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A systematic review on how the presence of a family member with learning disabilities affects the lived experience of siblings.

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REVIEW TITLE AND BASIC DETAILS

Review title
A systematic review on how the presence of a family member with learning disabilities affects the lived experie of siblings.

Review objectives
How does the presence of a family member with learning disabilities affect the lived family experience of unaffected siblings?
How do parents perceive the affect of the presence of a family member with learning disabilities on the lived experience of unaffected siblings?

Keywords
Affect, ASD, Attitude, Autism, Autistic Spectrum Disorder, Brother, Cerebral palsy, Cognitively impaired, Design: qualitative methods such as interviews, Developmental disability, Down's Syndrome, Evaluation: Experience of having a sibling with a learning disability, Experience, Family, Father, focus groups, Fragile X Syndrome, I/dd, Idd, Impact, Intellectual disability, Intellectual disability, Learning disability, Mental retardation, mixed-methods, Mother, Neurodevelopmental disorder, Parents, Perspectives, Phenomenon of interest: living with a sibling with a learning disability, Prader Willi Syndrome, Research type: qualitative, Sample: parents, Siblings, Sister, SYNGAP1, unaffected siblings of an individual with a learning disability, Views, visual methods e.g. photo elicitation etc., Williams Syndrome

SEARCHING AND SCREENING

Searches
Searches will be conducted by principal researcher. Literature published in English, over a 10 year period from January 2013, shall be searched from the following databases:
MEDLINE
Embase
PsycINFO
CINAHL
Web of Science
ERIC
Scopus
Social Care Online
Google Scholar
OpenGrey
Forward and backward search to identify further literature through article references.
Keywords to be used in search:
(learning disability OR intellectual disability OR developmental disability OR neurodevelopmental disorder OR idd

OR i/dd OR Autistic Spectrum Disorder OR ASD OR Autism OR mental retardation OR cognitively impaired OR intellectual deficiency OR Down's Syndrome OR Williams Syndrome OR Fragile X Syndrome OR Cerebral Palsy OR SYNGAP1 OR Prader Willi Syndrome)
AND
(siblings OR brother OR sister)
AND
(Experience OR attitude OR views OR perspectives OR impact OR affect)
Plus second including
AND
(Family OR parents OR mother OR father)

Study design

Included:
Literature which includes qualitative methods (any form of qualitative data extraction, including visual). This includes mixed methods.
Excluded:
Literature which only include quantitative data

ELIGIBILITY CRITERIA

Condition or domain being studied

The literature reviewed will relate to experiences of parents and siblings who have cohabited with an individual (their child or sibling) who has a learning disability.

Population

Inclusion:
• Parents/carers of an individual with a learning disability and at least one additional unaffected child.
• Siblings of an individual with a learning disability.
Exclusion:
• Parents/carers or siblings who have a learning disability.
Inclusion eligibility criteria:
• Qualitative studies which consider positive or negative impacts of learning disabilities on unaffected siblings.
• The individual with learning disabilities must live in the family home – or did so until adulthood.
• Experiences must relate to unaffected siblings of an individual with a learning disability.
• The learning disability must have been since childhood and must involve impaired cognitive functioning.
• No geographical restriction imposed but the study must be published in English.
• Publications must be dated between 2013 and 2023.
Exclusion criteria:
• Disability which does not impair cognitive function.
• Article not in English Language.
• Published prior to 2013.
• Disability only evident from adulthood.
• Parents* who do not have at least one other child who does not have a learning disability.
• Siblings who have a learning disability.
• Parents who have a learning disability.
*The term ‘parents’ is used to refer to those with parental responsibility for the individual with learning disabilities. This may include adoptive parents, step-parents and grandparents.

Intervention(s) or exposure(s)

Experience: Experience of having a sibling with a learning disability, from either the parent’s perspective or the unaffected sibling’s perspective.

Comparator(s) or control(s)

Not applicable

Context

Context must relate to having lived in the same household as the individual with a learning disability, even if they no longer live within the same household.

OUTCOMES TO BE ANALYSED

Main outcomes

The main outcome will be the relating of experiences (or views, or perspectives) of parents and unaffected siblings in relation to the presence of an family member with a learning disability within the home.

Additional outcomes

Additional outcomes could include personal factors such as impacts upon mental wellbeing, self-esteem, behavioural, stress, empathy, tolerance/understanding, self-efficacy and fatigue as well as broader factors such as sense of belonging, isolation, social support, educational outcomes, financial struggles and quality of life.

DATA COLLECTION PROCESS

Data extraction (selection and coding)

Screening process

The main researcher will undertake initial searches using the previously stated databases. Results will be incl from all disciplines.

The following screening procedure will be adhered to:

• Databases searched using keyword previously defined in section 16.

• Collect all retrieved literature into Endnote reference manager.

• Screening process will be recorded using PRISMA flow diagram.

• Remove duplicates.

• Full references and abstracts of selected literature inputted into excel spreadsheet.

• Two reviewers will conduct independent screening of retrieved literature.

• Potential relevance will be ascertained by screening titles and abstracts using the inclusion/ exclusion criteria defined in section 19. Literature will be marked on spreadsheet as yes, no or unsure to indicate whether it may be relevant.

• Any disagreements between reviewers will be discussed and resolved.

• Full text will be obtained for literature marked yes or unsure.

• Skim through full text to establish relevance.

• Forward and backward search to identify further literature through article references. Any further literature will be screened using process stated above.

Data extraction

Extracted data will be summarised in a table based upon an adaptation of the NICE qualitative data extraction table: https://www.nice.org.uk/process/pmg4/chapter/appendix-k-examples-of-evidence-tables#k2-example-of-evidence-table-for-qualitative-studies

The data extracted will include details on participants/population, sampling, geographical location, study methodology (e.g. phenomenology, ethnography, narrative, grounded theory, case study) and methods (e.g. focus groups, interviews, photo elicitation etc.), phenomena of interest, setting, key themes, limitations and funding.

Risk of bias (quality) assessment

JBI critical appraisal checklist for qualitative research will be used.

PLANNED DATA SYNTHESIS

Strategy for data synthesis

Following a narrative synthesis of the experiences of parents and siblings, thematic analysis will be conducted, as outlined in Thomas and Harden (2008), to synthesise the essence of the lived experiences of parents and unaffected siblings of individuals with a learning disability. Data will be coded inductively, rather than deductively, to reduce the risk of bias. Data will be managed using NVivo-20.

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. BMC Medical Research Methodology, 8(1), 45. https://doi.org/10.1186/1471-2288-8-45

Analysis of subgroups or subsets
Not applicable

REVIEW AFFILIATION, FUNDING AND PEER REVIEW

Review team members

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Funding source
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TIMELINE OF THE REVIEW

Review timeline
Start date: 28 November 2023. End date: 31 July 2024

Date of first submission to PROSPERO
08 December 2023

Date of registration in PROSPERO
08 December 2023

CURRENT REVIEW STAGE

Publication of review results
The intention is to publish the review once completed.The review will be published in English

Stage of the review at this submission

Review stage	Started	Completed
Pilot work		
Formal searching/study identification		
Screening search results against inclusion criteria		
Data extraction or receipt of IP		
Risk of bias/quality assessment		
Data synthesis		

Review status
The review is currently planned or ongoing.

ADDITIONAL INFORMATION

PROSPERO version history

- Version 1.0 published on 08 Dec 2023

Review conflict of interest
None known

Country
England

Medical Subject Headings
Family; Health Status; Humans; Learning Disabilities; Parents; Siblings

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