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Support programs for parents of children with intellectual disabilities: A scoping review protocol

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1 **Support programs for parents of children with intellectual disabilities: A**
2 **scoping review protocol**

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14 **ABSTRACT**

15 **Introduction:** Evidence shows that parents of children with intellectual disabilities experience high
16 levels of stress, emotional challenges and higher levels of depression. Despite these challenges,
17 support for parents has tended to be peripheral in healthcare services of children. There is a lack of
18 research attention given to support programs for parents of children with intellectual disabilities
19 despite the importance of parenting for the optimal development of children with intellectual
20 disabilities

21 **Methods and analysis:** This review will follow the Joanna Briggs Institute scoping review methods
22 manual. The search for relevant studies will be in Medline (EbscoHost), PsychARTICLES, PubMed,
23 CINHAL, Academic Search Complete and SAePublications. Reference mining of full review studies will
24 be conducted. A three-step search strategy will be utilized, including the use of information
25 management software to manage the search results and to remove duplications. An independent
26 reviewer will extract data using a data extraction tool. Furthermore, another reviewer will screen the
27 included articles in conjunction with the results of the scoping review. The data extracted will be
28 presented in a tabular format with a narrative summary related to the key findings.

29 **Ethics and dissemination:** This scoping review has received ethical approval (BM20/4/26). A
30 summary of the findings of the study will be published in a peer-reviewed journal. This scoping
31 review will contribute to a better understanding of the support programs available to parents of
32 children with intellectual disabilities. This could be the first step in highlighting the gaps and future
33 directions for the development and implementation of support programs for parents of children
34 with intellectual disabilities.

35 **Registration Details:** Marais JE, Wegner L, Mthembu T. Support programs for parents of children
36 with intellectual disabilities: A scoping review [Internet]. OSF; 2021. Available from: osf.io/en6cs

37 **Keywords:** Intellectual disabilities; parents; support programs

38 **Word count:** 2629

39 **Article Summary**

40 **Strengths and limitations of this study:**

- 41 • Results of the scoping review will contribute to a broader perspective on the evidence of
42 available support programs for parents of children with intellectual disabilities.
- 43 • It is a practical method to synthesis research in a wide range of methodological approaches,
44 settings and study populations on the available literature of support programs for parents of
45 children with intellectual disabilities.

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- 46 • This scoping review will inform a larger project to develop a support program for parents of
47 children intellectual disabilities drawing on the findings and evaluations of previous
48 programs.
- 49 • One of the limitations is that the methodological quality of included studies was not
50 assessed.
- 51 • The synthesis of data will be limited to English studies that were published in peer reviewed
52 journals.

For peer review only

54 INTRODUCTION

55 Intellectual disability (ID) affects four in 100 people in South Africa to some degree.¹ Intellectual
56 disabilities are neurodevelopmental disorders that begin in childhood and are characterized by
57 intellectual difficulties as well as difficulties in conceptual, social, and practical areas of living. The
58 DSM-5 diagnosis of intellectual disabilities requires the satisfaction of three criteria: 1) Deficits in
59 intellectual functioning— ‘reasoning, problem solving, planning, abstract thinking, judgment,
60 academic learning, and learning from experience’ —confirmed by clinical evaluation and
61 individualized standard IQ testing; 2) Deficits in adaptive functioning that significantly hamper
62 conforming to developmental and sociocultural standards for the individual's independence and
63 ability to meet their social responsibility; and 3) The onset of these deficits during the developmental
64 period.^{2(p33)} There is however, a lack of policy development and implementation for child and
65 adolescent mental health (CAMH) including children and adolescents with intellectual disabilities,
66 and this is particularly prevalent in low- and middle-income countries.³ Intellectual disability places a
67 high burden of disease on low- and middle-income countries and has become a public health priority
68 because of its continuation throughout the life cycle as well as the impact it has on the family.⁴

69 Parents of children with intellectual disabilities experience high levels of stress relating to subjective
70 factors such as feelings of social isolation and life dissatisfaction, and factors relating to societal and
71 institutional marginalization.⁵ There are a multitude of emotional challenges experienced by these
72 parents, in particular in relation to guilt over possibly being the cause of their child's disability
73 (reasons being both logical and illogical) by parents who have children with intellectual disabilities.⁵
74 Parenting a child with intellectual disabilities is often experienced as being more emotionally
75 demanding and stressful than parenting a child without those challenges.⁵ Depression is a measure
76 that has been used to assess the adverse effects of stress and adaptive capacities of parents who
77 have children with intellectual disabilities. It has been indicated that mothers of children with
78 intellectual disabilities experience elevated levels of depression when compared to control group.⁶
79 However, support for parents in the mental health care of children has tended to be a peripheral
80 focus. This indicates that there is a lack of research attention given to support for parents caring for
81 children with intellectual disabilities, even though parenting is vital for the optimal development and
82 general care of children with this condition.⁷ Studies conducted in South Africa on those caring for
83 individuals with mental disorders and disabilities focused mainly on informal caregiver burden with
84 mainly females being the carers of older persons in the community or the family.⁸ The caregivers'
85 burdens comprise financial strains, privacy issues, social life status and physical and sleep

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5 86 disturbances.⁸ In South Africa, people with mental illness and disabilities experience significant
6 87 amounts of stigma, which could lead to social isolation, low-self-esteem, depression, poor social
7 88 skills, marginalization, unemployment and housing difficulties.⁸
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10 89 There are many barriers to caring for children with intellectual disabilities. This is especially true
11 90 among families who have complex social situations. For the successful empowerment of families, it
12 91 is important to address the various obstacles parents of children with intellectual disabilities
13 92 consistently face. These obstacles include: the stigma attached to intellectual disabilities; belief
14 93 systems surrounding the child and social behavior (e.g. proper disciplining of the child will eradicate
15 94 the problem), and the attitudes parents have towards mental health care services (e.g. a lack of trust
16 95 in service providers based on previous experiences).⁹ Stigma not only affects individuals or groups of
17 96 individuals who carry the stigmatizing attribute (in this case intellectual disability) but also spills over
18 97 into those affiliated with them.¹⁰ Parents of children with intellectual disabilities often experience
19 98 affiliated stigma – the process of internalizing the public’s negative views towards themselves
20 99 because of their child’s disability.¹¹ Affiliated stigma can adversely affect the quality of life of parents
21 100 because they are undervalued by others and the continuous battles they encounter with service. To
22 101 cope with the stigma parents may withdraw socially or conceal their child’s disability.¹² The
23 102 continuous and long-term use of these coping strategies could potentially lead to lowered self-
24 103 esteem, and the individual with an intellectual disability experiencing increased levels of
25 104 discrimination.¹² It is imperative to understand the belief systems surrounding the child and social
26 105 behaviour. Parents’ perceptions about the nature of their child’s disability is a focal point in many
27 106 different cultural groups, and disabilities are also viewed differently across different cultures. The
28 107 perceptions held by parents’ and society shape the parents’ attitudes towards their children and
29 108 their disabilities. These perceptions are also instrumental in the resources and treatment that
30 109 parents will be able to invest in for the training and education of their children with a disability; as
31 110 well as the views parents have about their children’s future.¹³ It is also important to understand how
32 111 the contrasting perspectives of parents and clinicians influences their relations, the care and service
33 112 provision. This contrast too frequently leads to perpetual blame games between parents and
34 113 clinicians, where clinicians blame parents for their lack of commitment and parents complain about
35 114 the lack of understanding from clinicians. This results in children and adolescents not receiving the
36 115 proper care to address their disability and parents feeling overwhelmed. Therefore, for continuity of
37 116 care to occur in the treatments of children with intellectual disabilities through family-focused and
38 117 patient-centred medical care, collaboration between healthcare professionals and parents should be
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5 118 considered. It is crucial that families and physicians should not view each other as adversaries or
6 119 untrustworthy, but instead as partners striving to achieve the same goal.⁹
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9 120 A preliminary search of PROSPERO, MEDLINE, the Cochrane Database of Systematic Reviews and the
10 121 *JBIM Evidence Synthesis* was conducted. Dew et al¹⁴ reported on the peer support experiences of
11 122 mothers of children with intellectual disability and challenging behaviour. Stuttard et al¹⁵ reported
12 123 on the evaluation of a group-delivered intervention (Riding the Rapids); this program was developed
13 124 specifically for parents of children with a disability or autistic spectrum disorder. However, the
14 125 preliminary search found no current scoping or systematic reviews or systematic and scoping
15 126 reviews that are currently underway that focused on support programs for parents of children with
16 127 intellectual disabilities. Various studies have been done on support programs for parents of children
17 128 with intellectual disabilities however, not many have mapped and synthesized the different
18 129 elements of these programs to highlight the gaps for future programs. Therefore, a synthesis of the
19 130 body of evidence that is currently available in the area is needed to inform evidence-based program
20 131 development for parents of children with intellectual disabilities. A scoping review on the available
21 132 body of literature on support programs for parents of children with intellectual disabilities is
22 133 proposed. The objective of this scoping review is to describe, map and synthesize the available
23 134 literature on support programs for parents of children with intellectual disabilities.
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35 135 **METHODS AND ANALYSIS**

36 136 The various systematic approaches available were considered in order to review the published
37 137 literature on support programs for parents of children with intellectual disabilities. We chose to
38 138 undertake a scoping review of published literature as this was the best method to describe, map and
39 139 synthesize the evidence to identify the gaps in literature on parent support programs. The proposed
40 140 scoping review will be conducted in accordance with the Joanna Briggs Institute methodology for
41 141 scoping reviews.¹⁶
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48 142 **Review question(s)**

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51 143 1. What programs have been carried out and literature published in peer reviewed journals
52 144 around support programs for parents of children with intellectual disabilities?
53 145 2. What target populations are being addressed in peer reviewed published literature around
54 146 support programs for parents of children with intellectual disabilities?
55 147 3. What types of interventions are being carried out and evaluated around support for parents
56 148 who have children with intellectual disabilities?
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5 149 4. What are the key findings related to the studies carried out around support programs for
6 150 parents of children with intellectual disabilities?
7 151 5. What are the types of support offered in the support programs for parents of children with
8 152 intellectual disabilities?
9 153 6. Who offers the support programs to parents of children with intellectual disabilities?
10 154 7. What are the characteristics of support programs for parents of children with intellectual
11 155 disabilities?
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15 156 **Inclusion criteria**

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17 157 The inclusion criteria were categorized according to the Population, Concept and Context (PCC)
18 158 mnemonic recommended by the Joanna Briggs Institute for scoping reviews. This is less restrictive
19 159 than the Population, Intervention, Comparator, Outcome (PICO) mnemonic which is recommended
20 160 for systematic reviews.
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23 161 **Participants**

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25 162 • Studies that include parents of children (0-18 years) with intellectual disabilities. Parents are
26 163 defined as men and/or women who perform a parenting role in terms of caring for their child
27 164 and his/her needs. The term 'parents' will include, but is not limited to: biological, adoptive,
28 165 step, foster parents and guardians.
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33 166 **Concept**

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35 167 • Studies that explore parent support programs that are designed to support parents who have
36 168 children with intellectual disabilities carried out between 2003 and 2021. This timeframe was
37 169 chosen as in 2003 the CAMH policy framework was developed to be implemented in South
38 170 Africa.³
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40 171 • Included as concepts will be all types of programs, modes of delivery, setting, leadership and
41 172 duration. Examples of the types of programs that could be included are social support, peer
42 173 support, psychoeducational support, knowledge support, emotional support and all other
43 174 variants including multi component interventions. Examples of modes of delivery could
44 175 include support groups, telephonic interactions and self-delivery (through use of manuals)
45 176 Examples of settings could include clinical settings, home, community settings. Examples of
46 177 leadership could include: clinician led, family led and team led.
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48 178 • Full-text
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50 179 • Peer reviewed
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52 180 • Literature published in the English medium
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181 Context

- 182 • Clinical settings
- 183 • Community settings
- 184 • Virtual settings or any other settings where support programs for parents of children with
185 intellectual disabilities are delivered
- 186 • All countries and economic settings will be included in the study.
- 187 • Quantitative, qualitative, and mixed methods study approaches will be considered for
188 inclusion. Quantitative study designs to be considered for the review will include experimental
189 and quasi-experimental including randomized control trials, non-randomized control trials,
190 pre-test post-test studies, and interrupted time-series. In addition, cohort studies, case-
191 control studies and cross-sectional studies will be considered for inclusion. All qualitative
192 research including explanatory, exploratory, descriptive and applied types of research using
193 different application techniques will be considered for inclusion.

194 Exclusion criteria

195 Excluded from the study will be systematic reviews, scoping reviews and studies that were not
196 interventions and interventions supporting parents with intellectual disabilities.

197 Search strategy

198 The search strategy will follow a three-phase approach with an aim to find published studies. A
199 literature search will be conducted to identify parent support programs aimed at parents who have
200 children with intellectual disabilities. In the first phase, an initial limited search of Medline (EbscoHost)
201 and PubMed will be undertaken to identify articles on the topic. The text words contained in the titles
202 and abstracts of relevant articles, and the index terms used to describe the articles related to the
203 proposed scoping review will inform the second phase where a full search strategy for relevant
204 database platforms; these include Medline (Ebscohost), PsychARTICLES, CINAHL, PubMed, Academic
205 Search Complete and SA ePublications. PubMed is detailed in Appendix I. In the third phase of the
206 search, the reference lists of articles selected for full-text review will be screened for additional
207 papers.

208 Following the search, all identified records will be collated and uploaded into Mendeley (Mendeley
209 Ltd., Elsevier, Netherlands) and duplicates removed. Following a pilot test, titles and abstracts will
210 then be screened by one independent reviewers (JM) for assessment against the inclusion criteria for

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5 211 the review. Potentially relevant papers will be retrieved and their citations and details will be recorded
6 212 in Microsoft Excel. The full text of the selected studies will go through a detailed assessment against
7 213 the inclusion criteria by two independent reviewers (JM and LW). Disagreements will be resolved via
8 214 discussion and where no agreement can be reached a third independent reviewers (TM) will be
9 215 consulted for further discussion. Reasons for exclusion of full-text papers that do not meet the
10 216 inclusion criteria will be recorded and reported on in the final scoping review. The results of the search
11 217 will be reported in full in the final scoping review and presented in a Preferred Reporting Items for
12 218 Systematic Reviews and Meta-analyses (PRISMA) flow diagram (Figure 1).¹⁷

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20 21 22 220 **Data extraction**

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24 221 Data will be extracted from papers included in the scoping review by one independent reviewer (JM)
25 222 and assessed by two independent reviewers (LW and TM) using a data extraction tool developed by
26 223 the reviewers. The draft data extraction instrument (Appendix II) was adapted from the
27 224 Methodology for Joanna Biggs Institute scoping reviews¹⁷ and Hoagwood et al.⁷ to answer the
28 225 review question. The data extracted will include specific details about the population, concept,
29 226 context, methods leadership, program characteristics and key findings relevant to the research
30 227 question. Modifications of the JBI data extraction tool will consist of the following items:
31 228 intervention name, type of support provided, leadership (e.g. clinician led), and program
32 229 characteristics. If necessary modifications to the data extraction tool will be made and revised during
33 230 the data extraction process of each included study. All modifications made will be detailed in the full
34 231 scoping review. If any disagreements arise between reviewers (JM and LW), these will be resolved
35 232 through discussion with a third reviewer (TM). Authors of papers will be contacted to request
36 233 missing or additional data, where required.

37 38 39 40 41 42 43 44 45 46 47 48 234 **Synthesis and reporting of results**

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50 235 The data extracted will be presented in a tabular format with a narrative summary related to the key
51 236 findings. The results will be presented following the population, concept and context format as well
52 237 as the main conceptual categories used in the data extraction tool. A narrative description of the
53 238 findings will be guided by the thematic analysis of the qualitative findings. The tabulated results
54 239 using descriptive analysis, accompanied by the narrative results will be presented and framed in

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5 240 relation to the review objective and research question of this scoping review. A checklist for protocol
6 241 submission guidelines PRISMA-P has been completed (Appendix III).¹⁸
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10 242 **Public and patient involvement**

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12 243 No patient involved
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14 244 **ETHICS AND DISSEMINATION**

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16 245 This scoping review has received ethical approval from the University of the Western Cape
17 246 Biomedical Research Ethics Committee (BM20/4/26). A summary of the findings of the study will be
18 247 published in a peer-reviewed journal. This scoping review will contribute to a better understanding
19 248 of the support programs available to parents of children with intellectual disabilities. This could be
20 249 the first step in highlighting the gaps and future directions for the development and implementation
21 250 of support programs for parents of children with intellectual disabilities.
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27 251 **Acknowledgments**

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30 252 The authors would like to thank Prof Jose Frantz and Prof Mario Smith for their training and
31 253 continued guidance and support throughout this review.
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34 254 **Author Contributions**

35
36 255 All authors have contributed to the conceptualization and design of the study. All authors have read
37 256 and read and approved the final version of the manuscript. JM drafted the manuscript and LW and
38 257 TM made major and minor revisions throughout the process.
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42 258 **Funding**

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44 259 No funding was received for study
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46 260 **Conflict of interest**

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48 261 None declared
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51 262 **Data access statement**

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54 263 The data for the scoping review will be managed using Mendeley and all data will be store for 5
55 264 years after completion of the study.
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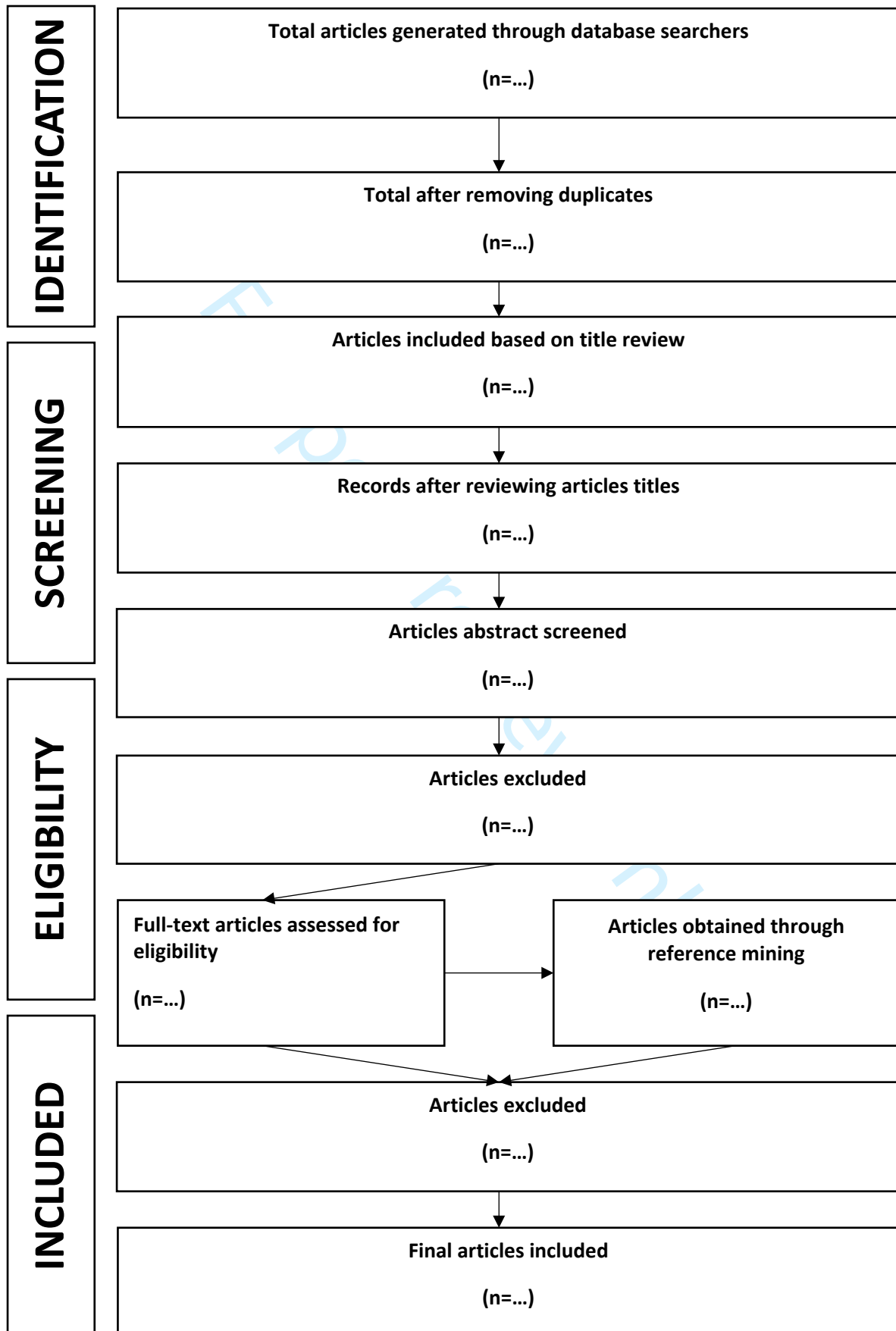
57 265 This review will contribute to the PhD for the lead author (JM).
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266 **Figure 1**267 **REFERENCES**

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Figure 1: PRISMA flow diagram



Appendix I: Search strategy

PubMed

Dec 2020

| Search | Query | Records retrieved |
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| #1 | ("child"[MeSH Terms] OR "child"[All Fields] OR "children"[All Fields] OR "child s"[All Fields] OR "children s"[All Fields] OR "childrens"[All Fields] OR "childs"[All Fields]) AND ("mental health"[MeSH Terms] OR ("mental"[All Fields] AND "health"[All Fields]) OR "mental health"[All Fields]) AND (("parent s"[All Fields] OR "parentally"[All Fields] OR "parentals"[All Fields] OR "parented"[All Fields] OR "parenting"[MeSH Terms] OR "parenting"[All Fields] OR "parents"[MeSH Terms] OR "parents"[All Fields] OR "parent"[All Fields] OR "parental"[All Fields]) AND ("support"[All Fields] OR "support s"[All Fields] OR "supported"[All Fields] OR "supporter"[All Fields] OR "supporter s"[All Fields] OR "supporters"[All Fields] OR "supporting"[All Fields] OR "supportive"[All Fields] OR "supportiveness"[All Fields] OR "supports"[All Fields]) AND "program*"[All Fields]) | 409 |
| #2 | ("child"[MeSH Terms] OR "child"[All Fields] OR "children"[All Fields] OR "child s"[All Fields] OR "children s"[All Fields] OR "childrens"[All Fields] OR "childs"[All Fields]) AND ("mental health"[MeSH Terms] OR ("mental"[All Fields] AND "health"[All Fields]) OR "mental health"[All Fields]) AND (("parent s"[All Fields] OR "parentally"[All Fields] OR "parentals"[All Fields] OR "parented"[All Fields] OR "parenting"[MeSH Terms] OR "parenting"[All Fields] OR "parents"[MeSH Terms] OR "parents"[All Fields] OR "parent"[All Fields] OR "parental"[All Fields]) AND ("support"[All Fields] OR "support s"[All Fields] OR "supported"[All Fields] OR "supporter"[All Fields] OR "supporter s"[All Fields] OR "supporters"[All Fields] OR "supporting"[All Fields] OR "supportive"[All Fields] OR "supportiveness"[All Fields] OR "supports"[All Fields]) AND ("intervention s"[All Fields] OR "interventions"[All Fields] OR "interventive"[All Fields] OR "methods"[MeSH Terms] OR | 742 |

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| | "methods"[All Fields] OR "intervention"[All Fields] OR "interventional"[All Fields]) | |
| #3 | "child"[MeSH Terms] OR "child"[All Fields] OR "children"[All Fields] OR "child s"[All Fields] OR "children s"[All Fields] OR "childrens"[All Fields] OR "childs"[All Fields]) AND ("mental health"[MeSH Terms] OR ("mental"[All Fields] AND "health"[All Fields]) OR "mental health"[All Fields]) AND (("parent s"[All Fields] OR "parentally"[All Fields] OR "parentals"[All Fields] OR "parented"[All Fields] OR "parenting"[MeSH Terms] OR "parenting"[All Fields] OR "parents"[MeSH Terms] OR "parents"[All Fields] OR "parent"[All Fields] OR "parental"[All Fields]) AND ("emoting"[All Fields] OR "emotion s"[All Fields] OR "emotions"[MeSH Terms] OR "emotions"[All Fields] OR "emotion"[All Fields] OR "emotional"[All Fields] OR "emotive"[All Fields]) AND "wellbeing"[All Fields]) | 53 |
| #4 | ("child"[MeSH Terms] OR "child"[All Fields] OR "children"[All Fields] OR "child s"[All Fields] OR "children s"[All Fields] OR "childrens"[All Fields] OR "childs"[All Fields]) AND ("mental health"[MeSH Terms] OR ("mental"[All Fields] AND "health"[All Fields]) OR "mental health"[All Fields]) AND (("parent s"[All Fields] OR "parentally"[All Fields] OR "parentals"[All Fields] OR "parented"[All Fields] OR "parenting"[MeSH Terms] OR "parenting"[All Fields] OR "parents"[MeSH Terms] OR "parents"[All Fields] OR "parent"[All Fields] OR "parental"[All Fields]) AND ("emoting"[All Fields] OR "emotion s"[All Fields] OR "emotions"[MeSH Terms] OR "emotions"[All Fields] OR "emotion"[All Fields] OR "emotional"[All Fields] OR "emotive"[All Fields]) AND ("health"[MeSH Terms] OR "health"[All Fields] OR "well"[All Fields] OR "well being"[All Fields])) | 270 |
| #5 | ("child"[MeSH Terms] OR "child"[All Fields] OR "children"[All Fields] OR "child s"[All Fields] OR "children s"[All Fields] OR "childrens"[All Fields] OR "childs"[All Fields]) AND ("mental health"[MeSH Terms] OR ("mental"[All Fields] AND "health"[All Fields]) OR "mental health"[All Fields]) AND (("parent s"[All Fields] OR "parentally"[All Fields] OR "parentals"[All Fields] | 209 |

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| | <p>OR "parented"[All Fields] OR "parenting"[MeSH Terms] OR "parenting"[All Fields] OR "parents"[MeSH Terms] OR "parents"[All Fields] OR "parent"[All Fields] OR "parental"[All Fields]) AND ("emoting"[All Fields] OR "emotion s"[All Fields] OR "emotions"[MeSH Terms] OR "emotions"[All Fields] OR "emotion"[All Fields] OR "emotional"[All Fields] OR "emotive"[All Fields]) AND ("support"[All Fields] OR "support s"[All Fields] OR "supported"[All Fields] OR "supporter"[All Fields] OR "supporter s"[All Fields] OR "supporters"[All Fields] OR "supporting"[All Fields] OR "supportive"[All Fields] OR "supportiveness"[All Fields] OR "supports"[All Fields]))</p> | |
| #6 | <p>("adolescences"[All Fields] OR "adolescence"[All Fields] OR "adolescent"[MeSH Terms] OR "adolescent"[All Fields] OR "adolescence"[All Fields] OR "adolescents"[All Fields] OR "adolescent s"[All Fields]) AND ("mental health"[MeSH Terms] OR ("mental"[All Fields] AND "health"[All Fields]) OR "mental health"[All Fields]) AND (("parent s"[All Fields] OR "parentally"[All Fields] OR "parentals"[All Fields] OR "parented"[All Fields] OR "parenting"[MeSH Terms] OR "parenting"[All Fields] OR "parents"[MeSH Terms] OR "parents"[All Fields] OR "parent"[All Fields] OR "parental"[All Fields]) AND ("support"[All Fields] OR "support s"[All Fields] OR "supported"[All Fields] OR "supporter"[All Fields] OR "supporter s"[All Fields] OR "supporters"[All Fields] OR "supporting"[All Fields] OR "supportive"[All Fields] OR "supportiveness"[All Fields] OR "supports"[All Fields]) AND "program*"[All Fields])</p> | 210 |
| #7 | <p>("adolescences"[All Fields] OR "adolescence"[All Fields] OR "adolescent"[MeSH Terms] OR "adolescent"[All Fields] OR "adolescence"[All Fields] OR "adolescents"[All Fields] OR "adolescent s"[All Fields]) AND ("mental health"[MeSH Terms] OR ("mental"[All Fields] AND "health"[All Fields]) OR "mental health"[All Fields]) AND (("parent s"[All Fields] OR "parentally"[All Fields] OR "parentals"[All Fields] OR "parented"[All Fields] OR "parenting"[MeSH Terms] OR "parenting"[All Fields] OR "parents"[MeSH Terms] OR "parents"[All Fields] OR "parent"[All Fields] OR "parental"[All Fields]) AND ("support"[All Fields] OR "support s"[All Fields] OR</p> | 426 |

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| | "supported"[All Fields] OR "supporter"[All Fields] OR "supporter s"[All Fields] OR "supporters"[All Fields] OR "supporting"[All Fields] OR "supportive"[All Fields] OR "supportiveness"[All Fields] OR "supports"[All Fields]) AND ("intervention s"[All Fields] OR "interventions"[All Fields] OR "interventive"[All Fields] OR "methods"[MeSH Terms] OR "methods"[All Fields] OR "intervention"[All Fields] OR "interventional"[All Fields])) | |
| #8 | ("adolescences"[All Fields] OR "adolescence"[All Fields] OR "adolescent"[MeSH Terms] OR "adolescent"[All Fields] OR "adolescence"[All Fields] OR "adolescents"[All Fields] OR "adolescent s"[All Fields]) AND ("mental health"[MeSH Terms] OR ("mental"[All Fields] AND "health"[All Fields]) OR "mental health"[All Fields]) AND (("parent s"[All Fields] OR "parentally"[All Fields] OR "parentals"[All Fields] OR "parented"[All Fields] OR "parenting"[MeSH Terms] OR "parenting"[All Fields] OR "parents"[MeSH Terms] OR "parents"[All Fields] OR "parent"[All Fields] OR "parental"[All Fields]) AND ("emoting"[All Fields] OR "emotion s"[All Fields] OR "emotions"[MeSH Terms] OR "emotions"[All Fields] OR "emotion"[All Fields] OR "emotional"[All Fields] OR "emotive"[All Fields]) AND "wellbeing"[All Fields]) | 21 |
| #9 | ("adolescences"[All Fields] OR "adolescence"[All Fields] OR "adolescent"[MeSH Terms] OR "adolescent"[All Fields] OR "adolescence"[All Fields] OR "adolescents"[All Fields] OR "adolescent s"[All Fields]) AND ("mental health"[MeSH Terms] OR ("mental"[All Fields] AND "health"[All Fields]) OR "mental health"[All Fields]) AND (("parent s"[All Fields] OR "parentally"[All Fields] OR "parentals"[All Fields] OR "parented"[All Fields] OR "parenting"[MeSH Terms] OR "parenting"[All Fields] OR "parents"[MeSH Terms] OR "parents"[All Fields] OR "parent"[All Fields] OR "parental"[All Fields]) AND ("emoting"[All Fields] OR "emotion s"[All Fields] OR "emotions"[MeSH Terms] OR "emotions"[All Fields] OR "emotion"[All Fields] OR "emotional"[All Fields] OR "emotive"[All Fields]) AND ("health"[MeSH Terms] OR "health"[All Fields] OR "well"[All Fields] OR "well being"[All Fields])) | 158 |

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| #10 | <p>("adolescences"[All Fields] OR "adolescence"[All Fields] OR "adolescent"[MeSH Terms] OR "adolescent"[All Fields] OR "adolescence"[All Fields] OR "adolescents"[All Fields] OR "adolescent s"[All Fields]) AND ("mental health"[MeSH Terms] OR ("mental"[All Fields] AND "health"[All Fields]) OR "mental health"[All Fields]) AND (("parent s"[All Fields] OR "parentally"[All Fields] OR "parentals"[All Fields] OR "parented"[All Fields] OR "parenting"[MeSH Terms] OR "parenting"[All Fields] OR "parents"[MeSH Terms] OR "parents"[All Fields] OR "parent"[All Fields] OR "parental"[All Fields]) AND ("emoting"[All Fields] OR "emotion s"[All Fields] OR "emotions"[MeSH Terms] OR "emotions"[All Fields] OR "emotion"[All Fields] OR "emotional"[All Fields] OR "emotive"[All Fields]) AND ("support"[All Fields] OR "support s"[All Fields] OR "supported"[All Fields] OR "supporter"[All Fields] OR "supporter s"[All Fields] OR "supporters"[All Fields] OR "supporting"[All Fields] OR "supportive"[All Fields] OR "supportiveness"[All Fields] OR "supports"[All Fields]))</p> | 124 |
| #11 | <p>("intellectual"[All Fields] OR "intellectualism"[All Fields] OR "intellectually"[All Fields] OR "intellectuals"[All Fields]) AND "disabilit*" [All Fields] AND (("parent s"[All Fields] OR "parentally"[All Fields] OR "parentals"[All Fields] OR "parented"[All Fields] OR "parenting"[MeSH Terms] OR "parenting"[All Fields] OR "parents"[MeSH Terms] OR "parents"[All Fields] OR "parent"[All Fields] OR "parental"[All Fields]) AND ("support"[All Fields] OR "support s"[All Fields] OR "supported"[All Fields] OR "supporter"[All Fields] OR "supporter s"[All Fields] OR "supporters"[All Fields] OR "supporting"[All Fields] OR "supportive"[All Fields] OR "supportiveness"[All Fields] OR "supports"[All Fields]) AND "program*" [All Fields])</p> | 31 |
| #12 | <p>("intellectual"[All Fields] OR "intellectualism"[All Fields] OR "intellectually"[All Fields] OR "intellectuals"[All Fields]) AND "disabilit*" [All Fields] AND (("parent s"[All Fields] OR "parentally"[All Fields] OR "parentals"[All Fields] OR "parented"[All Fields] OR "parenting"[MeSH Terms] OR "parenting"[All Fields] OR "parents"[MeSH Terms] OR "parents"[All Fields] OR "parent"[All Fields] OR "parental"[All Fields]) AND ("support"[All Fields] OR "support</p> | 60 |

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| #13 | ("intellectual"[All Fields] OR "intellectualism"[All Fields] OR "intellectually"[All Fields] OR "intellectuals"[All Fields]) AND "disabilit*" [All Fields] AND ("parent s"[All Fields] OR "parentally"[All Fields] OR "parentals"[All Fields] OR "parented"[All Fields] OR "parenting"[MeSH Terms] OR "parenting"[All Fields] OR "parents"[MeSH Terms] OR "parents"[All Fields] OR "parent"[All Fields] OR "parental"[All Fields]) AND ("emoting"[All Fields] OR "emotion s"[All Fields] OR "emotions"[MeSH Terms] OR "emotions"[All Fields] OR "emotion"[All Fields] OR "emotional"[All Fields] OR "emotive"[All Fields]) AND "wellbeing"[All Fields]) | 3 |
| #14 | ("intellectual"[All Fields] OR "intellectualism"[All Fields] OR "intellectually"[All Fields] OR "intellectuals"[All Fields]) AND "disabilit*" [All Fields] AND ("parent s"[All Fields] OR "parentally"[All Fields] OR "parentals"[All Fields] OR "parented"[All Fields] OR "parenting"[MeSH Terms] OR "parenting"[All Fields] OR "parents"[MeSH Terms] OR "parents"[All Fields] OR "parent"[All Fields] OR "parental"[All Fields]) AND ("emoting"[All Fields] OR "emotion s"[All Fields] OR "emotions"[MeSH Terms] OR "emotions"[All Fields] OR "emotion"[All Fields] OR "emotional"[All Fields] OR "emotive"[All Fields]) AND ("health"[MeSH Terms] OR "health"[All Fields] OR "well"[All Fields] OR "well being"[All Fields])) | 12 |
| #15 | ("intellectual"[All Fields] OR "intellectualism"[All Fields] OR "intellectually"[All Fields] OR "intellectuals"[All Fields]) AND "disabilit*" [All Fields] AND ("parent s"[All Fields] OR "parentally"[All Fields] OR "parentals"[All Fields] OR "parented"[All Fields] OR "parenting"[MeSH Terms] OR "parenting"[All | 12 |

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| #21 | #1 - #15 | 2740 |
| Limited to 2003-2020, English, full-text, books and documents, clinical trial, and randomized controlled trial | | |

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Appendix II: Data extraction instrument

| Author information | Year of publication | Country of origin | Aims/Purpose of the study | Study Population | Methodology | Intervention type | Duration | Outcomes | Key findings related to the study | Intervention name | Type of support | Leadership | Program characteristics |
|--------------------|---------------------|-------------------|---------------------------|------------------|-------------|-------------------|----------|----------|-----------------------------------|-------------------|-----------------|------------|-------------------------|
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PRISMA-P 2015 Checklist

This checklist has been adapted for use with protocol submissions to *Systematic Reviews* from Table 3 in Moher D et al: Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Systematic Reviews* 2015 4:1

| Section/topic | # | Checklist item | Information reported | | Line number(s) |
|-----------------------------------|----|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------|-------------------------------------|-----------------------------|
| | | | Yes | No | |
| ADMINISTRATIVE INFORMATION | | | | | |
| Title | | | | | |
| Identification | 1a | Identify the report as a protocol of a systematic review | <input checked="" type="checkbox"/> | <input type="checkbox"/> | 1-2 |
| Update | 1b | If the protocol is for an update of a previous systematic review, identify as such | <input type="checkbox"/> | <input checked="" type="checkbox"/> | |
| Registration | 2 | If registered, provide the name of the registry (e.g., PROSPERO) and registration number in the Abstract | <input checked="" type="checkbox"/> | <input type="checkbox"/> | 27-29 |
| Authors | | | | | |
| Contact | 3a | Provide name, institutional affiliation, and e-mail address of all protocol authors; provide physical mailing address of corresponding author | <input checked="" type="checkbox"/> | <input type="checkbox"/> | Title page |
| Contributions | 3b | Describe contributions of protocol authors and identify the guarantor of the review | <input checked="" type="checkbox"/> | <input type="checkbox"/> | 196,199,201,207,208,217,218 |
| Amendments | 4 | If the protocol represents an amendment of a previously completed or published protocol, identify as such and list changes; otherwise, state plan for documenting important protocol amendments | <input type="checkbox"/> | <input checked="" type="checkbox"/> | Not Applicable |
| Support | | | | | |
| Sources | 5a | Indicate sources of financial or other support for the review | <input type="checkbox"/> | <input checked="" type="checkbox"/> | Not Applicable |
| Sponsor | 5b | Provide name for the review funder and/or sponsor | <input type="checkbox"/> | <input checked="" type="checkbox"/> | Not Applicable |
| Role of sponsor/funder | 5c | Describe roles of funder(s), sponsor(s), and/or institution(s), if any, in developing the protocol | <input checked="" type="checkbox"/> | <input type="checkbox"/> | 20-21 and 228-229 |
| INTRODUCTION | | | | | |
| Rationale | 6 | Describe the rationale for the review in the context of what is already known | <input checked="" type="checkbox"/> | <input type="checkbox"/> | 44-121 |

| Section/topic | # | Checklist item | Information reported | | Line number(s) |
|-------------------------------------------|-----|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------|-------------------------------------|----------------------------------------------------------------------------------------------------|
| | | | Yes | No | |
| Objectives | 7 | Provide an explicit statement of the question(s) the review will address with reference to participants, interventions, comparators, and outcomes (PICO) | <input checked="" type="checkbox"/> | <input type="checkbox"/> | 129-142 (Population, concept, context method was used according to JBI manual for scoping reviews) |
| METHODS | | | | | |
| Eligibility criteria | 8 | Specify the study characteristics (e.g., PICO, study design, setting, time frame) and report characteristics (e.g., years considered, language, publication status) to be used as criteria for eligibility for the review | <input checked="" type="checkbox"/> | <input type="checkbox"/> | 144-179 |
| Information sources | 9 | Describe all intended information sources (e.g., electronic databases, contact with study authors, trial registers, or other grey literature sources) with planned dates of coverage | <input checked="" type="checkbox"/> | <input type="checkbox"/> | 184-204 |
| Search strategy | 10 | Present draft of search strategy to be used for at least one electronic database, including planned limits, such that it could be repeated | <input checked="" type="checkbox"/> | <input type="checkbox"/> | Appendix I |
| STUDY RECORDS | | | | | |
| Data management | 11a | Describe the mechanism(s) that will be used to manage records and data throughout the review | <input checked="" type="checkbox"/> | <input type="checkbox"/> | 194-198 |
| Selection process | 11b | State the process that will be used for selecting studies (e.g., two independent reviewers) through each phase of the review (i.e., screening, eligibility, and inclusion in meta-analysis) | <input checked="" type="checkbox"/> | <input type="checkbox"/> | 195-204 and 207-219 |
| Data collection process | 11c | Describe planned method of extracting data from reports (e.g., piloting forms, done independently, in duplicate), any processes for obtaining and confirming data from investigators | <input checked="" type="checkbox"/> | <input type="checkbox"/> | 207-219 |
| Data items | 12 | List and define all variables for which data will be sought (e.g., PICO items, funding sources), any pre-planned data assumptions and simplifications | <input checked="" type="checkbox"/> | <input type="checkbox"/> | 144-179 |
| Outcomes and prioritization | 13 | List and define all outcomes for which data will be sought, including prioritization of main and additional outcomes, with rationale | <input checked="" type="checkbox"/> | <input type="checkbox"/> | 129-182 |
| Risk of bias in individual studies | 14 | Describe anticipated methods for assessing risk of bias of individual studies, including whether this will be done at the outcome or study level, or both; state how this information will be used in data synthesis | <input type="checkbox"/> | <input checked="" type="checkbox"/> | |
| DATA | | | | | |

| Section/topic | # | Checklist item | Information reported | | Line number(s) |
|------------------------------------------|-----|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------|-------------------------------------|----------------|
| | | | Yes | No | |
| Synthesis | 15a | Describe criteria under which study data will be quantitatively synthesized | <input checked="" type="checkbox"/> | <input type="checkbox"/> | 221-225 |
| | 15b | If data are appropriate for quantitative synthesis, describe planned summary measures, methods of handling data, and methods of combining data from studies, including any planned exploration of consistency (e.g., I^2 , Kendall's tau) | <input type="checkbox"/> | <input checked="" type="checkbox"/> | |
| | 15c | Describe any proposed additional analyses (e.g., sensitivity or subgroup analyses, meta-regression) | <input type="checkbox"/> | <input checked="" type="checkbox"/> | |
| | 15d | If quantitative synthesis is not appropriate, describe the type of summary planned | <input checked="" type="checkbox"/> | <input type="checkbox"/> | 222-224 |
| Meta-bias(es) | 16 | Specify any planned assessment of meta-bias(es) (e.g., publication bias across studies, selective reporting within studies) | <input type="checkbox"/> | <input checked="" type="checkbox"/> | |
| Confidence in cumulative evidence | 17 | Describe how the strength of the body of evidence will be assessed (e.g., GRADE) | <input type="checkbox"/> | <input checked="" type="checkbox"/> | |

BMJ Open

Support programs for parents of children with intellectual disabilities: A scoping review protocol

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| Journal: | <i>BMJ Open</i> |
| Manuscript ID | bmjopen-2021-049965.R1 |
| Article Type: | Protocol |
| Date Submitted by the Author: | 01-Sep-2021 |
| Complete List of Authors: | Marais, Janene; University of the Western Cape Faculty of Community and Health Sciences Wegner, Lisa; University of the Western Cape Faculty of Community and Health Sciences, Department of Occupational Therapy Mthembu, Thuli; University of the Western Cape Faculty of Community and Health Sciences, Occupational Therapy |
| Primary Subject Heading: | Health services research |
| Secondary Subject Heading: | Global health, Mental health |
| Keywords: | Protocols & guidelines < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Public health < INFECTIOUS DISEASES, Delirium & cognitive disorders < PSYCHIATRY |
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1 **Support programs for parents of children with intellectual disabilities: A**
2 **scoping review protocol**

3 Janene E Marais¹

4 Lisa Wegner²

5 Thuli Mthembu²

- 6 1. Centre for Interdisciplinary Studies of Children, Families and Society, Faculty of
7 Community and Health Sciences, The University of Western Cape, South Africa
- 8 2. Department of Occupational Therapy, Faculty of Community and Health Sciences, The
9 University of the Western Cape, South Africa

11 **Corresponding author:**

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14 **ABSTRACT**

15 **Introduction:** Evidence shows that parents of children with intellectual disabilities experience high
16 levels of stress, emotional challenges and higher levels of depression. Despite these challenges,
17 support for parents has tended to be peripheral in healthcare services of children. There is a lack of
18 research attention given to support programs for parents of children with intellectual disabilities
19 despite the importance of parenting for the optimal development of children with intellectual
20 disabilities

21 **Methods and analysis:** This review will follow the Joanna Briggs Institute scoping review methods
22 manual. The search for relevant studies will be in Medline (EbscoHost), PsychARTICLES, PubMed,
23 CINHAL, Academic Search Complete and SAePublications. Reference mining of full review studies will
24 be conducted. A three-step search strategy will be utilized, including the use of information
25 management software to manage the search results and to remove duplications. An independent
26 reviewer will extract data using a data extraction tool. Furthermore, another reviewer will screen the
27 included articles in conjunction with the results of the scoping review. The data extracted will be
28 presented in a tabular format with a narrative summary related to the key findings.

29 **Ethics and dissemination:** This scoping review has received ethical approval (BM20/4/26). A
30 summary of the findings of the study will be published in a peer-reviewed journal. This scoping
31 review will contribute to a better understanding of the support programs available to parents of
32 children with intellectual disabilities. This could be the first step in highlighting the gaps and future
33 directions for the development and implementation of support programs for parents of children
34 with intellectual disabilities.

35 **Registration Details:** Marais JE, Wegner L, Mthembu T. Support programs for parents of children
36 with intellectual disabilities: A scoping review [Internet]. OSF; 2021. Available from: osf.io/en6cs

37 **Keywords:** Intellectual disabilities; parents; support programs

38 **Word count:** 2629

39 **Article Summary**

40 **Strengths and limitations of this study:**

- 41 • This scoping review will provide an evidenced base of available support programs for
42 parents of children with intellectual disabilities in a wide variety of settings.
- 43 • A scoping review is practical method to synthesis research in a wide range of methodological
44 approaches, settings and study populations on the available literature of support programs
45 for parents of children with intellectual disabilities.

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- 46 • This scoping review will highlight the key research gaps and research needs for
47 transformation in the health sector for the support needs of parents who have children with
48 intellectual disabilities.
- 49 • One of the limitations is that the methodological quality of included studies was not
50 assessed.
- 51 • The synthesis of data will be limited to English studies that were published in peer reviewed
52 journals.

For peer review only

54 INTRODUCTION

55 Intellectual disability (ID) affects four in 100 people in South Africa to some degree.¹ Intellectual
56 disabilities are neurodevelopmental disorders that begin in childhood and are characterized by
57 intellectual difficulties as well as difficulties in conceptual, social, and practical areas of living. The
58 DSM-5 diagnosis of intellectual disabilities requires the satisfaction of three criteria: 1) Deficits in
59 intellectual functioning— ‘reasoning, problem solving, planning, abstract thinking, judgment,
60 academic learning, and learning from experience’ —confirmed by clinical evaluation and
61 individualized standard IQ testing; 2) Deficits in adaptive functioning that significantly hamper
62 conforming to developmental and sociocultural standards for the individual's independence and
63 ability to meet their social responsibility; and 3) The onset of these deficits during the developmental
64 period.^{2(p33)} There is however, a lack of policy development and implementation for child and
65 adolescent mental health (CAMH) including children and adolescents with intellectual disabilities,
66 and this is particularly prevalent in low- and middle-income countries.³ Intellectual disability places a
67 high burden of disease on low- and middle-income countries and has become a public health priority
68 because of its continuation throughout the life cycle as well as the impact it has on the family.⁴

69 Parents of children with intellectual disabilities experience high levels of stress relating to subjective
70 factors such as feelings of social isolation and life dissatisfaction, and factors relating to societal and
71 institutional marginalization.⁵ There are a multitude of emotional challenges experienced by these
72 parents, in particular in relation to guilt over possibly being the cause of their child's disability
73 (reasons being both logical and illogical) by parents who have children with intellectual disabilities.⁵
74 Parenting a child with intellectual disabilities is often experienced as being more emotionally
75 demanding and stressful than parenting a child without those challenges.⁵ Depression is a measure
76 that has been used to assess the adverse effects of stress and adaptive capacities of parents who
77 have children with intellectual disabilities. It has been indicated that mothers of children with
78 intellectual disabilities experience elevated levels of depression when compared to control group.⁶
79 However, support for parents in the mental health care of children has tended to be a peripheral
80 focus. This indicates that there is a lack of research attention given to support for parents caring for
81 children with intellectual disabilities, even though parenting is vital for the optimal development and
82 general care of children with this condition.⁷ Studies conducted in South Africa on those caring for
83 individuals with mental disorders and disabilities focused mainly on informal caregiver burden with
84 mainly females being the carers of older persons in the community or the family.⁸ The caregivers'
85 burdens comprise financial strains, privacy issues, social life status and physical and sleep

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5 86 disturbances.⁸ In South Africa, people with mental illness and disabilities experience significant
6 87 amounts of stigma, which could lead to social isolation, low-self-esteem, depression, poor social
7 88 skills, marginalization, unemployment and housing difficulties.⁸
9
10 89 There are many barriers to caring for children with intellectual disabilities. This is especially true
11 90 among families who have complex social situations. For the successful empowerment of families, it
12 91 is important to address the various obstacles parents of children with intellectual disabilities
13 92 consistently face. These obstacles include: the stigma attached to intellectual disabilities; belief
14 93 systems surrounding the child and social behavior (e.g. proper disciplining of the child will eradicate
15 94 the problem), and the attitudes parents have towards mental health care services (e.g. a lack of trust
16 95 in service providers based on previous experiences).⁹ Stigma not only affects individuals or groups of
17 96 individuals who carry the stigmatizing attribute (in this case intellectual disability) but also spills over
18 97 into those affiliated with them.¹⁰ Parents of children with intellectual disabilities often experience
19 98 affiliated stigma – the process of internalizing the public’s negative views towards themselves
20 99 because of their child’s disability.¹¹ Affiliated stigma can adversely affect the quality of life of parents
21 100 because they are undervalued by others and the continuous battles they encounter with service. To
22 101 cope with the stigma parents may withdraw socially or conceal their child’s disability.¹² The
23 102 continuous and long-term use of these coping strategies could potentially lead to lowered self-
24 103 esteem, and the individual with an intellectual disability experiencing increased levels of
25 104 discrimination.¹² It is imperative to understand the belief systems surrounding the child and social
26 105 behaviour. Parents’ perceptions about the nature of their child’s disability is a focal point in many
27 106 different cultural groups, and disabilities are also viewed differently across different cultures. The
28 107 perceptions held by parents’ and society shape the parents’ attitudes towards their children and
29 108 their disabilities. These perceptions are also instrumental in the resources and treatment that
30 109 parents will be able to invest in for the training and education of their children with a disability; as
31 110 well as the views parents have about their children’s future.¹³ It is also important to understand how
32 111 the contrasting perspectives of parents and clinicians influences their relations, the care and service
33 112 provision. This contrast too frequently leads to perpetual blame games between parents and
34 113 clinicians, where clinicians blame parents for their lack of commitment and parents complain about
35 114 the lack of understanding from clinicians. This results in children and adolescents not receiving the
36 115 proper care to address their disability and parents feeling overwhelmed. Therefore, for continuity of
37 116 care to occur in the treatment of children with intellectual disabilities through family-focused and
38 117 patient-centred medical care, collaboration between healthcare professionals and parents should be
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5 118 considered. It is crucial that families and physicians should not view each other as adversaries or
6 119 untrustworthy, but instead as partners striving to achieve the same goal.⁹
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9 120 A preliminary search of PROSPERO, MEDLINE, the Cochrane Database of Systematic Reviews and the
10 121 *JBI Evidence Synthesis* was conducted. Dew et al¹⁴ reported on the peer support experiences of
11 122 mothers of children with intellectual disability and challenging behaviour. Stuttard et al¹⁵ reported
12 123 on the evaluation of a group-delivered intervention (Riding the Rapids); this program was developed
13 124 specifically for parents of children with a disability or autistic spectrum disorder. However, the
14 125 preliminary search found no current scoping or systematic reviews or systematic and scoping
15 126 reviews that are currently underway that focused on support programs for parents of children with
16 127 intellectual disabilities. Various studies have been done on support programs for parents of children
17 128 with intellectual disabilities however, not many have mapped and synthesized the different
18 129 elements of these programs to highlight the gaps for future programs. Therefore, a synthesis of the
19 130 body of evidence that is currently available in the area is needed to inform evidence-based program
20 131 development for parents of children with intellectual disabilities. A scoping review on the available
21 132 body of literature on support programs for parents of children with intellectual disabilities is
22 133 proposed. The objective of this scoping review is to describe, map and synthesize the available
23 134 literature on support programs for parents of children with intellectual disabilities.
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35 135 **METHODS AND ANALYSIS**

36 136 The various systematic approaches available were considered in order to review the published
37 137 literature on support programs for parents of children with intellectual disabilities. We chose to
38 138 undertake a scoping review of published literature as this was the best method to describe, map and
39 139 synthesize the evidence to identify the gaps in literature on parent support programs. The proposed
40 140 scoping review will be conducted in accordance with the Joanna Briggs Institute methodology for
41 141 scoping reviews.¹⁶
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48 142 **Review question(s)**

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51 143 1. What programs have been carried out and literature published in peer reviewed journals
52 144 around support programs for parents of children with intellectual disabilities?
53 145 2. What target populations are being addressed in peer reviewed published literature around
54 146 support programs for parents of children with intellectual disabilities?
55 147 3. What types of interventions are being carried out and evaluated around support for parents
56 148 who have children with intellectual disabilities?
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5 149 4. What are the key findings related to the studies carried out around support programs for
6 150 parents of children with intellectual disabilities?
7 151 5. What are the types of support offered in the support programs for parents of children with
8 152 intellectual disabilities?
9 153 6. Who offers the support programs to parents of children with intellectual disabilities?
10 154 7. What are the characteristics of support programs for parents of children with intellectual
11 155 disabilities?
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15 156 **Inclusion criteria**

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17 157 The inclusion criteria were categorized according to the Population, Concept and Context (PCC)
18 158 mnemonic recommended by the Joanna Briggs Institute for scoping reviews. This is less restrictive
19 159 than the Population, Intervention, Comparator, Outcome (PICO) mnemonic which is recommended
20 160 for systematic reviews.
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22

23 161 **Participants**

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25 162 • Studies that include parents of children (0-18 years) with intellectual disabilities. Parents are
26 163 defined as men and/or women who perform a parenting role in terms of caring for their child
27 164 and his/her needs. The term 'parents' will include, but is not limited to: biological, adoptive,
28 165 step, foster parents and guardians.
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33 166 **Concept**

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35 167 • Studies that explore parent support programs that are designed to support parents who have
36 168 children with intellectual disabilities carried out between 2003 and 2021. This timeframe was
37 169 chosen as in 2003 the CAMH policy framework was developed to be implemented in South
38 170 Africa.³
39
40 171 • Included as concepts will be all types of programs, modes of delivery, setting, leadership and
41 172 duration. Examples of the types of programs that could be included are social support, peer
42 173 support, psychoeducational support, knowledge support, emotional support and all other
43 174 variants including multi component interventions. Examples of modes of delivery could
44 175 include support groups, telephonic interactions and self-delivery (through use of manuals)
45 176 Examples of settings could include clinical settings, home, community settings. Examples of
46 177 leadership could include: clinician led, family led and team led.
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48 178 • Full-text
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50 179 • Peer reviewed
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52 180 • Literature published in the English medium
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181 Context

- 182 • Clinical settings
- 183 • Community settings
- 184 • Virtual settings or any other settings where support programs for parents of children with
185 intellectual disabilities are delivered
- 186 • All countries and economic settings will be included in the study.
- 187 • Quantitative, qualitative, and mixed methods study approaches will be considered for
188 inclusion. Quantitative study designs to be considered for the review will include experimental
189 and quasi-experimental including randomized control trials, non-randomized control trials,
190 pre-test post-test studies, and interrupted time-series. In addition, cohort studies, case-
191 control studies and cross-sectional studies will be considered for inclusion. All qualitative
192 research including explanatory, exploratory, descriptive and applied types of research using
193 different application techniques will be considered for inclusion.

194 Exclusion criteria

195 Excluded from the study will be systematic reviews, scoping reviews and studies that were not
196 interventions and interventions supporting parents with intellectual disabilities.

197 Search strategy

198 The search strategy will follow a three-phase approach with an aim to find published studies. A
199 literature search will be conducted to identify parent support programs aimed at parents who have
200 children with intellectual disabilities. In the first phase, an initial limited search of Medline (EbscoHost)
201 and PubMed will be undertaken to identify articles on the topic. The text words contained in the titles
202 and abstracts of relevant articles, and the index terms used to describe the articles related to the
203 proposed scoping review will inform the second phase where a full search strategy for relevant
204 database platforms; these include Medline (Ebscohost), PsychARTICLES, CINAHL, PubMed, Academic
205 Search Complete and SA ePublications. PubMed is detailed in Appendix I. In the third phase of the
206 search, the reference lists of articles selected for full-text review will be screened for additional
207 papers.

208 Following the search, all identified records will be collated and uploaded into Mendeley (Mendeley
209 Ltd., Elsevier, Netherlands) and duplicates removed. Following a pilot test, titles and abstracts will
210 then be screened by one independent reviewer (JM) for assessment against the inclusion criteria for

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5 211 the review. Potentially relevant papers will be retrieved and their citations and details will be recorded
6 212 in Microsoft Excel. The full text of the selected studies will go through a detailed assessment against
7 213 the inclusion criteria by two independent reviewers (JM and LW). Disagreements will be resolved via
8 214 discussion and where no agreement can be reached a third independent reviewer (TM) will be
9 215 consulted for further discussion. Reasons for exclusion of full-text papers that do not meet the
10 216 inclusion criteria will be recorded and reported on in the final scoping review. The results of the search
11 217 will be reported in full in the final scoping review and presented in a Preferred Reporting Items for
12 218 Systematic Reviews and Meta-analyses (PRISMA) flow diagram (Figure 1).¹⁷

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19 219 <insert Figure 1 here>

20 21 22 220 **Data extraction**

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24 221 Data will be extracted from papers included in the scoping review by one independent reviewer (JM)
25 222 and assessed by two independent reviewers (LW and TM) using a data extraction tool developed by
26 223 the reviewers. The draft data extraction instrument (Appendix II) was adapted from the
27 224 Methodology for Joanna Biggs Institute scoping reviews¹⁷ and Hoagwood et al.⁷ to answer the
28 225 review question. The data extracted will include specific details about the population, concept,
29 226 context, methods leadership, program characteristics and key findings relevant to the research
30 227 question. Modifications of the JBI data extraction tool will consist of the following items:
31 228 intervention name, type of support provided, leadership (e.g. clinician led), and program
32 229 characteristics. If necessary modifications to the data extraction tool will be made and revised during
33 230 the data extraction process of each included study. All modifications made will be detailed in the full
34 231 scoping review. If any disagreements arise between reviewers (JM and LW), these will be resolved
35 232 through discussion with a third reviewer (TM). Authors of papers will be contacted to request
36 233 missing or additional data, where required. If authors do not respond to the request a decision to
37 234 include or exclude the article based the information available.

38 39 40 41 42 43 44 45 46 47 48 49 235 **Synthesis and reporting of results**

50
51 236 The data extracted will be presented in a tabular format with a narrative summary related to the key
52 237 findings. The results will be presented following the population, concept and context format as well
53 238 as the main conceptual categories used in the data extraction tool. A narrative description of the
54 239 findings will be guided by the thematic analysis of the qualitative findings. The tabulated results

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5 240 using descriptive analysis, accompanied by the narrative results will be presented and framed in
6 241 relation to the review objective and research question of this scoping review. A checklist for protocol
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8 242 submission guidelines PRISMA-P has been completed (Appendix III).¹⁸
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11 243 **Public and patient involvement**

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14 244 No patient involved
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16 245 **ETHICS AND DISSEMINATION**

17 246 This scoping review has received ethical approval from the University of the Western Cape
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19 247 Biomedical Research Ethics Committee (BM20/4/26). A summary of the findings of the study will be
20
21 248 published in a peer-reviewed journal. This scoping review will contribute to a better understanding
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23 249 of the support programs available to parents of children with intellectual disabilities. This could be
24
25 250 the first step in highlighting the gaps and future directions for the development and implementation
26
27 251 of support programs for parents of children with intellectual disabilities.
28

29 252 **Acknowledgments**

30
31 253 The authors would like to thank Prof Jose Frantz and Prof Mario Smith for their training and
32
33 254 continued guidance and support throughout this review.
34

35 255 **Author Contributions**

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38 256 All authors have contributed to the conceptualization and design of the study. All authors have read
39
40 257 and approved the final version of the manuscript. JM drafted the manuscript and LW and TM made
41
42 258 major and minor revisions throughout the process.
43

44 259 **Funding**

45
46 260 No funding was received for study
47

48 261 **Conflict of interest**

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50 262 None declared
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53 263 **Data access statement**

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55 264 The data for the scoping review will be managed using Mendeley and all data will be store for 5
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57 265 years after completion of the study.
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5 266 This review will contribute to the PhD for the lead author (JM).

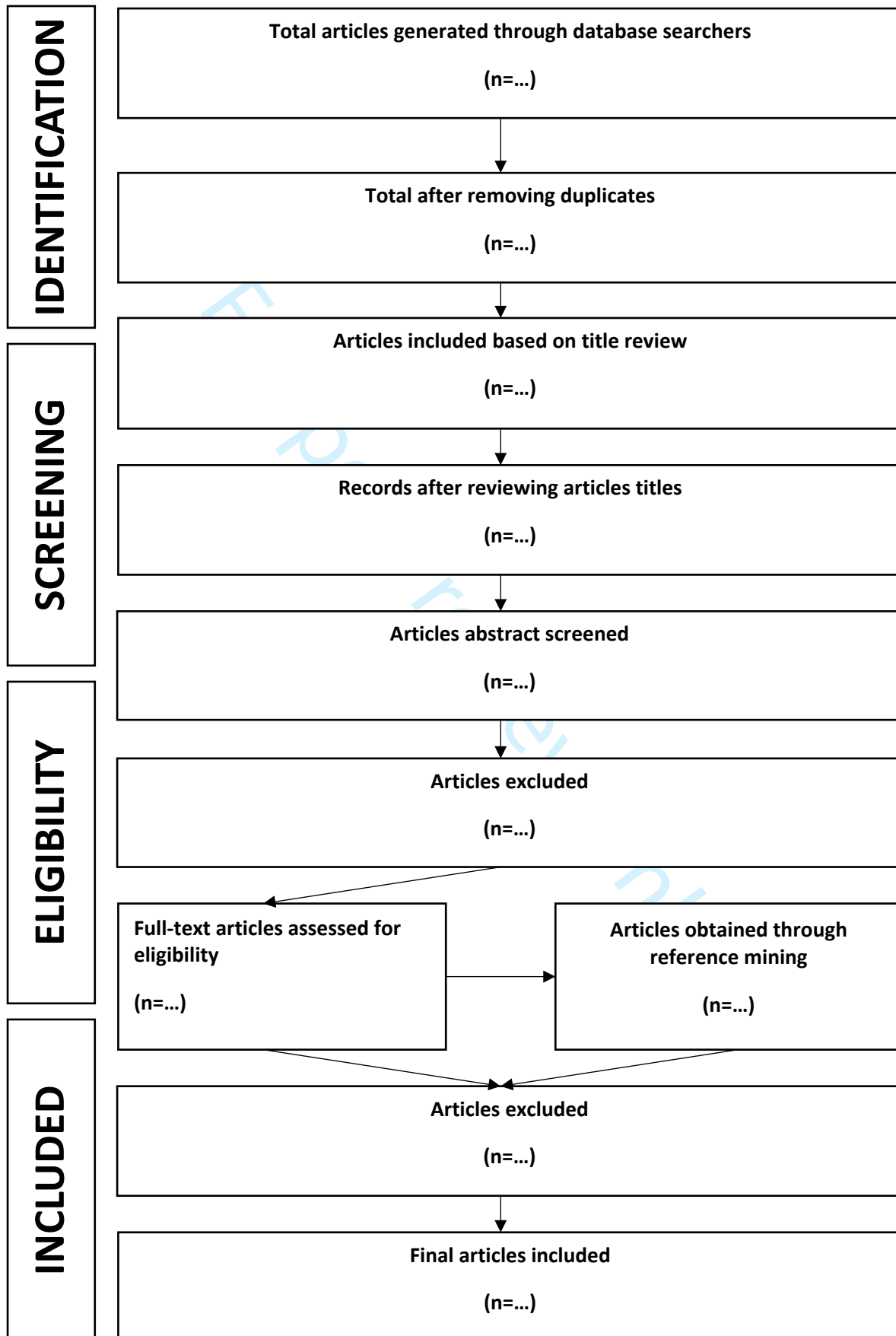
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7 267 **Figure 1: PRISMA flow diagram**

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Figure 1: PRISMA flow diagram



Appendix I: Search strategy

PubMed

Dec 2020

| Search | Query | Records retrieved |
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| #1 | ("child"[MeSH Terms] OR "child"[All Fields] OR "children"[All Fields] OR "child s"[All Fields] OR "children s"[All Fields] OR "childrens"[All Fields] OR "childs"[All Fields]) AND ("mental health"[MeSH Terms] OR ("mental"[All Fields] AND "health"[All Fields]) OR "mental health"[All Fields]) AND (("parent s"[All Fields] OR "parentally"[All Fields] OR "parentals"[All Fields] OR "parented"[All Fields] OR "parenting"[MeSH Terms] OR "parenting"[All Fields] OR "parents"[MeSH Terms] OR "parents"[All Fields] OR "parent"[All Fields] OR "parental"[All Fields]) AND ("support"[All Fields] OR "support s"[All Fields] OR "supported"[All Fields] OR "supporter"[All Fields] OR "supporter s"[All Fields] OR "supporters"[All Fields] OR "supporting"[All Fields] OR "supportive"[All Fields] OR "supportiveness"[All Fields] OR "supports"[All Fields]) AND "program*"[All Fields]) | 409 |
| #2 | ("child"[MeSH Terms] OR "child"[All Fields] OR "children"[All Fields] OR "child s"[All Fields] OR "children s"[All Fields] OR "childrens"[All Fields] OR "childs"[All Fields]) AND ("mental health"[MeSH Terms] OR ("mental"[All Fields] AND "health"[All Fields]) OR "mental health"[All Fields]) AND (("parent s"[All Fields] OR "parentally"[All Fields] OR "parentals"[All Fields] OR "parented"[All Fields] OR "parenting"[MeSH Terms] OR "parenting"[All Fields] OR "parents"[MeSH Terms] OR "parents"[All Fields] OR "parent"[All Fields] OR "parental"[All Fields]) AND ("support"[All Fields] OR "support s"[All Fields] OR "supported"[All Fields] OR "supporter"[All Fields] OR "supporter s"[All Fields] OR "supporters"[All Fields] OR "supporting"[All Fields] OR "supportive"[All Fields] OR "supportiveness"[All Fields] OR "supports"[All Fields]) AND ("intervention s"[All Fields] OR "interventions"[All Fields] OR "interventive"[All Fields] OR "methods"[MeSH Terms] OR | 742 |

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| | "methods"[All Fields] OR "intervention"[All Fields] OR "interventional"[All Fields]) | |
| #3 | "child"[MeSH Terms] OR "child"[All Fields] OR "children"[All Fields] OR "child s"[All Fields] OR "children s"[All Fields] OR "childrens"[All Fields] OR "childs"[All Fields]) AND ("mental health"[MeSH Terms] OR ("mental"[All Fields] AND "health"[All Fields]) OR "mental health"[All Fields]) AND (("parent s"[All Fields] OR "parentally"[All Fields] OR "parentals"[All Fields] OR "parented"[All Fields] OR "parenting"[MeSH Terms] OR "parenting"[All Fields] OR "parents"[MeSH Terms] OR "parents"[All Fields] OR "parent"[All Fields] OR "parental"[All Fields]) AND ("emoting"[All Fields] OR "emotion s"[All Fields] OR "emotions"[MeSH Terms] OR "emotions"[All Fields] OR "emotion"[All Fields] OR "emotional"[All Fields] OR "emotive"[All Fields]) AND "wellbeing"[All Fields]) | 53 |
| #4 | ("child"[MeSH Terms] OR "child"[All Fields] OR "children"[All Fields] OR "child s"[All Fields] OR "children s"[All Fields] OR "childrens"[All Fields] OR "childs"[All Fields]) AND ("mental health"[MeSH Terms] OR ("mental"[All Fields] AND "health"[All Fields]) OR "mental health"[All Fields]) AND (("parent s"[All Fields] OR "parentally"[All Fields] OR "parentals"[All Fields] OR "parented"[All Fields] OR "parenting"[MeSH Terms] OR "parenting"[All Fields] OR "parents"[MeSH Terms] OR "parents"[All Fields] OR "parent"[All Fields] OR "parental"[All Fields]) AND ("emoting"[All Fields] OR "emotion s"[All Fields] OR "emotions"[MeSH Terms] OR "emotions"[All Fields] OR "emotion"[All Fields] OR "emotional"[All Fields] OR "emotive"[All Fields]) AND ("health"[MeSH Terms] OR "health"[All Fields] OR "well"[All Fields] OR "well being"[All Fields])) | 270 |
| #5 | ("child"[MeSH Terms] OR "child"[All Fields] OR "children"[All Fields] OR "child s"[All Fields] OR "children s"[All Fields] OR "childrens"[All Fields] OR "childs"[All Fields]) AND ("mental health"[MeSH Terms] OR ("mental"[All Fields] AND "health"[All Fields]) OR "mental health"[All Fields]) AND (("parent s"[All Fields] OR "parentally"[All Fields] OR "parentals"[All Fields] | 209 |

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| | <p>OR "parented"[All Fields] OR "parenting"[MeSH Terms] OR "parenting"[All Fields] OR "parents"[MeSH Terms] OR "parents"[All Fields] OR "parent"[All Fields] OR "parental"[All Fields]) AND ("emoting"[All Fields] OR "emotions"[All Fields] OR "emotions"[MeSH Terms] OR "emotions"[All Fields] OR "emotion"[All Fields] OR "emotional"[All Fields] OR "emotive"[All Fields]) AND ("support"[All Fields] OR "support s"[All Fields] OR "supported"[All Fields] OR "supporter"[All Fields] OR "supporter s"[All Fields] OR "supporters"[All Fields] OR "supporting"[All Fields] OR "supportive"[All Fields] OR "supportiveness"[All Fields] OR "supports"[All Fields]))</p> | |
| #6 | <p>("adolescences"[All Fields] OR "adolescence"[All Fields] OR "adolescent"[MeSH Terms] OR "adolescent"[All Fields] OR "adolescence"[All Fields] OR "adolescents"[All Fields] OR "adolescent s"[All Fields]) AND ("mental health"[MeSH Terms] OR ("mental"[All Fields] AND "health"[All Fields]) OR "mental health"[All Fields]) AND (("parent s"[All Fields] OR "parentally"[All Fields] OR "parentals"[All Fields] OR "parented"[All Fields] OR "parenting"[MeSH Terms] OR "parenting"[All Fields] OR "parents"[MeSH Terms] OR "parents"[All Fields] OR "parent"[All Fields] OR "parental"[All Fields]) AND ("support"[All Fields] OR "support s"[All Fields] OR "supported"[All Fields] OR "supporter"[All Fields] OR "supporter s"[All Fields] OR "supporters"[All Fields] OR "supporting"[All Fields] OR "supportive"[All Fields] OR "supportiveness"[All Fields] OR "supports"[All Fields]) AND "program*"[All Fields])</p> | 210 |
| #7 | <p>("adolescences"[All Fields] OR "adolescence"[All Fields] OR "adolescent"[MeSH Terms] OR "adolescent"[All Fields] OR "adolescence"[All Fields] OR "adolescents"[All Fields] OR "adolescent s"[All Fields]) AND ("mental health"[MeSH Terms] OR ("mental"[All Fields] AND "health"[All Fields]) OR "mental health"[All Fields]) AND (("parent s"[All Fields] OR "parentally"[All Fields] OR "parentals"[All Fields] OR "parented"[All Fields] OR "parenting"[MeSH Terms] OR "parenting"[All Fields] OR "parents"[MeSH Terms] OR "parents"[All Fields] OR "parent"[All Fields] OR "parental"[All Fields]) AND ("support"[All Fields] OR "support s"[All Fields] OR</p> | 426 |

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| #8 | ("adolescences"[All Fields] OR "adolescence"[All Fields] OR "adolescent"[MeSH Terms] OR "adolescent"[All Fields] OR "adolescence"[All Fields] OR "adolescents"[All Fields] OR "adolescent s"[All Fields]) AND ("mental health"[MeSH Terms] OR ("mental"[All Fields] AND "health"[All Fields]) OR "mental health"[All Fields]) AND (("parent s"[All Fields] OR "parentally"[All Fields] OR "parentals"[All Fields] OR "parented"[All Fields] OR "parenting"[MeSH Terms] OR "parenting"[All Fields] OR "parents"[MeSH Terms] OR "parents"[All Fields] OR "parent"[All Fields] OR "parental"[All Fields]) AND ("emoting"[All Fields] OR "emotion s"[All Fields] OR "emotions"[MeSH Terms] OR "emotions"[All Fields] OR "emotion"[All Fields] OR "emotional"[All Fields] OR "emotive"[All Fields]) AND "wellbeing"[All Fields]) | 21 |
| #9 | ("adolescences"[All Fields] OR "adolescence"[All Fields] OR "adolescent"[MeSH Terms] OR "adolescent"[All Fields] OR "adolescence"[All Fields] OR "adolescents"[All Fields] OR "adolescent s"[All Fields]) AND ("mental health"[MeSH Terms] OR ("mental"[All Fields] AND "health"[All Fields]) OR "mental health"[All Fields]) AND (("parent s"[All Fields] OR "parentally"[All Fields] OR "parentals"[All Fields] OR "parented"[All Fields] OR "parenting"[MeSH Terms] OR "parenting"[All Fields] OR "parents"[MeSH Terms] OR "parents"[All Fields] OR "parent"[All Fields] OR "parental"[All Fields]) AND ("emoting"[All Fields] OR "emotion s"[All Fields] OR "emotions"[MeSH Terms] OR "emotions"[All Fields] OR "emotion"[All Fields] OR "emotional"[All Fields] OR "emotive"[All Fields]) AND ("health"[MeSH Terms] OR "health"[All Fields] OR "well"[All Fields] OR "well being"[All Fields])) | 158 |

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| #10 | <p>("adolescences"[All Fields] OR "adolescence"[All Fields] OR "adolescent"[MeSH Terms] OR "adolescent"[All Fields] OR "adolescence"[All Fields] OR "adolescents"[All Fields] OR "adolescent s"[All Fields]) AND ("mental health"[MeSH Terms] OR ("mental"[All Fields] AND "health"[All Fields]) OR "mental health"[All Fields]) AND (("parent s"[All Fields] OR "parentally"[All Fields] OR "parentals"[All Fields] OR "parented"[All Fields] OR "parenting"[MeSH Terms] OR "parenting"[All Fields] OR "parents"[MeSH Terms] OR "parents"[All Fields] OR "parent"[All Fields] OR "parental"[All Fields]) AND ("emoting"[All Fields] OR "emotion s"[All Fields] OR "emotions"[MeSH Terms] OR "emotions"[All Fields] OR "emotion"[All Fields] OR "emotional"[All Fields] OR "emotive"[All Fields]) AND ("support"[All Fields] OR "support s"[All Fields] OR "supported"[All Fields] OR "supporter"[All Fields] OR "supporter s"[All Fields] OR "supporters"[All Fields] OR "supporting"[All Fields] OR "supportive"[All Fields] OR "supportiveness"[All Fields] OR "supports"[All Fields]))</p> | 124 |
| #11 | <p>("intellectual"[All Fields] OR "intellectualism"[All Fields] OR "intellectually"[All Fields] OR "intellectuals"[All Fields]) AND "disabilit*" [All Fields] AND (("parent s"[All Fields] OR "parentally"[All Fields] OR "parentals"[All Fields] OR "parented"[All Fields] OR "parenting"[MeSH Terms] OR "parenting"[All Fields] OR "parents"[MeSH Terms] OR "parents"[All Fields] OR "parent"[All Fields] OR "parental"[All Fields]) AND ("support"[All Fields] OR "support s"[All Fields] OR "supported"[All Fields] OR "supporter"[All Fields] OR "supporter s"[All Fields] OR "supporters"[All Fields] OR "supporting"[All Fields] OR "supportive"[All Fields] OR "supportiveness"[All Fields] OR "supports"[All Fields]) AND "program*" [All Fields])</p> | 31 |
| #12 | <p>("intellectual"[All Fields] OR "intellectualism"[All Fields] OR "intellectually"[All Fields] OR "intellectuals"[All Fields]) AND "disabilit*" [All Fields] AND (("parent s"[All Fields] OR "parentally"[All Fields] OR "parentals"[All Fields] OR "parented"[All Fields] OR "parenting"[MeSH Terms] OR "parenting"[All Fields] OR "parents"[MeSH Terms] OR "parents"[All Fields] OR "parent"[All Fields] OR "parental"[All Fields]) AND ("support"[All Fields] OR "support</p> | 60 |

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| | s"[All Fields] OR "supported"[All Fields] OR "supporter"[All Fields] OR "supporter s"[All Fields] OR "supporters"[All Fields] OR "supporting"[All Fields] OR "supportive"[All Fields] OR "supportiveness"[All Fields] OR "supports"[All Fields]) AND ("intervention s"[All Fields] OR "interventions"[All Fields] OR "interventive"[All Fields] OR "methods"[MeSH Terms] OR "methods"[All Fields] OR "intervention"[All Fields] OR "interventional"[All Fields])) | |
| #13 | ("intellectual"[All Fields] OR "intellectualism"[All Fields] OR "intellectually"[All Fields] OR "intellectuals"[All Fields]) AND "disabilit*" [All Fields] AND ("parent s"[All Fields] OR "parentally"[All Fields] OR "parentals"[All Fields] OR "parented"[All Fields] OR "parenting"[MeSH Terms] OR "parenting"[All Fields] OR "parents"[MeSH Terms] OR "parents"[All Fields] OR "parent"[All Fields] OR "parental"[All Fields]) AND ("emoting"[All Fields] OR "emotion s"[All Fields] OR "emotions"[MeSH Terms] OR "emotions"[All Fields] OR "emotion"[All Fields] OR "emotional"[All Fields] OR "emotive"[All Fields]) AND "wellbeing"[All Fields]) | 3 |
| #14 | ("intellectual"[All Fields] OR "intellectualism"[All Fields] OR "intellectually"[All Fields] OR "intellectuals"[All Fields]) AND "disabilit*" [All Fields] AND ("parent s"[All Fields] OR "parentally"[All Fields] OR "parentals"[All Fields] OR "parented"[All Fields] OR "parenting"[MeSH Terms] OR "parenting"[All Fields] OR "parents"[MeSH Terms] OR "parents"[All Fields] OR "parent"[All Fields] OR "parental"[All Fields]) AND ("emoting"[All Fields] OR "emotion s"[All Fields] OR "emotions"[MeSH Terms] OR "emotions"[All Fields] OR "emotion"[All Fields] OR "emotional"[All Fields] OR "emotive"[All Fields]) AND ("health"[MeSH Terms] OR "health"[All Fields] OR "well"[All Fields] OR "well being"[All Fields])) | 12 |
| #15 | ("intellectual"[All Fields] OR "intellectualism"[All Fields] OR "intellectually"[All Fields] OR "intellectuals"[All Fields]) AND "disabilit*" [All Fields] AND ("parent s"[All Fields] OR "parentally"[All Fields] OR "parentals"[All Fields] OR "parented"[All Fields] OR "parenting"[MeSH Terms] OR "parenting"[All | 12 |

| | | |
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| | Fields] OR "parents"[MeSH Terms] OR "parents"[All Fields] OR "parent"[All Fields] OR "parental"[All Fields]) AND ("emoting"[All Fields] OR "emotion s"[All Fields] OR "emotions"[MeSH Terms] OR "emotions"[All Fields] OR "emotion"[All Fields] OR "emotional"[All Fields] OR "emotive"[All Fields]) AND ("support"[All Fields] OR "support s"[All Fields] OR "supported"[All Fields] OR "supporter"[All Fields] OR "supporter s"[All Fields] OR "supporters"[All Fields] OR "supporting"[All Fields] OR "supportive"[All Fields] OR "supportiveness"[All Fields] OR "supports"[All Fields])) | |
| #21 | #1 - #15 | 2740 |
| Limited to 2003-2020, English, full-text, books and documents, clinical trial, and randomized controlled trial | | |

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Appendix II: Data extraction instrument

| Author information | Year of publication | Country of origin | Aims/Purpose of the study | Study Population | Methodology | Intervention type | Duration | Outcomes | Key findings related to the study | Intervention name | Type of support | Leadership | Program characteristics |
|--------------------|---------------------|-------------------|---------------------------|------------------|-------------|-------------------|----------|----------|-----------------------------------|-------------------|-----------------|------------|-------------------------|
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PRISMA-P 2015 Checklist

This checklist has been adapted for use with protocol submissions to *Systematic Reviews* from Table 3 in Moher D et al: Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Systematic Reviews* 2015 4:1

| Section/topic | # | Checklist item | Information reported | | Line number(s) |
|-----------------------------------|----|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------|-------------------------------------|-----------------------------|
| | | | Yes | No | |
| ADMINISTRATIVE INFORMATION | | | | | |
| Title | | | | | |
| Identification | 1a | Identify the report as a protocol of a systematic review | <input checked="" type="checkbox"/> | <input type="checkbox"/> | 1-2 |
| Update | 1b | If the protocol is for an update of a previous systematic review, identify as such | <input type="checkbox"/> | <input checked="" type="checkbox"/> | |
| Registration | 2 | If registered, provide the name of the registry (e.g., PROSPERO) and registration number in the Abstract | <input checked="" type="checkbox"/> | <input type="checkbox"/> | 27-29 |
| Authors | | | | | |
| Contact | 3a | Provide name, institutional affiliation, and e-mail address of all protocol authors; provide physical mailing address of corresponding author | <input checked="" type="checkbox"/> | <input type="checkbox"/> | Title page |
| Contributions | 3b | Describe contributions of protocol authors and identify the guarantor of the review | <input checked="" type="checkbox"/> | <input type="checkbox"/> | 196,199,201,207,208,217,218 |
| Amendments | 4 | If the protocol represents an amendment of a previously completed or published protocol, identify as such and list changes; otherwise, state plan for documenting important protocol amendments | <input type="checkbox"/> | <input checked="" type="checkbox"/> | Not Applicable |
| Support | | | | | |
| Sources | 5a | Indicate sources of financial or other support for the review | <input type="checkbox"/> | <input checked="" type="checkbox"/> | Not Applicable |
| Sponsor | 5b | Provide name for the review funder and/or sponsor | <input type="checkbox"/> | <input checked="" type="checkbox"/> | Not Applicable |
| Role of sponsor/funder | 5c | Describe roles of funder(s), sponsor(s), and/or institution(s), if any, in developing the protocol | <input checked="" type="checkbox"/> | <input type="checkbox"/> | 20-21 and 228-229 |
| INTRODUCTION | | | | | |
| Rationale | 6 | Describe the rationale for the review in the context of what is already known | <input checked="" type="checkbox"/> | <input type="checkbox"/> | 44-121 |

| Section/topic | # | Checklist item | Information reported | | Line number(s) |
|-------------------------------------------|-----|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------|-------------------------------------|----------------------------------------------------------------------------------------------------|
| | | | Yes | No | |
| Objectives | 7 | Provide an explicit statement of the question(s) the review will address with reference to participants, interventions, comparators, and outcomes (PICO) | <input checked="" type="checkbox"/> | <input type="checkbox"/> | 129-142 (Population, concept, context method was used according to JBI manual for scoping reviews) |
| METHODS | | | | | |
| Eligibility criteria | 8 | Specify the study characteristics (e.g., PICO, study design, setting, time frame) and report characteristics (e.g., years considered, language, publication status) to be used as criteria for eligibility for the review | <input checked="" type="checkbox"/> | <input type="checkbox"/> | 144-179 |
| Information sources | 9 | Describe all intended information sources (e.g., electronic databases, contact with study authors, trial registers, or other grey literature sources) with planned dates of coverage | <input checked="" type="checkbox"/> | <input type="checkbox"/> | 184-204 |
| Search strategy | 10 | Present draft of search strategy to be used for at least one electronic database, including planned limits, such that it could be repeated | <input checked="" type="checkbox"/> | <input type="checkbox"/> | Appendix I |
| STUDY RECORDS | | | | | |
| Data management | 11a | Describe the mechanism(s) that will be used to manage records and data throughout the review | <input checked="" type="checkbox"/> | <input type="checkbox"/> | 194-198 |
| Selection process | 11b | State the process that will be used for selecting studies (e.g., two independent reviewers) through each phase of the review (i.e., screening, eligibility, and inclusion in meta-analysis) | <input checked="" type="checkbox"/> | <input type="checkbox"/> | 195-204 and 207-219 |
| Data collection process | 11c | Describe planned method of extracting data from reports (e.g., piloting forms, done independently, in duplicate), any processes for obtaining and confirming data from investigators | <input checked="" type="checkbox"/> | <input type="checkbox"/> | 207-219 |
| Data items | 12 | List and define all variables for which data will be sought (e.g., PICO items, funding sources), any pre-planned data assumptions and simplifications | <input checked="" type="checkbox"/> | <input type="checkbox"/> | 144-179 |
| Outcomes and prioritization | 13 | List and define all outcomes for which data will be sought, including prioritization of main and additional outcomes, with rationale | <input checked="" type="checkbox"/> | <input type="checkbox"/> | 129-182 |
| Risk of bias in individual studies | 14 | Describe anticipated methods for assessing risk of bias of individual studies, including whether this will be done at the outcome or study level, or both; state how this information will be used in data synthesis | <input type="checkbox"/> | <input checked="" type="checkbox"/> | |
| DATA | | | | | |

| Section/topic | # | Checklist item | Information reported | | Line number(s) |
|------------------------------------------|-----|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------|-------------------------------------|----------------|
| | | | Yes | No | |
| Synthesis | 15a | Describe criteria under which study data will be quantitatively synthesized | <input checked="" type="checkbox"/> | <input type="checkbox"/> | 221-225 |
| | 15b | If data are appropriate for quantitative synthesis, describe planned summary measures, methods of handling data, and methods of combining data from studies, including any planned exploration of consistency (e.g., I^2 , Kendall's tau) | <input type="checkbox"/> | <input checked="" type="checkbox"/> | |
| | 15c | Describe any proposed additional analyses (e.g., sensitivity or subgroup analyses, meta-regression) | <input type="checkbox"/> | <input checked="" type="checkbox"/> | |
| | 15d | If quantitative synthesis is not appropriate, describe the type of summary planned | <input checked="" type="checkbox"/> | <input type="checkbox"/> | 222-224 |
| Meta-bias(es) | 16 | Specify any planned assessment of meta-bias(es) (e.g., publication bias across studies, selective reporting within studies) | <input type="checkbox"/> | <input checked="" type="checkbox"/> | |
| Confidence in cumulative evidence | 17 | Describe how the strength of the body of evidence will be assessed (e.g., GRADE) | <input type="checkbox"/> | <input checked="" type="checkbox"/> | |