

Psychosocial impact, experiences and support needs of South Asian families of children with intellectual disabilities: An integrative systematic review

Citation

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Review question

1. How are south Asian families impacted by the presence of a child/sibling with intellectual disabilities in the family?
2. What are the south Asian family's perceptions and experiences of having a child/sibling with intellectual disabilities in the family?

Searches [1 change]

Searches will be conducted by the first author. English language peer-reviewed research articles covering a period of 10 years (1st June 2014 – 30th June 2024). Publications in English will be included due to unavailability of resources for translation for this review and the propensity of English as the medium of publication. Electronic databases from the health and social care domains will be searched as below:

ASSIA

CINAHL

EBSCO

Embase

PsycINFO

PubMed

Scopus

Web of Science

Reference lists of included studies will be checked to ensure we do not miss any relevant studies. In addition, the following will be searched:

The Cochrane Library (<https://www.cochranelibrary.com/>)

ProQuest Dissertation and Theses (PQDT) Global (<https://about.proquest.com/en/products-services/pqdtglobal/>)

WHO Iris (<https://apps.who.int/iris/>)

Google Scholar

("South Asia*" OR India* OR Pakistan* or Nepal* OR "Sri Lanka*" OR Bangladesh* OR "South Asian immigrant" or "South Asian diaspora") AND (parent* OR carer* OR caregiver* OR grandparent* OR adopt* OR foster* OR local authority* OR sibling OR brother OR sister OR "sibling* of child* with disability*" OR "brother of child* with disability*" OR "sister of child* with disability*" OR "parent* of child* with disability*" or "mother of child* with disability*" OR "father of child* with disability*") AND ("intellectual disab*" OR "developmental disab*" OR "learning disab*" OR "mental* retard*" OR "mental* handicap") AND (wellbeing OR "well-being" OR empower* OR stress OR sleep* OR "self-esteem" OR "self-efficacy" OR "mental health" OR burnout OR "burn* out" OR behavior* OR confidence OR "family system" OR "family communication" OR interaction OR "family relationship" OR attachment OR "social experiences" OR "Quality of Life" OR economic* OR education* OR occupational OR stigma OR community OR inclusion OR exclusion OR support* OR help* OR experience* OR perception* OR attitude* OR view* OR feeling* or emotion* or affect*)

Types of study to be included

This integrative systematic review will include studies using qualitative, quantitative and mixed methods, and a range of study designs.

Condition or domain being studied

This review concerns the family members related to a person with intellectual disabilities. Family members include parents/legal guardians/siblings/extended family members where there is at least one child with and one child without intellectual disabilities.

Participants/population

Inclusion criteria:

Family members from the South of Asia related to the child with intellectual disabilities, i.e. parents, siblings, and caregivers such as grandparents, uncles, aunts, cousins, carers, adoptive/foster parents.

Individuals with intellectual disabilities aged 0m onwards from South Asian families if present in the studies

Exclusion criteria:

Sample not related to intellectual disabilities

No direct evidence on family members.

Intervention(s), exposure(s)

Exposure: Experience of having a child/sibling/family member with intellectual disabilities

Comparator(s)/control

Not applicable.

Context

All settings will be considered, i.e community or acute or educational or residential. Studies conducted in any country will be considered that have sample from the South of Asia.

Main outcome(s) [1 change]

The main outcomes are validated or non-validated measures on the impact of having a child/sibling with intellectual disabilities from a psychosocial perspective: Psychological impact (wellbeing or empowerment or stress or sleep or self-esteem or self-efficacy or mental health or burnout or behavioural or confidence); Family related impact (family system or family communication or interaction or family relationship or attachment or Quality of Life or economic or educational or occupational); Social impact (stigma or community or inclusion or exclusion)

Measures of effect

Inclusion of both qualitative and quantitative studies means that providing information on measured effect will be unlikely. However, effect sizes using Cohen's d, will be reported where possible.

Additional outcome(s) [1 change]

Secondary outcomes are validated or non-validated measures on the family's experiences of having a child/sibling with intellectual disabilities: support or help or experience or perception or attitude or view or feeling or emotion or affect

Measures of effect

Inclusion of both qualitative and quantitative studies means that providing information on measured effect will be unlikely. However, effect sizes using Cohen's d, will be reported where possible.

Data extraction (selection and coding) [1 change]

The first author will undertake the initial searches and import results into Endnote to screen the titles and abstracts based on the inclusion criteria. The second author will review 200 or 20% hits from this list, whichever is lower. Both the authors will then independently screen the first 30 full texts or 30%, whichever is lower. Any disagreements or discrepancies will be discussed and resolved. An audit trail of excluded results will be kept using an Excel spreadsheet. The first author will be responsible for the data extraction. Data from each eligible study will be extracted using data extraction form. This form will be adapted based on the Cochrane guidance ('Cochrane Developmental, Psychosocial and Learning problems' form).

The following key data will be extracted:

Characteristics of the study: research aim(s) and question, details of the methods, data analyses, results and conclusions

Characteristics of participants: Sample size, age and gender of all family members considered in the study, family size and composition

Details of the intellectual disabilities including diagnostic journey, treatment plan and caring arrangements

Risk of bias (quality) assessment

The Mixed Methods Appraisal Tool (MMAT, Hong et al., 2018) will be used to check the quality of included studies. Study quality of 30% of the records will be reviewed by both the authors for inter-rater reliability.

Strategy for data synthesis [1 change]

Data synthesis will be done for characteristics of each of the included study and of the participant's to summarise the details of the methods and the sample that is represented in the evidence base.

The mixed methods nature of studies lends itself to the Thomas and Harden's (2008) recommendations for conducting a narrative synthesis by use of thematic analysis. The main themes will be identified from the results/findings and discussion sections of the included studies. This will be an iterative process, whereby the systematic coding of the texts

for themes will be developed iteratively. Narrative synthesis will present the lived experiences of the family members from South of Asia related to a person with intellectual disabilities including the psychosocial impact. Synthesis will be presented as flow chart(s) and tables. Effect sizes, i.e. Cohen's d, will be reported in these tables where available and possible to do so.

Additional tables will be used to present data on the primary and secondary factors.

All tables will be supplemented with textual details.

Analysis of subgroups or subsets

Not applicable.

Contact details for further information

Meghana Wadnerkar Kamble

m.kamble@uea.ac.uk

Organisational affiliation of the review

University of East Anglia

www.uea.ac.uk

Review team members and their organisational affiliations

Dr Meghana Wadnerkar Kamble. University of East Anglia

Dr Karen Bunning. University of East Anglia

Type and method of review [1 change]

Narrative synthesis, Synthesis of qualitative studies, Systematic review

Anticipated or actual start date

06 July 2024

Anticipated completion date

02 November 2024

Funding sources/sponsors

This review forms part of the Leverhulme Research Fellowship awarded to the first author.

Grant number(s)

State the funder, grant or award number and the date of award

RF202443310. March 2024.

Conflicts of interest

Language

English

Country

England

Stage of review

Review Ongoing

Subject index terms status

Subject indexing assigned by CRD

Subject index terms

MeSH headings have not been applied to this record

Date of registration in PROSPERO

12 July 2024

Date of first submission

10 July 2024

Details of any existing review of the same topic by the same authors

Not Applicable

Stage of review at time of this submission

Stage	Started	Completed
Preliminary searches	Yes	No
Piloting of the study selection process	No	No
Formal screening of search results against eligibility criteria	No	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

The record owner confirms that the information they have supplied for this submission is accurate and complete and they understand that deliberate provision of inaccurate information or omission of data may be construed as scientific

misconduct.

The record owner confirms that they will update the status of the review when it is completed and will add publication details in due course.

Versions

12 July 2024