower ability levels of their child with ID (Mactavish & Schleien, 2004).

281 *“There are a lot of things Damon just can’t do because of his disability – physically it’s*
282 *impossible... it makes it really hard to find things we can all do together.” (Mactavish &*
283 *Schleien, 2004, pg. 136)*

284 Parents also perceive that teachers have a lack of knowledge relating to the effects of their
285 child’s ID, which is a barrier to inclusion (Barr & Shields, 2011; Njelesani et al., 2015).

286 *“I spend a lot of time up skilling teachers and instructors . . . so they understand her and can*
287 *get the best out of her. – Clare (mother of a 6-year-old girl)” (Barr & Shields, 2011, pg. 1026)*

288 However, parents were found to have a high level of overprotection and negative views
289 relating to their child's competence due to the effects of their ID. Parents also perceived
290 that typically developing children did not want to participate in physical activity with
291 children with ID due their limited communication and understanding of rules (Njelesani et
292 al., 2015). Therefore, many of the barriers associated with child factors may be a result of
293 parent's perceptions of their child's competence, and how they believe others view the
294 effects of their child's ID, rather than actual competence and societal beliefs.

295 Regardless of the effects of ID, a child's determined to succeed and having the basic physical
296 and cognitive abilities required for activity facilitated participation (Barr & Shields, 2011;
297 Grandisson et al., 2012). Positive encouragement from others was also a facilitator (Barr &
298 Shields, 2011).

299 **3.3.3 Child's experiences of physical activity**

300 Two studies noted the child's experiences of physical activity as a facilitator and one as a
301 barrier. Although the extracted second-order concepts for this theme were limited, it was
302 widely noted within the first-order themes and was related to various other second-order
303 themes and, therefore, was deemed important enough to be an independent third-order
304 theme.

305 Participating in physical activity enables children with ID opportunities for success, both
306 against themselves and others with similar characteristics, and skill development which
307 facilitated future activity (Alesi & Pepi, 2015).

308 *"My child is benefiting from physical activities because of the opportunity to perform his*
309 *personal best effort (Father, age 53)" (Alesi & Pepi, 2015, pg. 7)*

310 Promoting activity and positive experiences from a young age also facilitated future activity,
311 whereas negative experiences at an early age was a barrier to children with ID participating
312 in future activity (Grandisson et al., 2012).

313 **3.3.4 Social motivation**

314 Three studies reported social motivation as a facilitator and three as a barrier, yet it was
315 frequently noted in first-order themes within studies. Social interactions was a powerful
316 motivator for activity (Barr & Shields, 2011). Interactions with peers (children with ID,

317 typically developing peers, and siblings) gave a purpose for physical activity and an
318 opportunity for peer support and peer modelling (Alesi & Pepi, 2015; Barr & Shields, 2011;
319 Melbøe & Ytterhus (2017); Menear, 2007).

320 *“Sport allows social interactions that help my child to make friends and to be like his peers*
321 *(Father, age 53)” (Alesi & Pepi, 2015, pg. 7)*

322 *“Recognising that the social part has to go with it has been really important for us to make*
323 *anything happen. He ties all physical activities to social events” (Menear, 2007, pg. 64)*

324 Without a social motivation, however, children with ID are less likely to participate in
325 physical activity and will instead choose sedentary activities (Menear, 2007). This is an
326 important barrier to activity as opportunities for free-living activity with typically developing
327 peers is scarce Melbøe & Ytterhus (2017), with 61% of parents describing their child with ID
328 as having a lack of friends (Levinson & Reid, 1991)

329 **3.3.5 Inclusive programmes & facilities**

330 Eight studies noted a lack of inclusive programmes and facilities as a barrier, with four
331 studies noting this theme as a facilitator.

332 Organised activity programmes and sports clubs were a widely reported barrier. This related
333 to a lack of disability-specific programmes in a geographical proximity, as well as limited
334 local programmes which were inclusive for children with ID (Alesi & Pepi, 2015; Barr &
335 Shields, 2011; Levinson & Reid, 1991). Studies reported numerous reasons for parents
336 viewing mainstream programmes as not being fully inclusive for children with ID, such as: a
337 lack of staff time, a lack of knowledge on integration (both relating to coaches and a lack of
338 scientific understanding), and others’ (coaches, non-disabled athletes, parents of typically
339 developing children) negative attitudes and stereotypes towards children with ID (Alesi &
340 Pepi, 2015; Barr & Shields, 2011; Grandisson et al., 2012; Levinson & Reid, 1991). Levinson &
341 Reid (1991) further reported that 53% of parents felt there were a lack of appropriate
342 inclusive programmes.

343 *“Lots of people can’t stand them [individuals with ID]! (Parent NS#2)” (Grandisson et al.,*
344 *2012, pg. 224)*

345 *“what I’m hearing is that the problems that our children have with physical activity are not*
346 *a consequence of their disability, they are a consequence of the outer world not providing*
347 *opportunities for everybody” (Menear, 2007, pg. 64)*

348 A lack of education and information were widely reported as reasons for exclusion. Parents
349 felt they required organised activities to provide opportunities for activity, due to their lack
350 of time, yet believed that inclusive programmes were not well advertised and did not
351 specify that children with ID were welcome to attend (Barr & Shields, 2011; Grandisson et
352 al., 2012; Menear, 2007).

353 *“A lack of APA programs and a lack of education for coaches limit the inclusion in sport*
354 *activities of children with special needs (Mother, age 58)” (Alesi & Pepi, 2015, pg. 7)*

355 With the lack of available information, parents were also a barrier, as they did not actively
356 seek out information (Barr & Shields, 2011). This information also relates to the accessibility
357 of facilities, such as the availability of suitable bathroom facilities (Mactavish & Schleien,
358 2004; Menear, 2007). Due to this lack of information on inclusive activities, parents felt they
359 instead required further information on how to conduct family-based activity (Menear,
360 2007).

361 Mainstream programmes which make adaptations for children with ID, e.g. coaches
362 knowing how to break down skills to a level children with ID can understand, and which
363 enable them to progress at their own pace, facilitated activity (Barr & Shields, 2011;
364 Grandisson et al., 2012). Expert gym instructors and access to specialised gym equipment
365 also facilitated activity (Alesi & Pepi, 2015). This highlights that, in contrast to the barriers,
366 education of coaches/instructors on disabilities is important in promoting physical activity
367 through inclusion.

368 This lack of inclusion and information/education was also identified specific to physical
369 education, with a need for teachers to be more sensitive to the needs of children with ID
370 (Fidler et al., 2003). Parents also viewed themselves as having a role in educating physical
371 education teachers on their child’s needs and working as a team with others (An & Hodge,
372 2013).

373 *“I’ve always taken the position that I’m a part of the team. I know Dale better than the*
374 *teacher does” (Mother, 17yo child; An & Hodge, 2013, pg. 155)*

375 Furthermore, parents of children with Prader-Willi syndrome (28.0%), Williams syndrome
376 (8.3%), and Down syndrome (5.1%) wanted improvements in adapted physical education.
377 However, the differing percentages of parents who wanted change demonstrates different
378 needs/parental views between disabilities (Fidler et al., 2003).

379 Further to organised programmes and physical education, studies also identified
380 environmental and cultural factors which limit activity, such as a lack of safe and accessible
381 parks, high costs, and the weather (Grandisson et al., 2012; Levinson & Reid, 1991;
382 Mactavish & Schleien, 2004; Njelesani et al., 2015).

383 INSERT TABLE 3 HERE

384 *3.4 Development of a theoretical understanding*

385 Figure 3 describes a model of how the developed third-order themes are related, based on
386 the results of the synthesis. This hierarchical model demonstrates the overarching role that
387 family, and in particular parents, have in supporting activity for their child with ID, with this
388 theme having a direct effect on all other themes. Parents play a vital role by providing
389 home-/family-based activities, or sourcing out external opportunities, e.g.
390 clubs/organisations. Children with ID are reliant on others (e.g. parents, teachers, coaches)
391 to provide suitable opportunities for activity; however, children with ID are not receiving the
392 necessary support and opportunities from others to enable them to be active. It is further
393 theorised that information and education will determine if these themes will be facilitators
394 or barriers to activity, e.g. programmes with a coach who is educated on including children
395 with ID will be a facilitator, whereas a coach with no information or education on inclusion
396 will be a barrier.

397 INSERT FIGURE 3 HERE

398 **4. Discussion**

399 This study systematically reviewed parental perceptions of facilitators and barriers to
400 physical activity for children with ID. Results highlight the importance of family, child factors,

401 inclusive programmes and facilities, social motivation, and children’s experiences of physical
402 activity, and the complex interactions between these facilitators and barriers. Furthermore,
403 a trend was identified whereby the identified themes can be facilitators or barriers,
404 depending on information and education.

405 The family has a vital role in promoting activity for children with ID. In research involving
406 typically developing children, parents have consistently been identified as playing an
407 integral “gatekeeper” role in their child’s physical activity behaviours (Bois et al., 2005; Trost
408 et al., 2003; Welk et al., 2003). However, children with ID face more complex barriers to
409 activity than their typically developing peers, with the role of parents and significant others
410 being more important. Although children with ID face additional barriers to physical activity,
411 such as reduced physical and cognitive abilities, parents also have negative perceptions of
412 their child’s competence for activity, which further promotes exclusion. Therefore, factors
413 specific to their child’s disabilities affect the promotion of activity by parents.

414 Parents reported that they feel responsible for making opportunities for their child to be
415 active, such as organising family activity time. Yet, the additional time and organisation
416 requirements suggest that structured family activity may not be the most effective way to
417 promote activity for children with ID. Instead, unstructured or spontaneous activity, which is
418 generally facilitated by siblings or peers, is an effective facilitator of activity. This also
419 provides a valuable social element, which concurrent with existing research, was identified
420 as a strong facilitator to activity (Hutzler & Korensky, 2010). The results from this study
421 highlight that children with ID almost never choose to be active on their own, which raises
422 important questions relating to their views of activity, and the effect of having a limited
423 number of friends and peers to be active with.

424 The role of parents in their child’s activity also extends beyond the family structure. Parents
425 viewed it as important to advocate for their child with ID and educate others (e.g. teachers
426 and coaches). This was an indirect method used by parents to turn perceived barriers to
427 activity, i.e. coaches not understanding how to include children with ID, into facilitators.
428 Although studies did not report on whether parents deemed this to be effective in
429 increasing inclusion or activity levels for their child, it further highlights the underlying role
430 that information and education could play in turning barriers into facilitators. In addition, as
431 inclusion/exclusion were associated with positive/negative experiences of activity,

432 respectively, increasing inclusive opportunities through education could promote positive
433 experiences and continued participation in activity for children with ID.

434 There is an underlying theme within the results of this review regarding who is responsible
435 for children with ID being active. The lower autonomy faced by this population creates an
436 environment where they are reliant on others to provide opportunities or support for
437 activity. With the busy schedules of parents and the time and planning demands required
438 for activity, parents do not seem to provide sufficient home-based activity. Furthermore,
439 the lack of inclusive facilities and external inclusive opportunities for activity do not make up
440 for the lack of home-based activity. This study highlights that parents' views regarding
441 activity are varied and fundamentally based on parental priorities; if activity is a priority,
442 parents will provide opportunities for activity; if activity is not a priority, activity
443 opportunities will not be provided. Therefore, if parents are not motivated to overcome the
444 barriers faced by their child with ID, i.e. sourcing inclusive opportunities, then this will lead
445 to inactivity.

446 *4.1 Theoretical and applied relevance*

447 The results of this study and the third-order themes developed provide additional support
448 for existing theories. The socio-ecological model provides a framework to examine the
449 effects and interactions of interpersonal, intrapersonal, organisational, and environmental
450 factors on physical activity participation. This framework is widely used in research
451 examining determinants of physical activity in typically developing children and has been
452 identified as a relevant theoretical framework for children with a broader range of
453 disabilities (Shields et al., 2012). Factors affecting children with disabilities' participation in
454 physical activity have previously been reported for all levels of this model (e.g.: child and
455 disability effects, parent behaviour, societal attitudes to disability, accessible facilities, and
456 staff information; Shields et al., 2012; Sterman et al., 2016). Therefore, the present
457 systematic review provides additional data identifying the specific facilitators and barriers
458 relevant to children with ID. However, the relevance of these social/ecological theories may
459 be exacerbated due to the theoretical frameworks used to guide the primary studies.

460 Previous research in children and adults with ID has raised questions on the appropriateness
461 of existing behaviour change theories and techniques for this population (Melville et al.,

2015; Willems, Hilgenkamp, Havik, Waninge, & Melville, 2017). The present review adds to this argument by demonstrating that children with ID have different and additional barriers to physical activity participation compared to typically developing children, e.g. reduced capabilities and increased overprotection; therefore, these population differences need to be considered when developing methods to change behaviour. Population-specific physical activity models have been developed for individuals with physical disabilities to overcome the limitations of existing theories; however, the same has not been done for individuals with ID (van der Ploeg, van der Beek, van der Woude, & van Mechelen, 2004). Therefore, the generation of population-specific theories relating to physical activity and behaviour change is important to ensure the appropriate development of theory-based interventions to increase physical activity in children with ID.

There is a growing body of research highlighting the need to develop effective interventions and policy to address the low activity levels of children with ID. In line with the epidemiological framework and Medical Research Council guidelines for developing effective interventions, identifying correlates of physical activity is an important first step (Biddle, Mutrie, & Gorely, 2015; Craig et al., 2008). Considering that physical activity in children with ID is a neglected area of research, it is necessary to build a strong evidence base to inform the development of effective and population-specific interventions (Frey, Stanish, & Temple, 2008). Therefore, this study adds important findings to the evidence-base by highlighting relevant barriers and facilitators which parents perceived to be important for the promotion of physical activity for children with ID.

4.2 Strengths and limitations

This study is the first to systematically review parental perceptions of facilitators and barriers to physical activity for children with ID. A robust and systematic methodology was employed, with screening, data extraction, quality assessment, and synthesis conducted by two reviewers to ensure reliability. A meta-ethnography approach enabled an accurate analysis and synthesis of relevant literature. Furthermore, this enabled conceptual and theoretical results to be developed.

Although using a meta-ethnographical approach to this review provided a structured approach to synthesis, some limitations with this approach affected the review. As the

492 development of third-order themes is focussed on the second-ordered themes from the
493 primary studies, the results of this review were influenced by the thoroughness and quality
494 of the primary studies. Therefore, this should be considered when interpreting the results of
495 this review. Furthermore, the depth of this review was limited by the relatively small
496 number of primary research studies which met the inclusion criteria.

497 **5. Conclusions**

498 In conclusion, children with ID face additional barriers to physical activity than have
499 previously been reported in typically developing children, such as disability-specific factors.
500 This study adds to the limited evidence-base by highlighting specific factors that are
501 important facilitators and barriers to activity. In addition, the influence of available
502 information and education could be a key factor for overcoming barriers to physical activity
503 for children with ID; it is theorised that if information and education for all relevant others
504 (e.g. parents, coaches, peers, parents of typically developing children, staff) can be
505 increased, then barriers can become facilitators. However, there was insufficient data to
506 draw definitive conclusions on how barriers to activity can be overcome in practice, which
507 requires further investigation.

1. (developmental adj2 (disab* OR disorder or difficult*)).tw
2. (intellectual* adj2 (disab* OR disorder or difficult*)).tw
3. (learning adj/2 (disab* OR disorder or difficult*)).tw
4. (mental* adj/2 (retard* OR deficiency)).tw
5. (cognitiv* adj/2 (disab* OR impair*)).tw
6. (physical* adj/2 (activ* OR fit* OR train* OR endur* OR education)).tw
7. (Exercis* adj/2 (train* OR physical* OR active* OR aerobic)).tw
8. Activ* adj/2 (lifestyle OR life-style).tw
9. Walk*.tw
10. Sport*.tw
11. Cycl*.tw
12. Exp parent/
13. Exp mother/
14. Exp father/
15. Exp family/
16. Limit Human
17. 1-5/OR
18. 6-11/OR
19. 12-16/OR
20. 16 AND 17 AND 18 AND 19

Figure 1. Embase search strategy

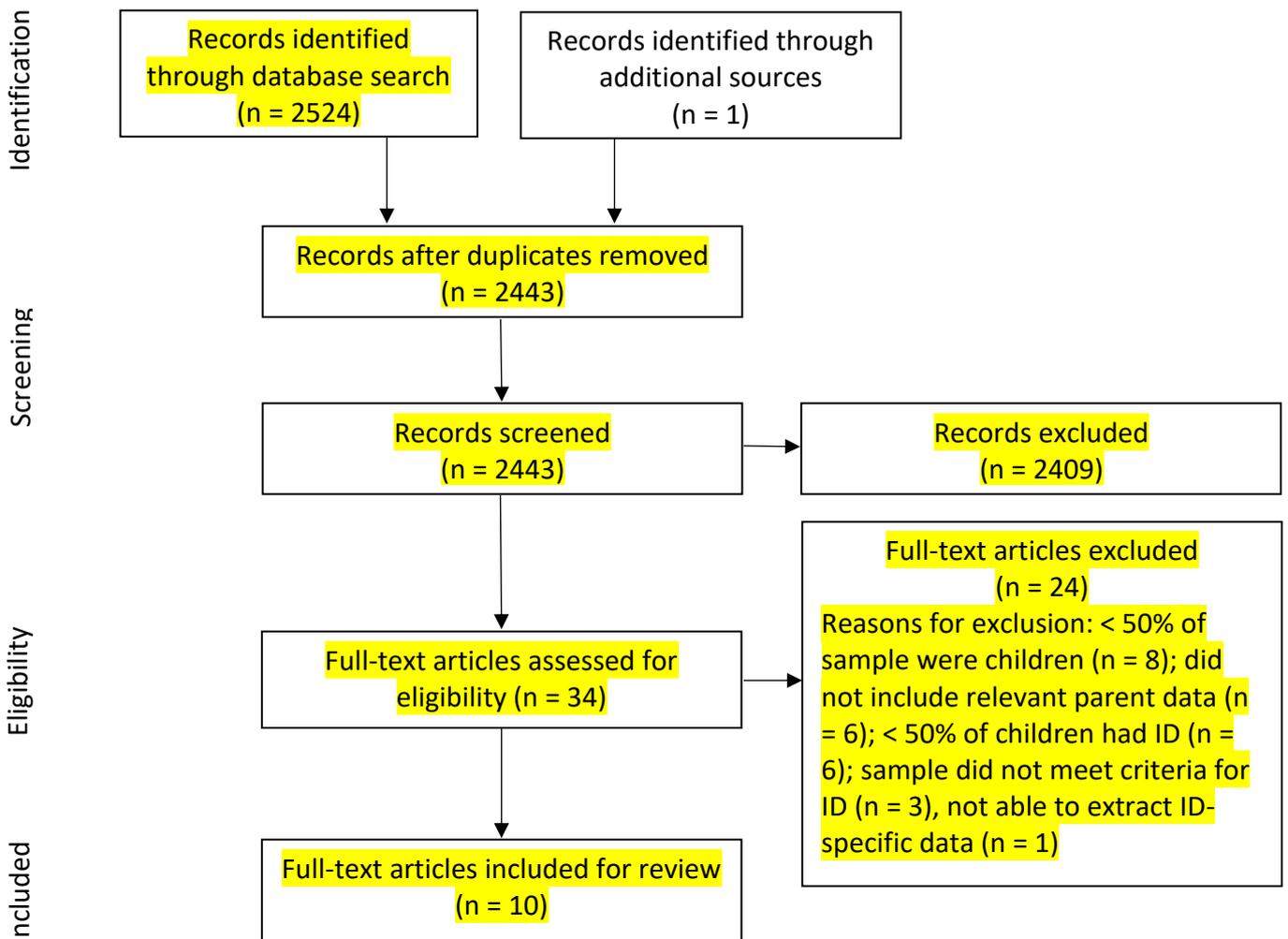


Figure 2. Search results and study selection process

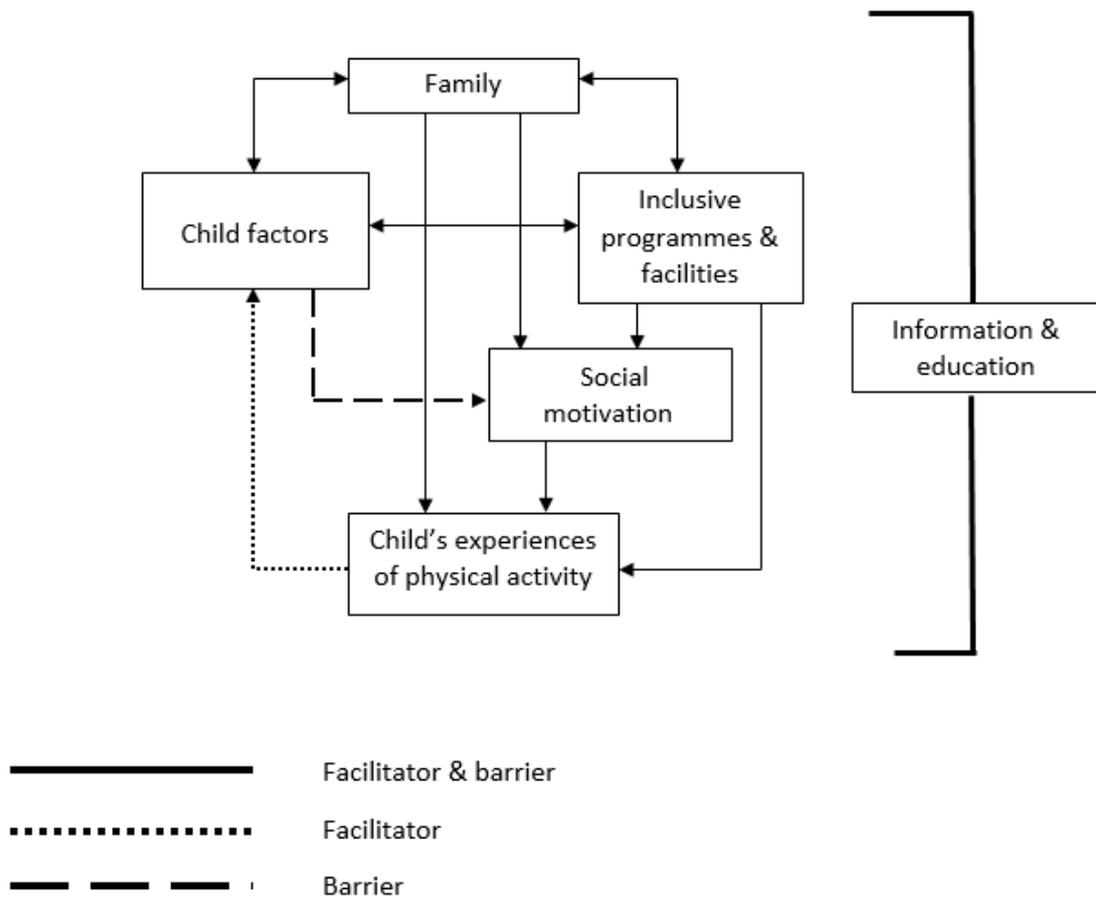


Figure 3. Hierarchical model illustrating interactions between the identified facilitators and barriers to physical activity for children with ID.

Table 1. Summary of seven-step meta-ethnography process

Phase	Summary of phase
1. Getting started	Decide on a research question
2. Deciding what is relevant	Search for relevant studies and decide which are to be included
3. Reading the studies	Repeated reading of the studies and noting key themes
4. Determining how the studies are related	Determining relationships between the studies based on first- and second-order themes extracted from primary studies
5. Translating the studies into one another	Comparing and understanding how the second-order themes from the studies translate into one another, e.g. are themes repeated across studies
6. Synthesising translations	Synthesis can be: 1) <i>reciprocal</i> if the translations (phase 5) are related; 2) <i>refutational</i> if the translations contrast one another; 3) <i>line of argument</i> if the studies are taken together. Second-order themes are synthesised to develop third-order themes.
7. Expressing the synthesis	Writing and presenting the results

Table 2. Summary of study characteristics and quality assessment

Reference	Aim	Participant characteristics	Context of physical activity	Method	Quality assessment
Alesi & Pepi (2015)	To explore parental beliefs concerning involvement, facilitators/barriers and beliefs of physical activity in young people with Down syndrome	<p><u>Parent characteristics</u> Sample size: 13 Male/female: 6/7 Age: 37-69 years, M = 51.85 ± 9.92 years Socioeconomic status: low (n = 8), medium (n = 4), high (n = 1).</p> <p><u>Child characteristics*</u> Age: 7-27 years, M = 17.38 ± 6.5 years Disability type: Down syndrome (n = 13) Disability severity: moderate ID.</p>	Free-living sport and physical activity	<p><u>Recruitment and sampling</u> Gyms and not-for-profit disability associations. Sampling method not specified.</p> <p><u>Data collection procedures</u> One-off face-to-face semi-structured interview (structured with 3 open-questions on: medical/personal history, engagement in physical activity, and parental beliefs on facilitators/barriers.</p> <p><u>Data analysis procedures</u> Thematic content analysis conducted by two researchers.</p>	Moderate: 55%
An & Hodge (2013)	To explore the meaning of parental involvement from the perspectives of parents of children with developmental disabilities.	<p><u>Parent characteristics</u> Sample size: 8 (6 individuals, 1 couple) Male/female: 1/7 Age: Not specified Socioeconomic status: middle class (n = 8) Ethnicity: white (n = 8) Education level: associate degree (n = 2), bachelor's degree (n = 6).</p> <p><u>Child characteristics*</u></p>	Physical education	<p><u>Recruitment and sampling</u> Purposeful sampling from inclusive physical education programme.</p> <p><u>Data collection procedures</u> Three face-to-face semi-structured interviews conducted; artefacts (e.g. photos) were discussed at interview and researcher's journal (noting interactions, behaviours, reflections on interview) was used.</p>	Strong: 90%

Age: 8-17 years, M = 12.29 years
 Male/female: 5/2
 Disability type: Down syndrome (n = 3),
 Autism (n = 2), global developmental
 delay and attention deficit disorder (n =
 1), Asperger's & obsessive compulsive
 disorder (n = 1).
 Siblings: 6 with siblings, 1 without.

Data analysis procedures
 Thematic analysis conducted by two
 researchers.

Theory framework used
 Ecological systems theory.

Barr & Shields (2011)	To explore facilitators and barriers to physical activity in children with Down syndrome	<u>Parent characteristics</u> Sample size: 20 parents of 18 children Male/female: 4/16 <u>Child characteristics*</u> Age: 2-17 years, M=9.9 ± 4.8 years Male/female: 8/10 Disability type: Down syndrome (n=18).	Free-living physical activity	<u>Recruitment and sampling</u> Purposeful sampling from non-for-profit organisations for parents of children with Down syndrome. <u>Data collection procedures</u> One-off semi-structured interview conducted by physiotherapy student. <u>Data analysis procedures</u> Thematic analysis conducted by two researchers. <u>Theory framework used</u> Phenomenological theoretical framework.	Moderate: 70%
Fidler et al. (2003)	To explore the modifications that parents of children with different genetic syndromes would	<u>Parent characteristics</u> Sample size: 88 Socioeconomic status: primarily middle-class	Physical education	<u>Recruitment and sampling</u> Recruited through national parent associations for each syndrome. <u>Data collection procedures</u>	Weak: 40% (Qualitative) Weak: 15% (Quantitative)

	make to their child's education	<p><u>Child characteristics*</u> Age: 5-21 years Disability type: Down syndrome (n=39), Prader-Willi syndrome (n=25), Williams syndrome (n=24) Disability severity: mild to moderate ID.</p>		<p>Questionnaires which included both quantitative and open-ended qualitative questions.</p> <p><u>Data analysis procedures</u> Quantitative: between group (syndrome) analysis. Qualitative data coded into themes by two researchers blinded to syndrome (specific analysis method used not reported).</p> <p><u>Theory framework used</u> Not specified.</p>	
Grandisson et al. (2012)	To explore facilitators and barriers to sports participation in adolescents with ID	<p><u>Parent characteristics</u> Sample size: 20 Involved in sport: male= 27%, female= 73%. Not involved in sport: male= 11%, female= 89% Employment status: 82% of sport group were employed; 44% of no sport group were employed</p> <p><u>Child characteristics**</u> Sample size: 20 Age: 12-19 years, M= 15.3 ± 2.0 years Involved in sport: male= 55%, female= 45%.</p>	Sport	<p><u>Recruitment and sampling</u> Recruited through rehabilitation centre and Special Olympics, Quebec.</p> <p><u>Data collection procedures</u> One-off face-to-face semi-structured interview.</p> <p><u>Data analysis procedures</u> Content analysis. Analysed by one researcher but validated and audited by a total of three researchers.</p> <p><u>Theory framework used</u> The Disability Creation Process theoretical model.</p>	Strong: 80%

Not involved in sport: male= 33%,
female= 67%
Disability severity: mild to moderate ID.

Levinson & Reid (1991)	To investigate patterns of physical activity and parental perceptions of barriers to physical activity for children with developmental disabilities	<p><u>Parent characteristics</u> Sample size: 105</p> <p><u>Child characteristics*</u> Age: 4-21 years Disability type: mental retardation, emotional disturbances, autism spectrum disorder, neurological impairments Disability severity: mild to moderate ID.</p>	Leisure-time physical activity	<p><u>Recruitment and sampling</u> Mailed recruitment through additional support needs schools.</p> <p><u>Data collection procedures</u> Questionnaire (quantitative) based on Canada Fitness Survey.</p> <p><u>Data analysis procedures</u> Descriptive.</p>	Weak: 45%
Mactavish & Schleien (2004)	To explore the nature, benefits, and constraints to family recreation in families with a child with developmental disabilities	<p><u>Parent characteristics</u> Sample size: 16 families (specific sample size not reported) <i>(Not able to extract data only for sample who participated in interviews).</i></p> <p><u>Child characteristics*</u> <i>(Not able to extract data only for sample of children with ID whose parents participated in interviews).</i></p>	Family recreation	<p><u>Recruitment and sampling</u> Mailed recruitment through a school, an advocacy organisation, and parent support group; sequential-purposive sampling for interview.</p> <p><u>Data collection procedures</u> One-off face-to-face interview.</p> <p><u>Data analysis procedures</u> Data coded by one researcher and analysed using systematic/constant comparative method. Themes reviewed by independent expert.</p>	Strong: 85%

				<u>Theory framework used</u> Family systems theory.	
Melbøe & Ytterhus (2017)	To investigate what kind of leisure activities, and when and how, do youths with ID participate in	<u>Parent characteristics</u> Sample size: 11 Male/female: 2/9 <u>Child characteristics**</u> Sample size: 10 Male/female: 6/4 Age: 14-16 years Disability type: ID Disability severity: mild to moderate	Leisure activity	<u>Recruitment and sampling</u> Recruited through educational and psychological counselling services and schools; purposeful sampling used. <u>Data collection procedures</u> One-off face-to-face semi-structured interview. <u>Data analysis procedures</u> Data analysed and interpreted by two researchers based on hermeneutic principles. <u>Theory framework used</u> Hermeneutic principles.	Weak: 50%

Menear (2007)	To investigate parents' perceptions of the health & physical activity needs of their children with Down syndrome	<u>Parent characteristics</u> Sample size: 21 Male/female: 5/16 <u>Child characteristics*</u> Age: 3-22 years Male/female: 8/5 Disability type: Down syndrome	Free-living physical activity	<u>Recruitment and sampling</u> Mailed recruitment through organisation for parents of children with Down syndrome <u>Data collection procedures</u> Participants attended one focus group [stratified by age of child (preschool, elementary, adolescent) and one was convenience for parents unable to attend age-specific focus group]. <u>Data analysis procedures</u> Data analysed by two researchers using thematic analysis. <u>Theory framework used</u> Not specified.	Moderate: 55%
Njelesani et al. (2015)	To explore the barriers perceived by parents of children with developmental disabilities	<u>Parent characteristics</u> Sample size: 9 Male/female: 3/6 <u>Child characteristics*</u> Age: 10-17 years Male/female: 6/3 Disability type: multiple disabilities Disability severity: moderate to severe ID	Free-living physical activity	<u>Recruitment and sampling</u> Purposeful sampling of parents recruited from a children's group, which was affiliated with international disability centre. <u>Data collection procedures</u> One-off face-to-face semi-structured interview. <u>Data analysis procedures</u>	Strong: 80%

Four researchers coded data, two researchers analysed data. Analysed using thematic analysis

Theory framework used
Occupational perspective.

* Children with ID were not study participants; this data is presented to provide additional context for parents

** Children with ID were study participants

Table 3. Development of third-order themes, based on organisational groupings for facilitators and barriers

Third-order theme	Organisational groupings: facilitators	Organisational groupings: barriers
Family	Parents understanding the benefits of activity	Lack of information for parents
	Parents providing opportunities for activity	Lack of expert coaches/physical education teachers
	Parental advocacy	Lack of parental time
	Family role models for activity	Cost and transportation requirements
		Parental concerns
Child factors	Abilities of child	Limited skills of child
		Disability characteristics
Child's experiences of physical activity	Positive experience of physical activity	Child's view and experiences of activity
Social motivation	Family/friends to be active with	Few friends
Inclusive programmes and facilities	Inclusive programmes	Lack of facilities
	Accessible facilities	Lack of inclusive programmes
	Coach knowledge	

* References for the primary studies which contributed to each organisational grouping are presented in Appendix 2 and Appendix 3.

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7. Appendices

Appendix 1. Quality assessment checklist

Criteria	Yes (2)	Partial (1)	No (0)	N/A
Quantitative quality checklist				
1	Question / objective sufficiently described?			
2	Study design evident and appropriate?			
3	Method of subject/comparison group selection <i>or</i> source of information/input variables described and appropriate?			
4	Subject (and comparison group, if applicable) characteristics sufficiently described?			
5	If interventional and random allocation was possible, was it described?			
6	If interventional and blinding of investigators was possible, was it reported?			
7	If interventional and blinding of subjects was possible, was it reported?			
8	Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? Means of assessment reported?			
9	Sample size appropriate?			
10	Analytic methods described/justified and appropriate?			
11	Some estimate of variance is reported for the main results?			
12	Controlled for confounding?			
13	Results reported in sufficient detail?			
14	Conclusions supported by the results?			
Qualitative quality checklist				
1	Question / objective sufficiently described?			
2	Study design evident and appropriate?			
3	Context for the study clear?			
4	Connection to a theoretical framework / wider body of knowledge?			
5	Sampling strategy described, relevant, and justified?			
6	Data collection methods clearly described and systematic?			
7	Data analysis clearly described and systematic?			
8	Use of verification procedure(s) to establish credibility?			
9	Conclusions supported by the results?			
10	Reflexivity of the account?			

* Adapted from Kmet, Lee, & Cook (2004)

Appendix 2. Summary of organisational groupings for translations of facilitators themes

Grouping theme	Summary	Reference
Parents understanding the benefits of activity	Parents who understood the benefits of physical activity for their child with ID, e.g. reduce obesity and improve self-perceptions, were more likely to encourage activity	Mactavish & Schleien (2004); Menear (2007)
Parents providing opportunities for activity	Due to the limited opportunities for activity in the community or schools, parents made time to facilitate activity by providing opportunities, e.g. family activity, sourcing inclusive programmes, and by facilitating inclusion with typically developing peers.	Barr & Shields (2011); Mactavish & Schleien (2004)
Parental advocacy	Parents advocating for their child with ID out with the family, e.g. schools, sports clubs, typically developing peers, helped facilitate inclusion	An & Hodge (2013); Melbøe & Ytterhus (2017)
Family role models for activity	Parents and sibling were role models for activity and provided motivation which promoted activity in children with ID.	Alesi & Pepi (2015); Barr & Shields (2011); Grandisson et al. (2012)
Abilities of child	Skills and abilities of children with ID (in terms of physical, cognitive, social, and emotional abilities; independence level; determination and enthusiasm) had an effect on activity	Barr & Shields (2011); Grandisson et al. (2012)
Positive experience of physical activity	Positive experiences for children with ID facilitated activity. Positive experiences were due to: having an interest in activity, individual activities (which limit the age-related effects of age on skill level), opportunity to progress skill level, integrated activity from a young age.	Alesi & Pepi (2015); Grandisson et al. (2012); Menear (2007)

Family/friends to be active with	Having friends (both children with ID and typically developing peers), siblings, and parents, to be active with, and who shared similar activity interests, facilitated activity.	Barr & Shields (2011); Levinson & Reid (1991)*; Melbøe & Ytterhus (2017); Menear (2007)
Inclusive programmes	Community programmes which were inclusive to children with ID, and which were sensitive to their needs and abilities, facilitate activity. Programmes which enabled parents to socialise with one another also facilitated activity through parents	Barr & Shields (2011); Grandisson et al. (2012); Levinson & Reid (1991)*; Mactavish & Schleien (2004)
Accessible facilities	Facilities which are accessible, in close proximity, and had specialised equipment facilitated activity	Alesi & Pepi (2015); Levinson & Reid (1991)*
Coach knowledge	Coaches who were educated in adapted activity, who were able to breakdown skills to a suitable level for children with ID, and who enabled skill progression at the child's own pace facilitate activity	Alesi & Pepi (2015); Barr & Shields (2011); Grandisson et al. (2012)

* Denotes quantitative data

Appendix 3. Summary of organisational groupings for translations of barriers themes

Grouping theme	Summary	Reference
Lack of information for parents	There was a lack of information available to parents on inclusive programmes and facilities, and how to conduct home-based activity.	Mactavish & Schleien (2004); Meneer (2007); Grandisson et al. (2012)
Lack of expert coaches/physical education teachers	There is lack of coaches and teachers who are skilled and knowledgeable on how to integrate children with ID and appropriately adapt programmes and classes. This is further limited by a lack of funding for coach education/specialised instructors and small physical education class sizes.	Alesi & pepi (2015); An & Hodge (2013); Fidler et al. (2009); Grandisson et al. (2012); Levinson & Reid (1991)*; Njelesani et al. (2015)
Lack of parental time	The time and organisational demands required for parents to facilitate activity was difficult to accommodate due to competing time demands.	Levinson & Reid (1991)*; Mactavish & Scheien (2004); Barr & Shields (2011); Njelesani et al. (2015); An & Hodge (2013)
Cost and transportation requirements	Cost and transportation requirements were a barrier to activity participation	Grandisson et al. (2012); Njelesani et al., 2015
Parental concerns	Parents were concerned about their child's safety and ability to participate in physical activity due to cognitive limitations.	Alesi & Pepi (2015); Barr & Shields (2011)

Limited skills of child	The limited skill level of children with ID limited activity opportunities within the family and organised clubs/groups. The skill gap between children with ID and their typically developing peers widened with age, which further promotes exclusion.	Barr & Shields (2011); Grandisson et al. (2012); Levinson & Reid (1991); Mactavish & Schleien (2004); Melbøe & Ytterhus (2017); Njelesani et al. (2015)
Disability characteristics	Characteristics associated with specific disabilities had an effect on participation in physical activity, although this varies between specific syndromes.	Alesi & Pepi (2015); Fidler et al. (2009)*
Child's view and experiences of activity	Children's negative experiences of sport, or not being interested in sport, was a barrier to activity.	Grandisson et al. (2012)
Few friends	Children with ID have a limited number of friends to participate in activity with.	Levinson & Reid (1991)*; Melbøe & Ytterhus (2017); Menear (2007)
Lack of facilities	Lack of accessible facilities in close proximity, with other environmental factors, e.g. the weather, being a barrier to outdoor activity.	Levinson & Reid (1991)*; Menear (2007); Njelesani et al. (2015)
Lack of inclusive programmes	There was a lack of programmes (including physical education) which were inclusive for children with ID. Reasons included: attitudes of others towards children with ID, lack of procedures for integrating children with ID, cost of inclusive programmes.	Grandisson et al. (2012); Levinson & Reid (1991)*; Menear (2007)

* Denotes quantitative data

