Citation: Prest, K., Barnicot, K., Drew, S., Hurt, C., Nicklin, D., Harden, A. & Heys, M. (2026). Group Programmes to Improve the Skills, Confidence and Wellbeing of Caregivers of Children with Neurodisability: a Systematic Review of Effects. Journal of Developmental and Physical Disabilities, doi: 10.1007/s10882-026-10059-7

Journal of Developmental and Physical Disabilities
https://doi.org/10.1007/s10882-026-10059-7

Group Programmes to Improve the Skills, Confidence and Wellbeing of Caregivers of Children with Neurodisability: a Systematic Review of Effects

Kirsten Prest[1,2] · **Kirsten Barnicot**[1] · **Stewart Drew**[4] · **Catherine Hurt**[1] · **David Nicklin**[1,3] · **Angela Harden**[1] · **Michelle Heys**[2,4]

Received: 24 September 2025 / Accepted: 19 March 2026

Abstract

Caregiver skills training programmes are well-researched in the fields of autism and intellectual disability, but children with motor disorders such as cerebral palsy remain underrepresented despite their high prevalence. These caregivers face unique challenges, and group programmes may provide family-centred care through information provision, problem-solving and peer support. Systematic searches of five databases (CINAHL, Medline, Embase, PsychINFO and ERIC) were conducted for interventional studies of group programmes aiming to improve the skills, confidence and wellbeing of caregivers of children with neurodisability focusing on motor disorders. Data were extracted on study and intervention characteristics and outcomes. Risk of bias was assessed, effect sizes calculated, and results summarised descriptively using forest plots. Of 6093 studies identified, 21 studies met inclusion criteria (nine randomised-controlled trials, two quasi-experimental and ten pre-post designs). Most reported on programmes developed in resource-constrained settings and addressed caregiver skills, coping strategies, or health-promoting behaviours. Outcomes were grouped according to caregiver wellbeing, caregiver skills and confidence, and social support and family functioning. Child outcomes were reported separately. Most caregiver outcomes showed positive effects, though most studies had high risk of bias due to self-reported outcomes and lack of blinding of intervention allocation and outcome measurement. Group-based training programmes show promise for improving caregiver skills and wellbeing. Clinicians and stakeholders in high-income countries may learn from these innovations in low-resource settings. Future research should strengthen protocol reporting, address attrition, control for confounding factors, and establish a core set of caregiver-reported outcomes to better capture programme impact.
Systematic review registration:
PROSPERO registration CRD42024595002.

Angela Harden and Michelle Heys contributed equally to this work.

Extended author information available on the last page of the article

Keywords Caregiver · Parents · Neurodisability · Cerebral palsy · Childhood disability · Community-based programmes · Support groups · Family functioning

Background

'Neurodisability', often referred to as 'neurodevelopmental disabilities', can be described as an umbrella term for a heterogeneous group of long-term health conditions that result in functional difficulties following a neurological cause such as injury to the brain or neuromuscular system (Morris et al., 2013). This definition is kept intentionally broad to include children without specific diagnoses, however cerebral palsy (CP) is often used as an exemplar condition (Rosenbaum, 2007). Cerebral palsy affects 1.6 per 1000 live births in high-income countries (HICs) and an estimated 3.4 per 1000 in low- and middle-income countries (LMICs) (McIntyre et al., 2022). The Global Burden of Disease- WHO Rehabilitation Need Estimator Database has suggested a higher global prevalence of 0.9% for children with moderate to severe motor impairments. This higher figure likely reflects the inclusion of cases from LMICs, where children with CP and related conditions are often underrepresented in the wider literature (Olusanya et al., 2023).

Almost all children with CP or other neurodevelopmental disabilities affecting motor function present with at least one co-occurring condition, with many having multiple and complex diagnoses that require simultaneous management (Hollung et al., 2020). Examples range from autism (Leader et al., 2022), Attention Deficit and Hyperactivity Disorder (ADHD) (Påhlman et al., 2021), challenges with sleep, the gastrointestinal system, behaviour and pain (Horwood et al., 2019), to visual impairment (Rauchenzauner et al., 2021), and epilepsy (Pavone et al., 2021). Managing the multitude of needs and accompanying health systems involves a high burden of care for the children's caregivers (Nygård & Clancy, 2018). Caregivers in this paper refers to the parent of the child or the person primarily involved in caring for the child. Caregivers frequently present with reduced physical and psychological health, which impacts on their Quality of Life (QoL) (Cohn et al., 2020; Gokcin Eminel et al., 2021; Pousada et al., 2013; Yılmaz et al., 2013).

Family-centred care refers to the way in which families and healthcare professionals work together to make decisions using principles relating to collaboration, negotiation, information sharing, respecting differences, and understanding the family and community context (Kuo et al., 2012). It is well-established that family-centred care is the gold standard for this population to ensure that healthcare professionals work in partnership with families and children (Rosenbaum et al., 1998, 2024; King et al., 1999; Kuhlthau et al., 2011). This contrasts with the biomedical model of disability, assisting healthcare professionals to look beyond the inherent diagnosis of the child (Rosenbaum & Novak-Pavlic, 2021) and rather at the holistic picture of the family, community and wider society (Rosenbaum & Gorter, 2012). Family-centred care has been found to be significantly inversely associated with parent stress (Dempsey et al., 2009). A key component of family-centred care is the provision of information about the diagnosis and specific information about the child, which families have reported to be lacking (Prest et al., 2024a; Shevell et al., 2019). In England and Wales in the

UK, the National Institute for Health and Care Excellence (NICE) clinical guidelines for cerebral palsy in those under 25 years state that caregivers of children with cerebral palsy require timely and up-to-date information about their child's diagnosis, prognosis, expected development, co-occurring conditions, availability of equipment, financial support, social care, educational placements, and transition to adults' services (National Institute and for Health and Care Excellence (NICE), 2017). An identified gap in service delivery is failure to provide specific information about the child, such as clinicians not explaining results of assessments to parents/caregivers, or therapists not explaining what is happening for the child in a session (Terwiel et al., 2017).

The Peninsula Cerebra Research Unit (PenCRU) in the UK have proposed a model for working in partnership with families of children with neurodisability to provide clear, accessible, relevant and up-to-date information (McHugh et al., 2013). However, the most significant component of family-centred care moves beyond the pure provision of information. It involves working in partnership to enable parents and caregivers to feel competent to request information and support, and to confidently advocate for their child's needs (McCarthy & Guerin, 2022). This forms part of parent activation which refers to their ability to manage, coordinate and advocate for their child's healthcare needs (Mirza et al., 2018). When parents are supported in developing their skills and confidence in these areas, they are able to cultivate a more collaborative partnership with healthcare professionals, resulting in better outcomes for the child (McDowell, 2021).

Supporting caregivers to improve their skills and confidence to care for their child with a neurodisability is an example of a low-cost intervention. This is pertinent for low- and middle-income countries (LMICs), where for example, the prevalence of CP is higher due to factors such as reduced access to skilled health professionals both at birth and in the post-natal period, birth asphyxia, neonatal infections, and untreated jaundice (Donald et al., 2014). Low-cost interventions are also relevant to high-income countries (HICs), given constraints such as the National Health Service (NHS) workforce crisis in the UK (The King's Fund, 2024).

Much of the literature around caregiver skills training lies within the fields of autism and intellectual disability, rather than motor disorders like CP. Within these fields, positive evidence has been found for the effectiveness of caregiver skills training for both caregivers and children (Chakraborti et al., 2021; Reichow et al., 2024). Elements of caregiver skills training have been researched in the field of neurodisability. For example, parent-delivered therapy, as opposed to resource-heavy therapist-delivered sessions, has been found to be effective when trusting relationships are built, when parents have strong support, and when all parties are motivated (Lord et al., 2018). Parent education, including co-designed home programmes and coaching, allows for self-efficacy to be built, along with a willingness to learn. This not only improves therapy adherence and child outcomes, but can also influence parental wellbeing (Harniess et al., 2022; Lord et al., 2018). It may be particularly valuable to focus on groups for caregivers of children with neurodisability, since these can provide valuable opportunities for peer support and community building through problem-solving, learning from each other and forming a sense of belonging (Shilling et al., 2013).

Although studies and reviews are moving towards a “noncategorical approach” to health services research, whereby mixed groups are included of children with varied long-term health conditions (Nagel et al., 2008), having a heterogenous group with different diagnoses can be a barrier to the functioning of peer support groups, particularly when there may be more services and funding opportunities for children with autism (Hammarberg et al., 2014; Prest et al., 2024a). Although there are examples of successful group programmes focusing on improving the skills, confidence and wellbeing of caregivers of children with diverse needs (Borek et al., 2018; Miller et al., 2023), this systematic review focuses on children with physical disabilities that have a neurological cause. This is an attempt to address the underrepresentation of these families in neurodevelopmental research.

Systematic review registers revealed no prior or ongoing reviews with the same objective, although several related reviews were identified (Supplementary file 1). Only one review conducted by He et al. (2024) focused specifically on group-based programmes, many of which are highly relevant to this review although studies were limited to LMICs and covered a broad range of diagnoses. The review conducted by Whittingham et al. (Whittingham et al., 2011), focused on improving children’s behaviour and parenting style, which differs from the aims of this review to explore programmes that improve caregivers’ knowledge and skills in how to care for their child, and themselves. The reviews conducted by Irwin et al. (Irwin et al., 2019), Branjerdporn et al. (Branjerdporn et al., 2022) and Poojari et al. (Poojari et al., 2024) focused on exploring important elements of family-centred care and peer support for this population of interest, but did not focus on group delivery. Novak-Pavlic and colleagues’ ongoing systematic review (Novak-Pavlic et al., 2022) is also relevant for this study, however, there remains a broad focus on all diagnoses without extracting specific data relevant to children with neurodisability, particularly motor disorders such as cerebral palsy. Finally, Reichow and colleagues’ systematic review (Reichow et al., 2024) aimed to review skills training programmes for caregivers of individuals with neurodevelopmental disorders. However, the review excluded children whose primary diagnosis was a motor disorder, such as cerebral palsy whereas the systematic review described in this paper aims to focus on those children who were excluded.

Objectives

This review aims to answer the question; ‘Do group programmes aimed at caregivers of children with neurodisability characterised by physical impairment improve caregiver wellbeing, skills and confidence?’.

The question can be framed using PICO:

- Population: caregivers of children with neurodisability (focusing specifically on physical disabilities)
- Intervention: group programmes (operationalised as a structured intervention delivered to more than one caregiver simultaneously, comprising of more than one session)

- Comparisons: (if any) no treatment or usual care
- Outcomes: relating to the skills and confidence required to care for their child along with outcomes relating to their own wellbeing.

The review objectives are to:

1. Understand the types of group programmes that focus on caregiver skills training, increasing knowledge and confidence and improving wellbeing for caregivers of children with neurodisability.
2. Systematically review the evidence on the caregiver group programmes described above, to determine pre-post changes and on caregiver outcomes such as confidence/ self-efficacy, empowerment, wellbeing, health literacy and quality of life.

Methods

The review is registered with the PROSPERO database for systematic reviews (CRD42024595002) and the protocol has been made publicly available (Prest et al., 2024b). The review has been reported in accordance with the guidelines outlined in The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Page et al., 2021). Deviations from the pre-specified protocol are described at the end of the methods section.

Study Selection

Types of Studies

Randomised controlled trials (RCTs), quasi-experimental studies and observational studies were included in this review. The rationale for not solely including RCTs is that there have not been many completed in this field, particularly as programmes for parents/carers of children with neurodisability, for example cerebral palsy, have been under researched in comparison to children with autism or other developmental disabilities (Reichow et al., 2024). Including other designs in the study allowed the review to describe more fully the current scope of the evidence base. No date restrictions were applied to the search in order to capture the full breadth of available evidence and to trace the development of group-based caregiver programmes over time.

Studies were restricted to those published or translated into English, due to limited resources for translation.

Types of Participants

Inclusion Criteria

Studies that recruited parents or primary caregivers of a child (< 18 years) who have a diagnosis of neurodisability were included. As described in the introduction, the term ‘neurodisability’ in this instance refers to children or young people with a long-term health condition and functional impairments due to a neurological cause. In addition, children and young people in this review needed to have physical difficulties with movement and posture. They may have additional co-occurring conditions, but their primary diagnosis should be a motor disorder due to injury in the brain or neuromuscular system, either present at birth or acquired. Cerebral palsy is an example diagnosis, but other metabolic and genetic disorders can mimic CP. Further examples may include Duchenne Muscular Dystrophy, Rett Syndrome, brain injury, spina bifida, Spinal Muscular Atrophy (SMA), and occasionally children are diagnosed with Syndrome Without A Name (SWAN). It was also decided that studies would be excluded if their population included caregivers of children with acquired brain injuries that resulted primarily in behavioural and social communication difficulties, particularly when the intervention targeted children's behaviour.

Exclusion Criteria

Parents/ caregivers of children whose primary diagnosis is linked with behaviour (e.g. autism, Attention Deficit and Hyperactivity Disorder (ADHD), dyspraxia, or Tourette syndrome), cognition (e.g. intellectual disability, learning disability), or sensory differences (e.g. blindness, deafness) were excluded, although it was expected that many had these as co-occurring diagnoses. These exclusion criteria were applied to ensure the review focused primarily on programmes targeting families of children with motor difficulties, enabling more meaningful interpretation of findings within this population.

Types of Settings

Studies were not excluded based on where they were delivered. We included studies based in a range of settings including, but not limited to, primary care clinics, child development centres, schools, children's centres, hospices or hospitals.

Types of Interventions and Comparators

We included any group intervention or programme aimed at parents or caregivers of children and young people with neurodisability that had a purpose of improving caregiver skills, confidence, empowerment, health literacy, quality of life, physical or psychological wellbeing. For the purposes of this review, a group programme was operationally defined as a structured intervention delivered to more than one caregiver simultaneously, comprising of more than one session. The programmes could include the children and other members of the family, but there needed to be an element which focused particularly on the skills, confidence and/or wellbeing of the caregivers.

Types of Outcome Measures

We aimed to evaluate the effectiveness of the programmes for caregiver outcomes, including quality of life, physical and psychological health, skills, confidence, and/

or knowledge (primary outcomes). We also extracted data relating to child and family functioning outcomes (secondary outcomes). In terms of outcome measures, we included any quantitative measure reported by study authors, with no restriction on the specific tools or instruments used. Although sometimes used interchangeably, for the purposes of this review, self-efficacy and confidence refer to a caregiver's belief in their ability to perform specific caregiving tasks (Bandura, 1977), whilst empowerment is understood as a broader concept encompassing an active, informed and collaborative role in care across family, service and community levels (Koren et al., 1992).

Search Strategy

We searched five electronic databases: CINAHL (EBSCOhost), Medline (EBSCOhost), Embase (Ovid), APA PsychINFO (EBSCOhost), and ERIC in October 2024. Reference lists of the reviews described in Supplementary file 1, along with the included studies were hand searched and checked for eligibility. Potential studies were also found through expert contacts and relevant organisations in the field.

The search strategy was developed with City St George's, University of London's librarian for the School of Health and Medical Sciences. Subject headings and key words relating to the population, intervention and outcomes were included in the search. Specific keywords were drawn from Novak-Pavlic's systematic review (Novak-Pavlic et al., 2022) relating to our population of interest. Table 1 demonstrates an example search strategy for CINAHL.

Selection Process

The results from the literature searches were collated and uploaded onto EPPI-Reviewer (Thomas et al., 2023), which integrated with Zotero referencing manager. EPPI-Reviewer is a web-based software programme for managing and analysing data in literature reviews. Duplicates were removed, and titles and abstracts screened against the eligibility criteria by one main reviewer (KP). A second reviewer (SD) screened titles and abstracts from 10% of the results to ensure consistency. Any discrepancies were discussed between the two reviewers, and a third senior reviewer (MH) was available for consultation if consensus could not be reached. Where relevant information needed to determine eligibility or extract data was missing or unclear, study authors were contacted by email by the main reviewer (KP), with one follow-up email sent if no response was received. Where studies identified during the search alluded to forthcoming papers reporting relevant outcomes, study authors were contacted to request these upon publication, provided the original study had already been identified through the systematic search.

Data Extraction

Data extraction was carried out using a data extraction form developed using guidance from the Cochrane Handbook for Systematic Reviews (Higgins et al., 2011).

Table 1 CINAHL search strategy

	Search terms
(P) Population: Parents/ caregivers of children with neurodisability	**Parents/ Caregivers:** 1. (MH "Parents") OR (MH "Fathers") OR (MH "Mothers") 2. (MH "Caregivers") 3. AB parents or mothers or fathers or carers or caregivers 4. 1 OR 2 OR 3 **Children with neurodisability** 5. (MH "Child") OR (MH "Adolescence") OR (MH "Child, Preschool") OR (MH "Infant") OR (MH "Infant, Newborn") OR (MH "Infant, Low Birth Weight") 6. AB child* or infan* or adolescen* or teenage* or "young people" or babies or youth 7. 5 OR 6 8. (MH "Cerebral Palsy") OR (MH "Hypoxia–Ischemia, Brain, Neonatal") OR (MH "Hypoxia–Ischemia, Brain") 9. (MH "Brain Injuries") 10. (MH "Motor Skills Disorders") 11. AB "cerebral palsy" or AB cp or AB "spastic quadriplegi*" or AB "brain injur*" or AB "Hypoxia–Ischemia" or AB hie or AB "complex neurodisabilit*" or AB "motor disorder" or AB "neurological condition" or AB "neurological disorder" or AB "neurodevelopment* dis*" or AB hemiplegi* or AB diplegi* or AB dyskinetic or AB dystoni* or AB "spina bifida" or AB "muscular dystroph*" or AB Duchenne or AB "Rett's Syndrome" or AB "spinal muscular atrophy" or AB sma or AB "syndrome without a name" 12. 8 OR 9 OR 10 OR 11 13. 7 AND 12
(I)Intervention: Caregiver group programmes	14. (MH "Program Implementation") OR (MH "Community Programs") OR (MH "Adult Education") OR (MH "Support Groups") OR (MH "Family Centered Care") OR (MH "Peer Counseling") 15. AB program* or service or intervention or educat* or training or treatment or therap* or "support group*" or "peer counseling" or "peer counselling" or peer-to-peer or "peer to peer" or "family centered care" or "family centred care" or "skills training" 16. 14 OR 15
(O) Outcomes:	17. (MH "Confidence") OR (MH "Psychological Well-Being") OR (MH "Empowerment") OR (MH "Health Literacy") 18. AB skills or AB confiden* or AB "self efficacy" or AB self-efficacy AB wellbeing or AB "well being" or AB well-being or AB "mental health" or AB psychological or AB "quality of life" or AB qol or AB empower* or AB "health literacy" or AB activation or AB "parent activation" or AB motivat* or AB satisfaction or AB "family functioning" 19. 17 OR 18 20. 4 AND 13 AND 16 AND 19

MH Indexing term (CINAHL heading); *AB* Terms in the abstract

Study authors were contacted if further information was required. The following data items were collected:

1. General information: Authors details, date published, place of publication, and location.
2. Study characteristics: Study aim, design, start and end dates, duration of participation, and ethical approval.

3. Participants: Description of population (the parents/caregivers and their children's diagnoses including level of severity and co-morbidities), setting, inclusion and exclusion criteria, methods of recruitment, sampling strategy, randomisation, total number at start of study, baseline imbalances, withdrawals and exclusions, age, sex, ethnicity
4. Intervention: Description of intervention using an adapted version of the Template for Intervention Description and Replication (TIDieR) Checklist (Hoffmann et al., 2014). Items include rationale or goal of intervention, materials required, activities included, the provider, mode of delivery, location, dosage, and costs.
5. Outcomes: The primary outcomes of interest related to the parent/caregiver. In line with the pre-specified protocol, outcomes were grouped a priori into two categories through discussion between the review authors. The categories were *caregiver wellbeing* outcomes (e.g. anxiety, depression, stress, pain, fatigue, quality of life), and *caregiver skills and confidence* outcomes (e.g. skills, knowledge, self-efficacy, empowerment and adaptation to the child). A third category of caregiver outcomes was formed during the review process that related to *social support and family functioning* as they did not fit easily into the first two groups. Although these outcomes did not directly address the primary research question, they were felt to meaningfully contribute to understanding the broader effects of the programmes on caregivers and their families. Outcomes related to the child were extracted too.
6. Information about the above outcomes: Timepoints measured and reported, outcome definition and whether it was validated, the person measuring, scales (upper and lower limits), sample size, type of outcome (dichotomous or continuous), results (numbers or statistics for dichotomous data and mean and standard deviation for continuous data).

Template data collection forms and data extracted from excluded studies can be made available upon request.

Risk of Bias

The Cochrane Risk of Bias-2 tool (RoB 2) (Sterne et al., 2019) and the Risk Of Bias In Non-randomised Studies–of Interventions–I (ROBINS-I) (Sterne et al., 2016) tool were used to assess the risk of bias for included studies. The ROBINS-I is a domains-based tool using signalling questions, with guidance provided on the interpretation of judging each domain and overall risk of bias (Sterne et al., 2016).

The risk of bias assessments were carried out by two independent reviewers for each of the study outcomes (KP and either SD or DN). Any disagreements were discussed, and a third reviewer brought in if consensus could not be reached. Reporting bias was assessed by referring to the protocol of the study (if available), to ensure that the pre-specified outcomes were sufficiently reported in the results.

Data Synthesis and Analysis

A meta-analysis was not appropriate for this review due to the diverse nature of the outcome measures and interventions in the included studies (McKenzie & Brennan, 2024). Data synthesis instead followed the 'Synthesis without meta- analysis (SWiM) guideline' (Campbell et al., 2020). First, results from all studies were grouped according to three broad categories of outcomes relating to either (1) caregiver wellbeing outcomes, (2) caregiver skills and confidence outcomes, and (3) social support and family outcomes.

Means and standard deviations were extracted for all outcomes in the included studies. Data from continuous outcomes were converted to a Standardised Mean Difference (SMD) (Cohen's d effect size) with a Standard Error (SE) using slightly varying formulas for independent-groups designs and single-group pre-post designs (Morris & DeShon, 2002). Effect sizes were interpreted as no effect (<0.2), small (0.2–0.49), medium (0.5–0.79) and large (≥ 0.8) (Cohen, 1988). For the few studies that reported dichotomous outcomes, the pre-post change in proportion was converted to Odds Ratios (ORs) and then to SMDs (Borenstein et al., 2009). If results were presented as medians and interquartile ranges, then means and standard deviations were estimated from these (Wan et al., 2014). Confidence intervals (CIs) for each SMD were calculated.

SMDs were adjusted so that positive values demonstrated improvement in the outcome (e.g. a lower score on a depression scale was adjusted to be a positive value). The SMDs and CIs were then inputted to create a forest plot visually presenting the data under the three caregiver outcome categories (1) caregiver wellbeing outcomes, (2) caregiver skills and confidence outcomes, and (3) social support and family outcomes. The SMDs are presented separately (often within each forest plot) for studies with independent-group designs (RCTs and quasi experimental designs) and studies with single group pre-post designs. Data relating to child outcomes were extracted and descriptively presented in a summary table. In the narrative synthesis of these findings, more weight is given to those with larger numbers and a lower risk of bias (McKenzie & Brennan, 2024).

The GRADE approach was applied to the most frequently reported outcomes (five or more studies reporting on one outcome) to assess the confidence in the effect estimates (Schünemann et al., 2013). The final GRADE score representing certainty of the evidence was given ('very low', 'low', 'moderate' or 'high') depending on the quality of the evidence (study design, risk of bias, inconsistency of results, indirectness of evidence, imprecision and other factors such as publication bias).

Descriptions of the intervention components and mechanisms were framed according to the TIDieR Checklist (Hoffmann et al., 2014).

Protocol Deviations

Post-protocol, several modifications were made including (i) data were synthesised using the SWiM guideline rather than meta-analysis, with effect sizes converted to SMDs and displayed in forest plots, (ii) outcomes were grouped under three domains instead of the two originally specified, (iii) child outcomes were additionally extracted and presented descriptively, and (iv) the GRADE approach was applied to assess the certainty of evidence for the most frequently reported outcomes.

Results

Selection of Studies

A total of 9583 studies were identified during the initial search of databases, including CINAHL (1537), MEDLINE (2439), Embase (3441), APA PsychINFO (1386) and ERIC (666). Additional titles were identified through searching reference lists of similar review topics, included studies and through contacts in the field (114). After duplicates (3490) were removed, 6093 papers remained and were screened based on title and abstract. A total of 64 studies underwent full-text eligibility screening, resulting in 21 studies being included for this review (see Fig. 1).

Study Characteristics

Out of the 21 studies, including a total of 1491 caregivers, nine were randomised controlled trials, two were quasi-experimental design and ten were single-group pre-post designs (often part of a wider mixed method study) (Table 2 study characteristics). Only four studies were set in high-income countries (HICs) (Australia, Hong Kong and United States) with the majority being in low-middle income countries (LMICs). Five of these studies were from South Asia (Bangladesh and India), four from the Middle East and North Africa (Iran and Egypt), one from Europe (Turkey), one from Latin America (Colombia) and six were based in Sub-Saharan Africa (Tanzania, Uganda, South Africa and Ghana). Most studies ($n = 16$) included children with a diagnosis of cerebral palsy and of these, ten studies reported the children being classified as having moderate to severe impairments. Whilst the inclusion criteria intentionally narrowed the broad umbrella of neurodisability to those with physical and motor impairments, they were not restricted to CP specifically. The predominance of CP in the included studies therefore reflects the fact that it is the most common form of childhood physical disability and is often used as an exemplar condition within the broader umbrella of motor neurodisability. The other five studies referenced diagnoses such as neurodevelopmental impairments or special healthcare needs, of which a large proportion of the children had motor difficulties. Thirteen studies reported the mean or median age of the child to be 5 years or under (one study did not report child age). There were wide ranges in the number of participants included in each study with the smallest studies including 5 or 6 participants and the largest including 251 participants. Twelve studies mentioned that the majority of parents/caregivers were female. Most studies were published between 2018–2025, however two were published considerably earlier (in 1985 and 2000).

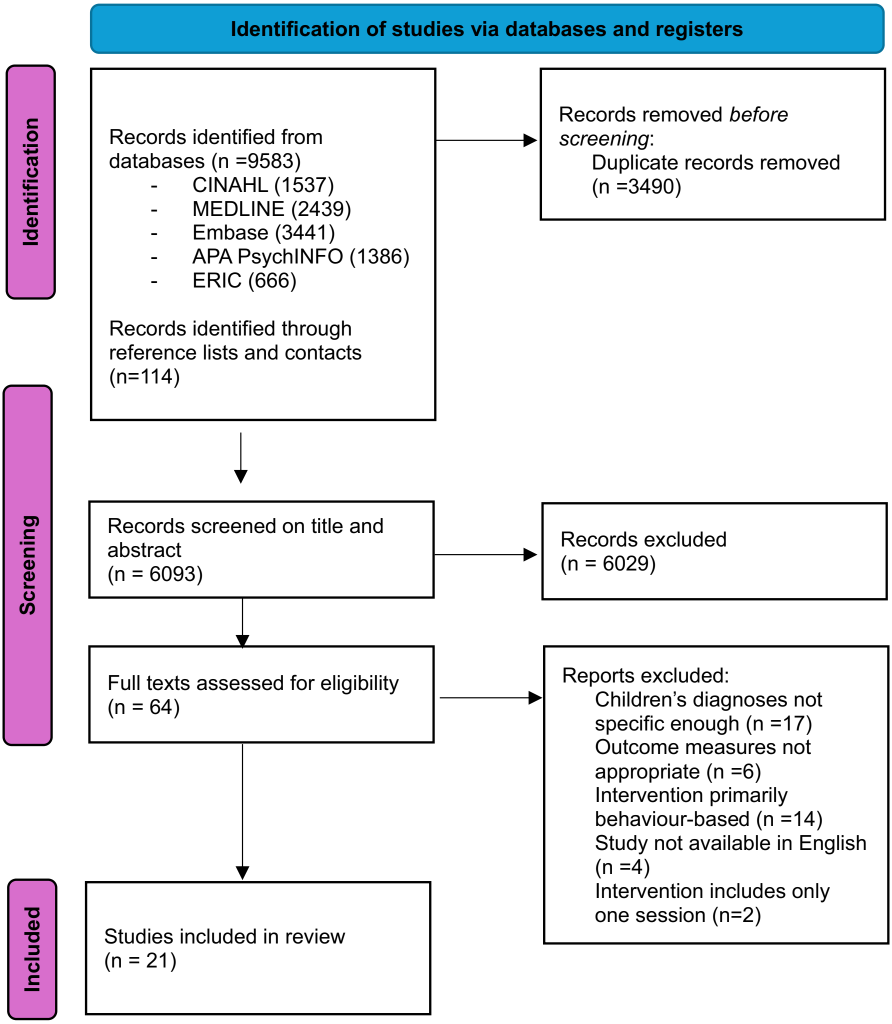


Fig. 1 PRISMA flow diagram

Intervention Characteristics

The interventions in the 21 included studies tend to be complex interventions with multiple components that were often located in several settings and provided by a variety of professionals, community workers or parents with lived experience (Supplementary file 2). From an overarching perspective, 15 studies reported on a type of intervention that included learning or practising skills about how to care for their child while providing support to each other in a group. Two of these were focused specifically on feeding and another two reported on the same intervention. Five studies described interventions focusing on providing psychological support and promot-

Table 2 Study characteristics

Study (year)	Country	Study design	Setting	Participants	Age of parents/ Caregivers (years)	Age of children	Diagnoses of children and severity	Further information about caregivers presented in study report
Adams et al. (2011)	Bangladesh	Pre-post intervention study with no control	Child Development and Neurology Unit of the Dhaka Shishu (Children's) Hospital and in three slums of Dhaka	22 caregivers of children with CP (ages 1- 11 years) of moderate to severe disability (GMFCS levels III-V) with feeding difficulties	Not reported	M (SD) = 3.9 (2.3) years	CP mostly with spasticity and GMFCS level V	74% of caregivers scored above the threshold for psychological disturbance at baseline
Alibakhshi et al. (2024)	Iran	Randomised Controlled Trial	Rehabilitation clinics in Semnan	52 mothers of children with CP	Intervention group: M (SD) = 32.04 (4.42) Control group: M (SD) = 31.16 (2.98)	Range = 2–11 years	CP mostly spasticity and GMFCS levels III-V	In order to be included, mothers had to be married and have a primary education level of literacy
Al Imam et al. (2022)	Bangladesh	Randomised Controlled Trial	In the community in three rural subdistricts of Sirajganj district	251 primary caregivers of children with CP under 5 years with the family classified as ultra-poor according to World Bank criteria	Not reported	M (SD) = 3.5 (1.1) years	CP mostly GMFCS levels III-V	49% of the children's mothers and 43% of fathers had an education level of secondary and above
Alirahmi et al. (2023)	Iran	Randomised Controlled Trial	Occupational Therapy centres in the city of Ilam	60 mothers of children with CP who scored highly on a preliminary screening for depression and rumination	M = 34.13 (no SD)	Not reported	CP	Mothers' education levels ranged from diploma to masters
Asige et al. (2025a)	Uganda	Randomised Controlled Trial	65 villages in Eastern Uganda	94 caregivers of children/young people with CP	Ranges: 26–45 (46%) 46–65 (42%) 66–85 (12%)	Range = 2–23 years	CP with various levels of severity spread across the five levels of the GMFCS and MACS scales	Most participants were mothers (53%), followed by grandmothers (27%). 51% were subsistence farmers, 68% were married, 28% had secondary education or higher, 71% lived in a rural area

Table 2 (continued)

Study (year)	Country	Study design	Setting	Participants	Age of parents/ Caregivers (years)	Age of children	Diagnoses of children and severity	Further information about caregivers presented in study report
Atilgan et al. (2021)	Turkey	Randomised Controlled Trial	Paediatric rehabilitation Centre in Batman—a major rehabilitation centre in this region	43 mothers of children with Special Healthcare Needs suffering from chronic low back pain	M (SD) = 34.7 (7.1)	M (SD) = 5 (2.6) years	Mixed diagnoses but mostly CP (37%) followed by Down's Syndrome, Developmental Delay and Spina Bifida	More than half the mothers spent 12 h or more per day caring for their child
Bourke-Taylor et al. (2019)	Australia	Pre-post intervention study with no control (part of wider mixed methods study)	Mothers recruited from disability organisations and specialised schools supporting students with disabilities	36 mothers of school-aged children with childhood disabilities	M (SD) = 44.3 (6)	M (SD) = 10.1 (4) years	Mixed diagnoses but 61% had CP and 36% of children needed to be lifted during care	Nearly two-thirds of mothers had professional training, a degree or higher. Most (86%) were partnered. Half (50%) reported that they had been diagnosed with a health condition since their child's diagnosis and half had a mental health diagnosis
Fung et al. (2011)	Hong Kong	Pre-post intervention study with no control	Follow-up clinics at the Department of Orthopaedics and Traumatology, the Duchess of Kent Children's Hospital, Hong Kong	Six primary caretakers of children with CP	Range = 39–56	Range = 8–19 years	CP either hemiplegia, dyskinetic CP or quadriplegia and mostly at Special Schools	All female, mostly married and not in paid employment with varying levels of education
Hashem et al. (2018)	Egypt	Pre-post intervention study with no control	Outpatient clinic and neurological department at Mansoura University Children's Hospital	65 caregivers of children with CP	M (SD) = 30.4 (7.5)	M (SD) = 6.19 (4.60) years	CP, with most having a dyskinetic type of CP	79% were housewives living in rural areas, less than half had secondary education (46%). Most had multiple children and 62% weren't related to their husbands

Table 2 (continued)

Study (year)	Country	Study design	Setting	Participants	Age of parents/ Caregivers (years)	Age of children	Diagnoses of children and severity	Further information about caregivers presented in study report
Karim et al. (2021)	Bangladesh	Quasi-experimental design	Early intervention and rehabilitation centre in a rural subdistrict in Northern Bangladesh	156 caregivers of children with CP identified through the Bangladesh CP Register	Not reported	Intervention group: M (SD) = 4.3 (2.9) years Control group: M (SD) = 11.1 (4.0) years	CP	Most participants lived in mud houses without drinking tap water. Many caregivers were illiterate, and few had secondary education. Most mothers were unemployed; fathers worked in garments, agriculture, or business
McConachie et al. (2000)	Bangladesh	Randomised Controlled Trial	Two settings in the wider study but only the urban groups (near Dhaka) met inclusion criteria	27 children with cerebral palsy and their mothers	M (SD) = 26.3 (6)	M (SD) = 34.4 (10.9) months	CP,65% were considered moderate -severe and 54% had severe malnourishment	19% of mothers had no education and 55% of families had no land
McMillan et al. (2020)	Australia	Quasi-experimental design using a modified stepped wedge cluster	The Royal Children's Hospital (RCH) in Melbourne Australia	26 parents of children with severe CP aged 12 months to 9 years	Not reported	Range = 12 months—9 years	CP with GMFCS levels IV or V, 31% had epilepsy and 69% were fully tube fed	77% of parents were female and 80% were married. 65% were not born in Australia. 61% were not in paid employment
Mlinda et al. (2018)	Tanzania	Randomised Controlled Trial	CP clinic at Muhimbili National Hospital (MNH) in Dar es Salaam, Tanzania	110 children with moderate—severe CP under 5 and their caregivers	M (SD) = 30.8 (5.3)	M (SD) = 28 (12.3) months	CP, around half with spasticity and all moderate—severe	56% of caregivers had an education level of secondary or above. Just over half of caregivers were employed
Muthukaruppan et al. (2022)	India	Pre-post intervention study with no control	A non-governmental organization in South India (ASSA) based in 8 rural locations (blocks) in the District of Tirunelveli, State of Tamil Nadu	135 primary caregivers of children with CP who were able to understand Tamil	Not reported	M (SD) = 3 (1.5) years	CP mostly GMFCS levels IV and V	Most caregivers were female
Nanyunja et al. (2022)	Uganda	Mixed methods randomised pilot and feasibility trial	Two sites in Uganda—one urban (Kampala) and one rural (Nakaseke) neither of which had existing formal support services for children with developmental disabilities	126 caregivers of children with moderate-severe neurodevelopmental impairment	Not reported	Median (IQR) = 9.5 (7.5—10.2) months Range = 6—12.6 months	Moderate—severe neurodevelopmental impairment	62% of mothers had secondary education or higher. 70% of fathers had secondary education or higher

Table 2 (continued)

Study (year)	Country	Study design	Setting	Participants	Age of parents/ Caregivers (years)	Age of children	Diagnoses of children and severity	Further information about caregivers presented in study report
Nobakht et al. (2020)	Iran	Randomised Controlled Trial	Occupational therapy clinics in Tehran, Karaj, and Shiraz, (three main cities of Iran)	91 mothers of children with CP aged 4–12 years	M (SD) = 33.6 (5.8)	M (SD) = 82.62 (29.87) months	CP- GMFCS levels III, IV and V	35.2% of caregivers had university education and 91.2% were not in paid employment
Smythe et al. (2023)	Colombia	Pre-post intervention study with no control (part of wider mixed methods study)	Community primary school in Cali, Valle del Cauca	34 caregivers of children with congenital Zika syndrome, CP or toxoplasmosis	Ranges: 15–20 (9%), 21–25 (32%), 26–29 (18%), 30–39 (32%), 40–60 (6%), 61 + (3%)	M (SD) = 26 (11) months	Congenital Zika syndrome (commonly includes spasticity, seizures, eating difficulties, irritability, ocular anomalies, hearing loss, and abnormal neuroimaging). 41% had a diagnosis of epilepsy	97% of caregivers were female, 38% of caregivers attended senior school, 15% had job training and none had attended university. 65% of caregivers were unable to work in the previous month. 74% were married or in a civil partnership. 29% owned their home
Tann et al. (2021)	Uganda	Pre-post intervention study with no control (part of wider mixed methods study)	Mulago National Referral Hospital in Kampala	28 caregivers of infants (under 2 years) with moderate to severe neurodevelopmental impairment	Not reported	M (SD) = 6.7 (0.7) months	Moderate—severe neurodevelopmental impairment. 32% had feeding difficulties, 11% had acute malnutrition and a third were underweight	Not reported
Pilon and Smith (1985)	United States	Pre-post intervention study with no control	Cerebral Palsy Clinic at Los Angeles Orthopaedic Hospital	5 Spanish-speaking parents of children with CP (ages 1–17)	Not reported	Range = 1–17 years	CP	All who attended were women, most of them single parents

Table 2 (continued)

Study (year)	Country	Study design	Setting	Participants	Age of parents/ Caregivers (years)	Age of children	Diagnoses of children and severity	Further information about caregivers presented in study report
van Aswegen et al. (2019)	South Africa	Pre-post intervention study with no control	The Baby Therapy Centre in Mamelodi, a township northeast of Pretoria,	18 caregivers of children with CP	M (SD) = 32.1 (5.6)	M (SD) = 36.5 (6) months	CP mostly GMFCS level V (66.7%)	All participants were mothers except for one who was a grandmother fulfilling the role of the primary caregiver. 82.4% were unemployed and 61% were single
Zuurmond et al. (2018)	Ghana	Pre-post intervention study with no control (part of wider mixed methods study)	Community settings in 8 districts and 4 regions (Upper East, Greater Accra, Brong Ahafo, Ashanti) in Ghana	75 caregivers of children with CP	Ranges: >30 (30%), 30- 40 (45%), >40 (20%)	M (SD) = 3.8 (2.69) years	CP, with half the children considered to have severe CP	98% of the caregivers were female, with 80% mothers and 16% grandmothers. 67% were married and only half of the biological fathers lived in the same house as their child. 89% described their profession as farming, trading, or a small business such as tailoring. Only 42% had been able to work in the past month

CP Cerebral palsy; *GMFCS* Gross Motor Function Classification System; *MACS* Manual Ability Classification System ing healthy behaviours in a group. One study described a group exercise programme aiming at improving the wellbeing of the parents/caregivers.

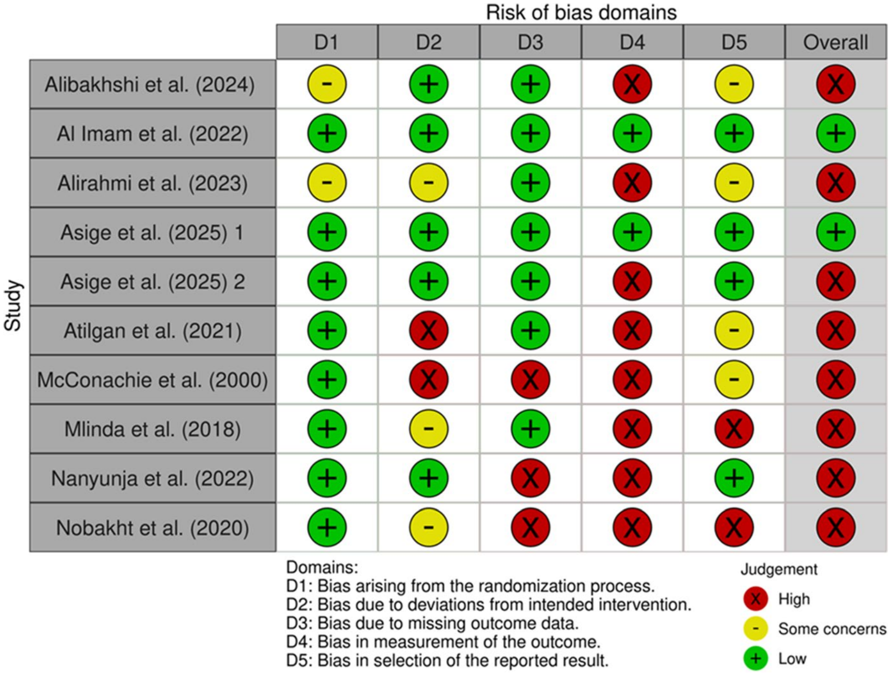
Therapists (physiotherapists, occupational therapists or speech and language therapists) were the most common group to deliver the programmes ($n = 10$). Other professionals involved in group delivery were psychologists or psychotherapists ($n = 5$), community-based workers ($n = 5$), nurses ($n = 2$), teachers ($n = 1$), doctors ($n = 1$) and social workers ($n = 1$). Five studies described caregivers themselves delivering the intervention. Physiotherapists, occupational therapists and speech and language therapists were grouped together as they were frequently reported collectively in the included studies, whereas psychologists and psychotherapists were more commonly identified as a distinct discipline and therefore reported separately. Most programmes had a combination of individuals described above delivering various aspects of the intervention. Number of sessions included was mostly 5–10 ($n = 11$), followed by 15+($n = 7$), with three studies reporting 10–15 sessions. Group sessions were mostly weekly or monthly. Eleven studies reported the intervention location to be in community healthcare settings, local centres or schools. Two programmes were provided online. Few studies reported on the costs of the programme.

The most common activity components of the interventions were provision of information ($n = 20$) and participatory discussions ($n = 20$). Other frequently described activities included practising caregiving skills ($n = 12$), watching videos ($n = 5$), home visits (n = 5), and assessment/goal setting ($n = 8$). Reflective or mindfulness activities were described in all five studies that focused on psychological support or promoting healthy behaviours. The materials required for each intervention were less well reported, however visual aids were frequently mentioned or alluded to ($n = 11$). Equipment for the children, mats, gym balls and toys were mentioned in six studies. Eight studies described using handouts for caregivers and the four programmes required the use of an internet connection and/or electronic device (either to access the programme online or to watch videos).

Risk of Bias

Risk of bias was found to be high for most of the included randomised controlled trials (Fig. 2). Domain 4 (measurement of the outcome) was found to be at high risk of bias for most of the RCTs due to the nature of the interventions, where blinding was not possible, and the outcome measures themselves which were often self-reported (Fig. 3). Three RCTs had published protocols which allowed for the comparison between the intended and actual reported results. Most studies had a high proportion of loss to follow up or non-adherence to the inteull.

Full ROBINS-I assessments were conducted with three out of a potential twelve non-randomised studies (Fig. 4). The rest were defaulted to being at ‘critical risk of bias’ due to not being able to evidence any attempt at controlling for confounding. The three that were assessed fully were either at ‘moderate’, ‘serious’ or ‘critical’ risk of bias due to issues with confounding, missing data, or in the measurement of the outcomes.



Risk of bias domains

Study	D1	D2	D3	D4	D5	Overall
Alibakhshi et al. (2024)	-	+	+	X	-	X
Al Imam et al. (2022)	+	+	+	+	+	+
Alirahmi et al. (2023)	-	-	+	X	-	X
Asige et al. (2025) 1	+	+	+	+	+	+
Asige et al. (2025) 2	+	+	+	X	+	X
Atilgan et al. (2021)	+	X	+	X	-	X
McConachie et al. (2000)	+	X	X	X	-	X
Mlinda et al. (2018)	+	-	+	X	X	X
Nanyunja et al. (2022)	+	+	X	X	+	X
Nobakht et al. (2020)	+	-	X	X	X	X

Domains:
D1: Bias arising from the randomization process.
D2: Bias due to deviations from intended intervention.
D3: Bias due to missing outcome data.
D4: Bias in measurement of the outcome.
D5: Bias in selection of the reported result.

Judgement
X High
- Some concerns
\+ Low

Asige et al. (2025) 1 refers to the outcomes in the study assessed by blinded assessors (e.g. caregiver skills videoed and scored by blinded assessors) while Asige et al. (2025) 2 refers to the self-reported outcomes (e.g. caregiver burden and stress and family functioning)

Fig. 2 Risk of bias for included randomised controlled trials

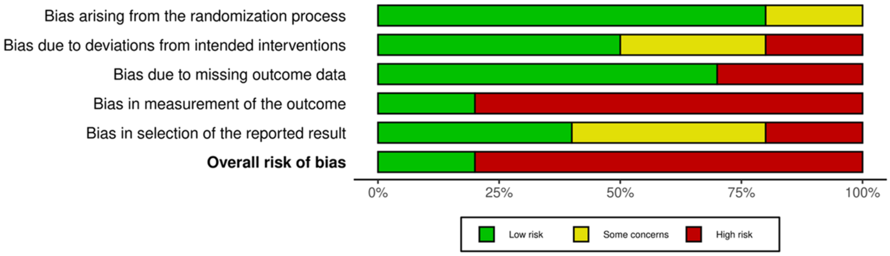


Fig. 3 Summary of domains for included Randomised Controlled Trials

Caregiver Wellbeing Outcomes

Of the outcomes relating to caregiver wellbeing (Figs. 5 and 6), most commonly reported were stress and anxiety ($n=18$), followed by general wellbeing (including physical activity and mindfulness) ($n=15$), pain ($n=6$), depression ($n=7$), quality of life ($n=7$), fatigue ($n=1$) and sleep ($n=1$).

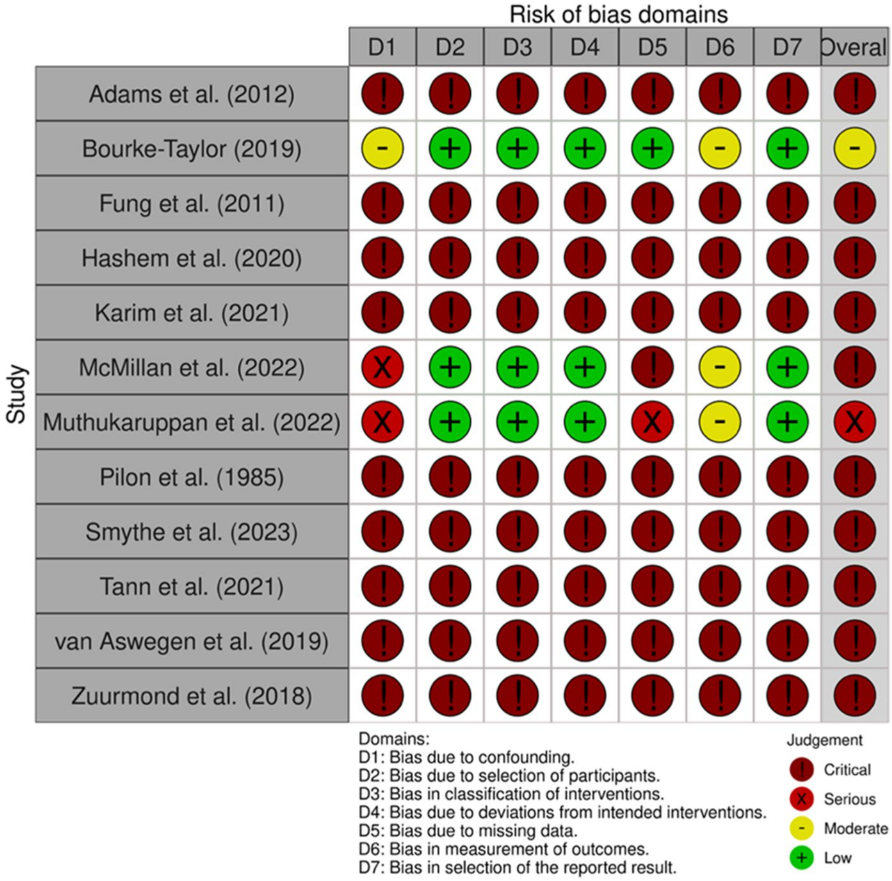
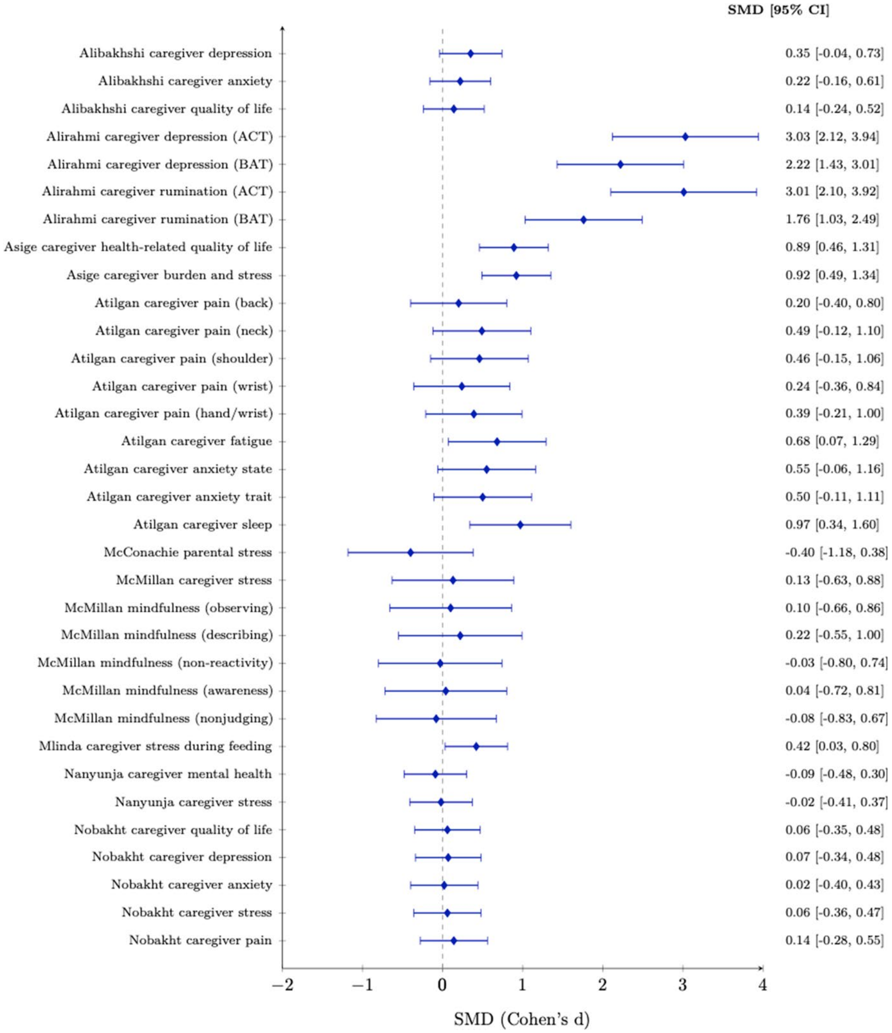


Fig. 4 Risk of Bias for included non-randomised studies

Independent Group Designs

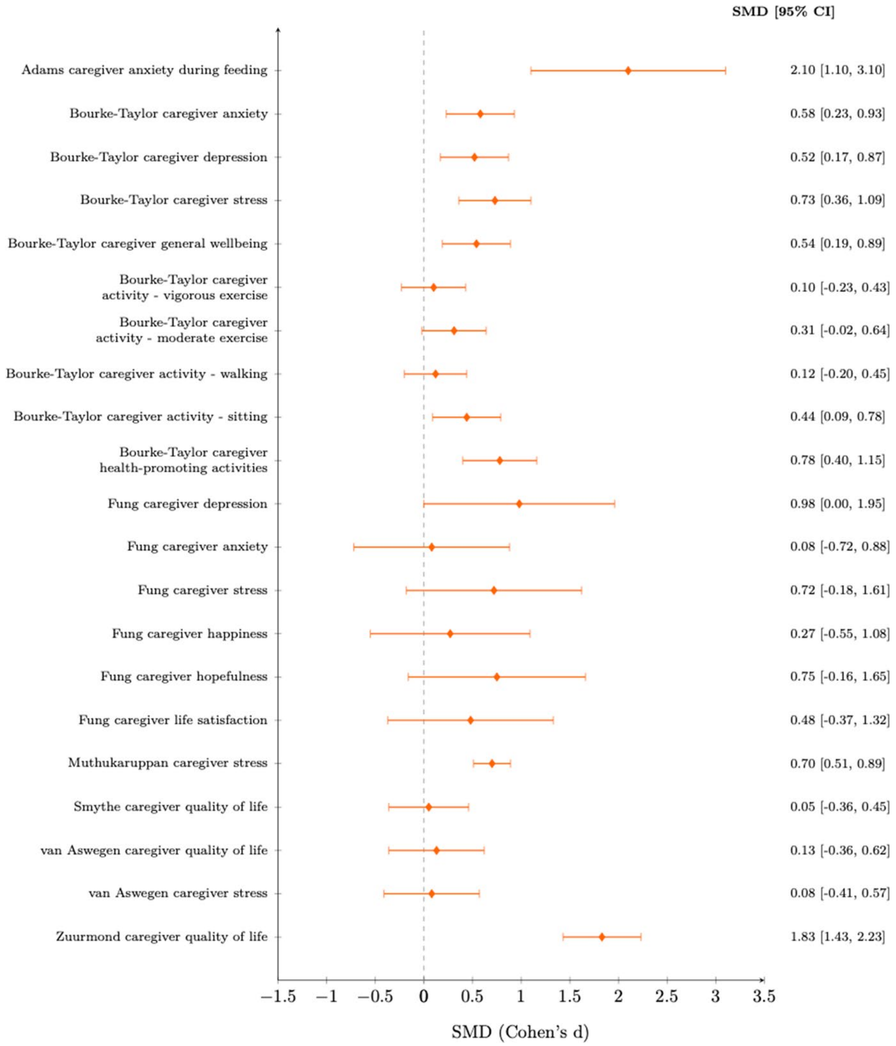
Although the results from the independent-group studies generally favoured the intervention groups, most are not statistically significant (Fig. 5). Asige et al. (2025a), one of the larger RCTs ($n = 94$) of a multi-faceted programme with a lower risk of bias, found medium to large effects in improving caregiver health-related QoL (d = 0.89), and reducing caregiver burden and stress (d = 0.92) compared with usual care (Asige et al., 2025a). Another RCT with over 100 participants found a small effect in reducing caregiver stress during feeding following a nutrition programme compared to usual care (d = 0.42) (Mlinda et al., 2018). Although this is supported by a large effect size in the reduction of caregiver stress in a single-group pre-post study design for the same nutrition programme (Adams et al., 2011), outcomes were unclear, non-standardised and dichotomous. Alibakhshi et al. (2024), an RCT of a psychoeducation programme with over 50 participants found small effects for improving caregiver depression (d = 0.35) and anxiety (d = 0.22) with no effect found on caregiver QoL (d = 0.14) compared to no intervention (Alibakhshi et al., 2024). Another large fea-



ACT=Acceptance and Commitment Therapy, BAT=Behavioural Activation Therapy, SMD=Standardised Mean Difference (Cohen's d), CI=Confidence Interval

Fig. 5 Caregiver wellbeing outcomes for independent group designs (intervention and control groups)

sibility RCT of a peer-led caregiver programme with over 100 participants found no effect on caregiver mental health (d=-0.09) and stress (d=-0.02) compared to standard care (Nanyunja et al., 2022). Karim et al. (2021), a large quasi-experimental study (*n*=156) on a community-based early intervention programme had positive effects on caregiver depression, anxiety and stress in the short-term, however these were not sustained at follow up (Karim et al., 2021). Results were presented descriptively using ordinal data with no means or SDs available, thus this was the only study which could not be included in the forest plot. The improved outcomes with large effect sizes relating to caregiver depression and rumination after participating



Standardised Mean Difference (Cohen's d), CI = Confidence Interval

Fig. 6 Caregiver wellbeing outcomes for single group pre-post designs (no control)

in Behavioural Activation Therapy or Acceptance and Commitment Therapy compared with usual care (Alirahmi et al., 2023) were from the only study with concerns relating to the randomisation process, with minimal information available relating to baseline characteristics, loss to follow up or intervention adherence.

Single-group Pre-post Designs

Similar patterns of positive impact are seen in the single group pre-post designs (Fig. 6), particularly in relation to the reduction of anxiety, depression and stress

(Bourke-Taylor et al., 2019; Fung et al., 2011; Muthukaruppan et al., 2022). Muthukaruppan et al. (2022), the largest pre-post study (*n* = 135) of a family-centred, village-based early intervention programme with a lower risk of bias than many of the other studies found a medium effect in reducing caregiver stress (d = 0.70) (Muthukaruppan et al., 2022). A smaller study (*n* = 36) of a health and empowerment group programme with the lowest risk of bias compared to the other pre-post designs, found medium effects for reducing caregiver anxiety (d = 0.58) and depression (d = 0.52), and improving general wellbeing (d = 0.54) and health promoting activities (d = 0.78) (Bourke-Taylor et al., 2019).

No negative effects were reported in the single-group pre-post design outcomes.

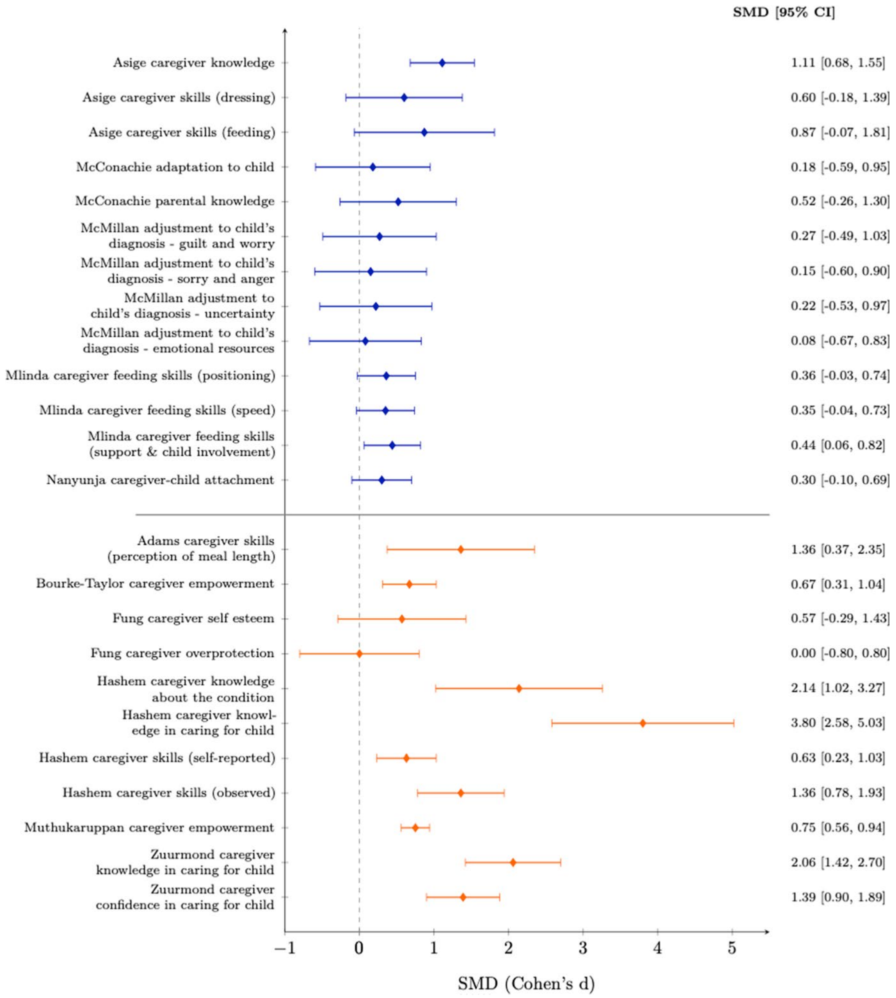
Caregiver Skills and Confidence Outcomes

The outcomes in this category were broad (Fig. 7) and explored caregiver adaptation to the child (including adjusting to the child's diagnosis and degree of overprotection) (*n* = 6), caregiver skills often in relation to feeding (*n* = 8), caregiver confidence, self-esteem and empowerment (*n* = 3) and caregiver knowledge about their child's condition and care (*n* = 5). All outcomes in this category were positive with varying degrees of significance. Of the independent group designs, the greatest effects were seen in one of the larger RCTs (*n* = 94), with the lowest risk of bias, in caregiver knowledge (d = 1.11), and skills related to dressing (d = 0.67) and feeding (d = 0.87) (Asige et al., 2025a). Many of the outcomes relating to confidence or knowledge were assessed using non-standardised measures, however two studies used the Family Empowerment Scale (both pre-post single group design but with lower risk of bias compared to others in this review) and both found significant medium effect sizes (Bourke-Taylor et al., 2019; Muthukaruppan et al., 2022).

Social Support and Family Outcomes

Outcomes relating to social support, social capital, family quality of life and family functioning were grouped in this category (Fig. 8). The greatest effects found in this category come from Al Imam et al. (2022), the largest study in this review (*n* = 251); a cluster-randomised controlled trial with a lower risk of bias compared to most of the other RCTs in this review (Al Imam et al., 2022). Compared with care as usual, an integrated microfinance/livelihood and community-based rehabilitation (CBR) programme greatly improved caregiver social capital (d = 1.95) and a group receiving CBR without the livelihood component demonstrated greatly improved social capital compared to usual care too (d = 1.83).

Although social support outcomes showed a positive impact, none were significant across the two studies that measured these with both studies either being smaller or at a higher risk of bias (Fung et al., 2011; McConachie et al., 2000). Mixed results were seen in relation to the impact of these programmes on family quality of life (PedsQL Family Impact Measure) with significant large effect sizes found in three studies (one of which is a large RCT with a lower risk of bias) (Asige et al., 2025a; Tann et al., 2021; Zuurmond et al., 2018) and no effect seen in the other three (Aswegen et al., 2019; Nanyunja et al., 2022; Smythe et al., 2023). Family cohesion and



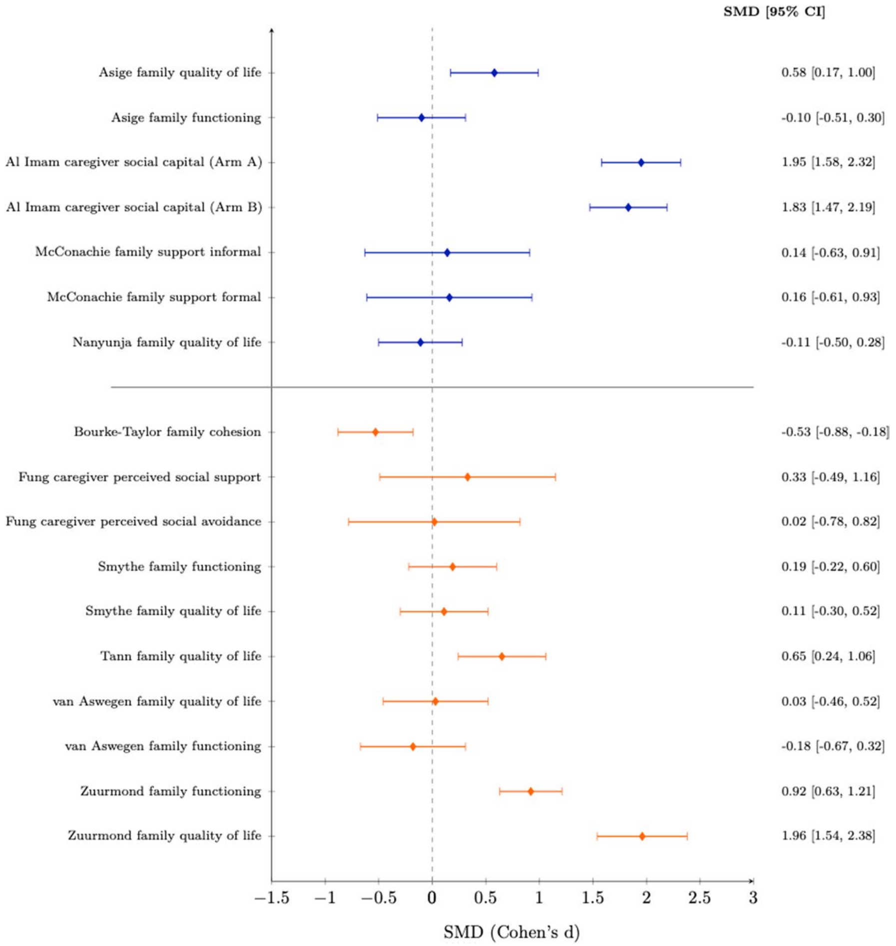
SMD = Standardised Mean Difference (Cohen's d), CI = Confidence Interval Independent group designs (intervention and control groups) presented first, followed by single group pre-post designs (no control)

Fig. 7 Caregiver skills and confidence outcomes

family functioning were two outcomes that were negatively impacted in three studies (Asige et al., 2025a; Aswegen et al., 2019; Bourke-Taylor et al., 2019).

Child-related Outcomes

Child-related outcomes are summarised in Table 3. Overall, effects on child outcomes were mixed, with the two larger RCTs with the lowest risk of bias reporting small or no effects on child motor function and quality of life (Al Imam et al., 2022; Asige et al., 2025b). Small to medium effects on child feeding skills and mood during feeding were reported in one large RCT and a smaller pre-post study of the same nutrition



Al Imam Arm A = integrated microfinance/livelihood and community-based rehabilitation (CBR) programme, Al Imam Arm B = CBR alone. SMD = Standardised Mean Difference (Cohen's d), CI = Confidence Interval. Independent group designs (intervention and control groups) presented first, followed by single group pre-post designs (no control)

Fig. 8 Social support and family outcomes

programme (Adams et al., 2011; Mlinda et al., 2018). Small and mixed effects on child growth, motor and cognitive function were found in a feasibility RCT (*n* = 126) of a peer-led programme (Nanyunja et al., 2022), whilst one pre-post study found small to large effects on child quality of life physical and psychosocial functioning (d = 0.48, 0.83) (Bourke-Taylor et al., 2019).

Certainty of the Evidence

The most frequently reported outcomes were assessed for certainty using the GRADE approach (Table 4) (Schünemann et al., 2013). All outcomes were either 'low' or 'very low' in the confidence of the effect estimates. Caregiver anxiety/stress and care-

Table 3 Child-related outcomes

Study	Outcome	Standardised mean difference (Cohen's d)	Standard error	Effect size	Lower CI	Upper CI	Measure
Independent group designs (intervention and control groups)							
Al Imam et al. (2022) Arm A	Child quality of life	0.09	0.15	no effect	-0.21	0.39	TNO-AZL Preschool children Quality of Life questionnaire (TAPQOL)
Al Imam et al. (2022) Arm B	Child quality of life	-0.24	0.15	small	-0.54	0.06	TNO-AZL Preschool children Quality of Life questionnaire (TAPQOL)
Al Imam et al. (2022) Arm A	Child motor function	0.04	0.15	no effect	-0.26	0.34	Gross Motor Function Measure (GMFM)-66
Al Imam et al. (2022) Arm B	Child motor function	0.07	0.15	no effect	-0.23	0.37	Gross Motor Function Measure (GMFM)-66
Asige et al. (2025a)	Child motor function	0.13	0.21	no effect	-0.30	0.51	Gross Motor Function Measure (GMFM)-66
Asige et al. (2025a)	Child mobility	0.11	0.21	no effect	-0.23	0.59	Ugandan version of the Pediatric Evaluation of Disability Inventory (PEDI-UG)
Asige et al. (2025a)	Child self-care	0.18	0.21	no effect	-0.23	0.59	Ugandan version of the Pediatric Evaluation of Disability Inventory (PEDI-UG)
Asige et al. (2025a)	Child social function	0.20	0.21	small	-0.20	0.61	Ugandan version of the Pediatric Evaluation of Disability Inventory (PEDI-UG)
Karim et al. (2021)	Child motor function	0.35	0.17	small	0.01	0.69	Gross Motor Function Measure(GMFM)-66
McConachie et al. (2000)	Child skills	0.26	0.39	small	-0.51	1.03	Independent Behaviour Assessment Scale
Milinda et al. (2018)	Child's mood during feeding	0.63	0.20	medium	0.24	1.02	Percentage increase of those rated 'good' vs 'poor'

Table 3 (continued)

Study	Outcome	Standardised mean difference (Cohen's d)	Standard error	Effect size	Lower CI	Upper CI	Measure
Milinda et al. (2018)	Child feeding skills (functional skills)	0.45	0.20	small	0.07	0.84	Percentage increase of 'yes' vs 'no'
Mliinda et al. (2018)	Child feeding skills (oral motor)	0.16	0.19	no effect	-0.22	0.53	Percentage increase of 'yes' vs 'no'
Nanyunja et al. (2022)	Child cognitive function	-0.45	0.20	small	-0.84	-0.05	Griffiths Mental Developmental Scales (GMDS)
Nanyunja et al. (2022)	Child motor function	0.45	0.20	small	0.06	0.85	Pediatric Evaluation Disability Inventory (PEDI-CAT)
Nanyunja et al. (2022)	Child growth (weight for age)	-0.40	0.20	small	-0.79	0.00	Weight-for-age z-score
Nanyunja et al. (2022)	Child growth (height for age)	-0.32	0.20	small	-0.71	0.07	Height for-age z-score
Nanyunja et al. (2022)	Child growth (head circumference)	-0.23	0.20	small	-0.62	0.16	Head circumference (HC) for age z-score
Nanyunja et al. (2022)	Child growth (mid-upper arm circumference)	-0.24	0.20	small	-0.63	0.15	Mid-upper arm circumference (MUAC) z-score
Pre-post one group designs (no control)							
Adams et al. (2011)	Child chest health	0.96	0.37	large	0.25	1.68	Frequency of chest-related illness occurring at least once every 3 months
Adams et al. (2011)	Child growth (weight for age)	0.41	0.22	small	-0.02	0.85	Weight for age z-score
Adams et al. (2011)	Child growth (mid-upper-arm circumference)	0.50	0.23	medium	0.06	0.95	MUAC (cm)
Adams et al. (2011)	Child feeding skills (munching/chewing)	1.37	0.40	large	0.58	2.16	Observed number of munching/chewing
Adams et al. (2011)	Child mood during feeding	1.69	0.48	large	0.75	2.64	Reported number with predominantly negative mood
Bourke-Taylor et al. (2019)	Child quality of life—physical functioning	0.48	0.18	small	0.14	0.83	PedsQL – Physical & Psychosocial Functioning Subscale
Bourke-Taylor et al. (2019)	Child quality of life—psychosocial functioning	0.83	0.19	large	0.45	1.21	PedsQL – Physical & Psychosocial Functioning Subscale
Fung et al. (2011)	Caregiver perceived disability severity	0.67	0.45	medium	-0.22	1.55	Caregiver perception of their child's disability on a Likert scale
Pilon and Smith (1985)	Child's number of emergency hospital visits	0.61	0.33	medium	-0.03	1.26	Number of emergency hospital visits
Pilon and Smith (1985)	Child's number of school days missed	0.61	0.33	medium	-0.03	1.26	Number of school days missed

Table 3 (continued)

Study	Outcome	Standardised mean difference (Cohen's d)	Standard error	Effect size	Lower CI	Upper CI	Measure
Tann et al. (2021)	Child neurological function	0.34	0.19	small	-0.04	0.72	Hammersmith Infant Neurological Examination (HINE)
Tann et al. (2021)	Child developmental progress	-0.09	0.19	no effect	-0.46	0.28	Developmental Quotient (DQ)
Tann et al. (2021)	Child growth (mid-upper-arm circumference in cm)	0.42	0.20	small	0.03	0.80	MUAC (cm)
Tann et al. (2021)	Child growth (mid-upper-arm circumference z score)	0.18	0.19	no effect	-0.19	0.56	MUAC z-score
Tann et al. (2021)	Child growth (weight for age)	-0.23	0.19	small	-0.61	0.14	Weight-for-age z-score
Tann et al. (2021)	Child growth (height for age)	-0.41	0.20	small	-0.80	-0.03	Height for-age z-score
Zuurmond et al. (2018)	Caregiver perception of child's physical health	0.92	0.21	large	0.50	1.34	Caregiver perception of child's physical health
Zuurmond et al. (2018)	Caregiver perception of child's emotional health	0.64	0.20	medium	0.24	1.04	Caregiver perception of child's emotional health
Zuurmond et al. (2018)	Child health problems	0.08	0.21	no effect	-0.33	0.49	Percentage of children who had a serious health problem in the past year
Zuurmond et al. (2018)	Child growth (weight for age)	-0.20	0.03	small	-0.26	-0.14	Weight-for-age z-score
Zuurmond et al. (2018)	Child growth (height for age)	-0.40	0.04	small	-0.48	-0.32	Height for-age z-score
Zuurmond et al. (2018)	Child growth (weight for height -under 5 s only)	0.20	0.05	small	0.10	0.30	Weight for height z-score
Zuurmond et al. (2018)	Child growth (child mid upper arm circumference -under 5 s only)	-0.02	0.42	no effect	-0.85	0.81	MUAC (mm)

Table 4 GRADE evidence profile for most frequently reported outcomes

Outcome	Study design & number	Starting certainty & rationale	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Overall certainty
Caregiver anxiety and stress	7 RCTs, 1 quasi-experimental, 5 pre-post studies	High – mostly RCTs	Downgraded 1 for serious RoB – most studies high risk	Not serious – consistent effects; 2 outliers (but with higher RoB)	Not serious – directly relevant	Downgraded 1 for serious imprecision – small N, wide CIs	No upgrade – no large effect identified; no downgrade – no clear evidence of publication bias	Low (⊕⊕◯◯)
Caregiver depression	3 RCTs, 2 pre-post studies	High – mostly RCTs	Downgraded 1 for serious RoB – most studies high risk	Not serious – consistent effects; 1 outlier (but with higher RoB)	Not serious – directly relevant	Downgraded 1 for serious imprecision – small N, wide CIs	No upgrade – no large effect identified; no downgrade – no clear evidence of publication bias	Low (⊕⊕◯◯)
Caregiver quality of life	3 RCTs, 3 pre-post studies	Moderate – equal RCT and pre-post studies	Downgraded 1 for serious RoB – most studies high risk	Not serious – most showed small improvement, similar sizes	Not serious – directly relevant	Downgraded 1 for serious imprecision – some no effect or wide CIs	No upgrade – no large effect identified; no downgrade – no clear evidence of publication bias	Very Low (⊕◯◯◯)
Caregiver knowledge and skills	3 RCTs, 3 pre-post studies	Moderate – equal RCT and pre-post studies	Downgraded 1 for serious RoB – most studies high risk	Not serious – consistent improvements; 1 outlier explained by measurement tool	Not serious – directly relevant	Downgraded 1 for serious imprecision – mixed N and CI widths	No upgrade – no large effect identified; no downgrade – no clear evidence of publication bias	Very Low (⊕◯◯◯)

Table 4 (continued)

Outcome	Study design & number	Starting certainty & rationale	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Overall certainty
Family quality of life	2 RCTs, 4 pre-post studies	Low – mostly pre-post studies	Downgraded 1 for serious RoB – most studies high risk	Downgraded 1 for serious inconsistency – varying sizes; 1 negative effect	Downgraded 1 for serious indirectness – proxy outcome for caregiver wellbeing	Downgraded 1 for serious imprecision – small N, wide CIs	No upgrade – no large effect identified; no downgrade – no clear evidence of publication bias	Very Low (⊕◯◯◯)
Family functioning	1 RCT, 4 pre-post studies	Low – mostly pre-post studies	Downgraded 1 for serious RoB – most studies high risk	Downgraded 1 for serious inconsistency – varying effects (positive, negative or no effect)	Downgraded 1 for serious indirectness – proxy outcome for caregiver wellbeing	Downgraded 1 for serious imprecision – small N, wide CIs	No upgrade – no large effect identified; no downgrade – no clear evidence of publication bias	Very Low (⊕◯◯◯)

RCT Randomised controlled trial; *RoB* Risk of bias; *N* Number of participants in study; *CIs* Confidence Intervals giver depression both scored ‘low’ for overall certainty while the rest of the outcomes scored ‘very low’ (caregiver quality of life, caregiver knowledge/skills, family quality of life and family functioning). The high risk of bias in most included studies resulted in downgrading all the outcomes. Caregiver anxiety/stress, depression and quality of life were all consistent in the direction of effects and showed similar effect sizes. These three outcomes were directly related to the research question; however, family quality of life and family functioning were seen as more of a proxy outcome and both showed inconsistency in the results. All outcomes were downgraded based on imprecision due to frequently relying on small study numbers and wide confidence intervals.

Discussion

Key Findings

This systematic review synthesised data on the effects of group programmes targeting improved skills, knowledge and confidence amongst caregivers of children with neurodisability, particularly those with a physical impairment from a neurological cause. Twenty-one studies met the inclusion criteria (*n* = 1491) (RCTs = 9, quasi-experimental = 2, single-group pre-post = 10) with 95 outcomes extracted for synthesis and grouped into three caregiver categories; (1) caregiver wellbeing outcomes, (2) caregiver skills and confidence outcomes, and (3) social support and family outcomes, with child-related outcomes (*n* = 43) presented separately. Most studies took place in LMICs, and most programmes targeted female caregivers of children with CP under 5 years. The review found varying effects of the interventions, with almost all outcomes associated with a positive impact, however most were at a high risk of bias due to being self-reported measures with blinding not possible. Intervention characteristics were well described in relation to the goal of the programme, intervention provider, location, dosage and activities included. There was limited reporting of intervention costs and materials required. There were three studies that were high quality and the least at risk of bias, all demonstrated significant improvements in outcomes relating to caregiver social capital, wellbeing, quality of life, skills, knowledge and empowerment. The first was an RCT (Al Imam et al., 2022) with 251 caregivers of children with CP in Bangladesh who participated in either a microfinance/livelihood and community-based rehabilitation (CBR) programme or CBR alone (both arms were compared with usual care). The programmes in both arms involved caregiver education workshops. Social capital outcome measures (caregiver participation in their community and social networks) improved significantly (d = 1.95, 1.83). The authors confirmed that further caregiver outcomes will be published in the future, and these would be meaningful for this review. The second noteworthy study was an RCT with 94 caregivers of children/young people with CP in Uganda who participated in a multi-component intervention, of which a key part was the caregiver training programme. Medium to large effects were seen in the blinded assessor outcomes of caregiver knowledge (d = 1.11), dressing and feeding skills (d = 0.60, 0.87). Self-reported outcomes also demonstrated significant improvement (caregiver quality of life d = 0.89, caregiver burden and stress d = 0.92). The final study was a single group pre-post design with 36 mothers of children with disabilities in Australia who participated in a health and empowerment group-based workshop programme (Bourke-Taylor et al., 2019). The authors demonstrated appropriate methods for controlling for confounding factors and, despite the small sample size, significant improvements were seen in caregiver anxiety (d = 0.58), depression (d = 0.52), stress (d = 0.73), caregiver general wellbeing (d = 0.54), caregiver health-promoting activities (d = 0.78), and empowerment (d = 0.67).

Evidence Limitations

The findings from almost all outcomes from the 21 included studies were rated as subject to a high risk of bias due to a variety of factors. Firstly, in the independent group studies, due to the nature of the interventions, participants could not be blinded to group allocation, and outcomes were often self-reported which meant assessor blinding was often not possible either. There was frequent uncertainty in the selection of the reported results due to studies not having published protocols or trial registrations available. Missing data was another difficulty found in most studies as there was often a high proportion of loss to follow up or non-adherence to programmes. Most single group pre-post study designs did not attempt to control for confounding factors and results therefore need to be interpreted with caution as the evidence may be influenced by uncontrolled confounders.

There is a wider issue in the measurement of caregiver-related outcomes following complex, multi-component interventions. Caregiver wellbeing can be negatively influenced by financial difficulties, and restricted time to follow their own interests or work (Davis et al., 2010; McCann et al., 2012). Difficulties that caregivers face often move beyond the diagnosis of the child and can relate to external factors such as seeking out appropriate services, coping with discrimination and stigma, and advocating for their child in the community (Rosenbaum & Novak-Pavlic, 2021). If all these factors can influence outcomes relating to caregiver wellbeing, it is difficult to know whether improvement seen is due to an intervention, and if so which aspect of the intervention had an impact. In relation to the high proportion of non-adherence, it is well known that caregivers of children with complex neurodisability have a high-caregiving burden (Dlamini et al., 2023) and their baseline level of wellbeing is often very low (Scherer et al., 2019). These factors can impact a caregiver’s time and capacity to take part in a programme, even if the programme is aimed at improving said factors. Finally, these difficulties can be compounded when caregivers live in poverty as external factors such as transport to the intervention can impact on their ability to participate (Vadivelan et al., 2020).

Comparison with Existing Literature

There has been mixed findings from similar reviews in relation to the impact of programmes on the wellbeing or quality of life of caregivers of children (He et al., 2024; Irwin et al., 2019; Poojari et al., 2024). Most of the group programmes in this review were positively linked to caregiver wellbeing, with programmes targeting caregiver skills and knowledge often associated with greater improvements in wellbeing than those specifically aimed at psychological wellbeing. This reflects what parents of children with CP have rated as important in family-centred care in other studies, which is the provision of knowledge about the child (Prest et al., 2024a; Terwiel et al., 2017). It also reflects the importance of peer support, regardless of the intervention aim, which has found to be a protective factor for caregiver psychological wellbeing in another systematic review (Shilling et al., 2013). Most studies in this review reported improved social support outcomes (Al Imam et al., 2022; Fung et al., 2011; McConachie et al., 2000), however outcomes relating to family functioning (the daily activities and family relationships in the context of the child's health condition) were more mixed (Aswegen et al., 2019; Bourke-Taylor et al., 2019; Smythe et al., 2023; Zuurmond et al., 2019). This relates back to the many external factors that impact a family's life when they have a child with a disability (Rosenbaum & Novak-Pavlic, 2021) and raises the question whether an intervention can have an impact on this.

The Family Empowerment Scale (Koren et al., 1992) was used in two studies in this review describing different programmes in Australia (Bourke-Taylor et al., 2019) and South India (Muthukaruppan et al., 2022) and in both instances, the improved results were statistically significant and showed medium effect sizes (d = 0.67, 0.75). These two studies showed improved caregiver wellbeing too. Most studies in this review that reported improved caregiver skills and confidence outcomes also had improved wellbeing outcomes (Adams et al., 2011; Bourke-Taylor et al., 2019; Fung et al., 2011; Mlinda et al., 2018; Muthukaruppan et al., 2022; Zuurmond et al., 2019), This result is echoed by a previous study that demonstrated a link between self-efficacy, a key part of empowerment and confidence, and the mental health of caregivers of children with CP (Guillamón et al., 2013).

A few programmes reported no or negative effects but provided rich qualitative data describing the impact on the caregivers' lives. For example, the 'Hambisela' training programme in South Africa helped caregivers to understand what CP was, to accept their children and to know how to care for them appropriately (Aswegen et al., 2019) however no effects were found for caregiver quality of life or stress levels. Nanyunja et al. (2022) found similar qualitative results with the 'Baby Ubuntu' programme in Uganda relating to improved attitudes towards the child, improved wellbeing and confidence, and improved peer support and information sharing, even though these were not reflected in the quantitative data. The online Acceptance and Commitment Therapy group in Australia reported qualitative data relating to parents feeling more mindful, less alone, being more present with family, and accepting their emotions (McMillan et al., 2020). This was not always reflected in the quantitative results relating to mindfulness and stress. These findings echo previous research showing that quantitative tools often miss the true impact programmes have on caregivers. For example, in a UK RCT of the 'Healthy Parent Carers' programme, some participants felt the questionnaires failed to reflect their positive experiences (Bjornstad et al., 2021). Similarly, a recent qualitative study found a widely used wellbeing scale sometimes overlooked important changes, especially negative ones, and did not always reflect caregivers' lived realities (McGlinchey et al., 2024).

Although most studies were published between 2018 and 2023, the fact that a study published in 1985 met the inclusion criteria and demonstrated effectiveness of their group programme in improving outcomes for caregivers and children, demonstrates that this approach is not novel. It is worth acknowledging, however, that the context in which such programmes are delivered has changed considerably over the past 40 years, with family-centred care becoming increasingly embedded in service delivery frameworks and a growing recognition of the importance of actively involving families in the care process. Caregivers of children with complex neurodisability have been seeking support in the form of information or connections with others in similar situations for decades. Recent literature confirms that caregivers experiences of healthcare services continue to not adequately meet their needs (Anderson et al., 2013; Bellin et al., 2011; Campbell et al., 2021; Jindal et al., 2018; Kiernan et al., 2020; Liptak et al., 2006; Prest et al., 2024a), which perhaps explains why interventions continue to be developed and tested today as they are not yet a part of mainstream services.

Review Strengths and Limitations

Limitations

A few studies were not picked up through the search strategy but were instead found through key contacts in the field. This was due to the journals not being indexed in the databases searched. It cannot be ruled out that other studies may have been missed in the same way, although effort was made to hand search reference lists of similar reviews and the included studies, as well as contacting key authors. Another limitation was that studies were excluded if they were not published in English, for example a study in Korea examined the effects of a group empowerment program on mothers of children with CP (Eo, 2017), which would have been relevant to this review, but the full-text was not available in English.

As most of the studies reported complex interventions with multiple components, it was difficult to tease apart which components of the programmes were linked to improved outcomes. For example, a family-centred village-based early intervention programme in India for 135 children with disabilities (including a caregiver intervention) (Muthukaruppan et al., 2022) was associated with significant improvements in caregiver empowerment ($d = 0.75$) and reduced caregiver stress ($d = 0.70$). The programme included therapy for the children as well as parent groups, and it is impossible to know which aspects contributed to the improved empowerment and stress. Future reviews on this topic may benefit from using Qualitative Comparative Analysis to identify key components of interventions associated with success (Melendez-Torres et al., 2019). Another helpful way to overcome this is to report on qualitative data which can provide context to the results. For example, Zuurmond et al.'s study (2018, 2019) described how caregivers attributed improved wellbeing to increased understanding of their child's condition, feeling more hopeful and positive towards their child, and the social support that the group provided.

Strengths

The effectiveness of caregiver skills training programmes has been widely researched in the field of autism and social communication difficulties, particularly when interventions and outcomes relate to child behaviour (Reichow et al., 2024; Salomone et al., 2022; Tekola et al., 2020). This review clearly maps out different types of caregiver skills training programmes that target children with motor disorders and are delivered in a group format, providing an opportunity for clinicians and researchers to consider various intervention components relevant for implementation in their settings. Many of these programmes were developed in low-resource settings, which may be because community-based, group programmes are more cost-effective, or because task-shifting (Kumurenzi et al., 2023; World Health Organization, 2007; Zhao et al., 2021) is a necessity due to lack of resources and access to healthcare. This review highlights the innovations taking place in LMICs and provides an opportunity to learn about low-cost, community-based participatory approaches to supporting caregivers of children with complex neurodisability.

Implications and Recommendations

From a wider systematic perspective, the findings from this review demonstrated the vast expertise to be found in resource constrained settings in relation to the development, testing and implementation of group-based caregiver training programmes for children with neurodisability, particularly with diagnoses like CP. This finding suggests that practitioners in HIC settings, where caregivers' needs are often unmet, could draw on innovations from LMICs and reconsider assumptions that learning cannot occur in this direction (Harris, 2023). It is important to challenge these assumptions as Harris and colleagues' (2015) note; 'They hear "Africa" and they think they there can't be any good services'. Another key learning relevant to practice, is that despite the different aims and components of the group-based programmes, associations with outcomes were broadly similar. It may be that being in a group with others who have similar experiences, is more important than the aim or content of the programme itself. Clinicians and other key partners working with families who have children with neurodisability may consider providing their support, in whichever form this may take, in a group setting. Given the limitations and uncertainty of the evidence in this review, it is recommended that future research in this topic consider better reporting of protocols and trial registrations. Researchers should anticipate the characteristics of this population and the risk of high attrition in studies and plan accordingly, for example covering participants' transport costs. If conducting a single-group pre-post intervention study, consideration needs to be taken in adjusting for confounding factors to reduce the risk of bias and increase confidence in the results. It is also recommended that future studies incorporate economic evaluations alongside effectiveness data, given the limited reporting of intervention costs across included studies and the growing need for cost-effectiveness evidence to inform policy adoption and implementation, particularly in LMICs. Finally, it is recommended that a core outcome set be developed to effectively capture the impact of such programmes on caregivers.

Conclusion

This review has synthesised the existing research on group-based programmes to support the skills and wellbeing of caregivers of children with neurodisability presenting with motor impairments, such as cerebral palsy. It complements previous systematic reviews which have focused on similar interventions for caregivers of children with autism, social communication, and behavioural difficulties. Nearly all studies included in the reviews, regardless of the aims or components of the group programmes, were associated with a positive impact on caregiver wellbeing, confidence, skills, social support and family quality of life. However, most outcomes had a high risk of bias and low levels of certainty in the effects, which poses difficulties for interpretation and drawing strong conclusions or recommendations. Future studies should pay attention to adequate statistical power, robust randomised controlled trial methodology, outcome measurement, confounding factors, costs and the use of qualitative methods to explore quantitative effects.

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1007/s10882-026-10059-7.

Acknowledgements The first author (KP) was funded by the HARP PhD Programme to conduct this research. AH is supported by the National Institute for Health and Care Research ARC North Thames. MH is supported by the NIHR Global Health Research Professorial Fellowship (NIHR302422). This research was supported by the National Institute for Health Research (NIHR) Great Ormond Street Hospital Biomedical Research Centre. The views expressed are those of the authors and not necessarily those of the National Health Service (NHS), the NIHR or the UK Department of Health. The funders had no role in study design, data collection, analysis, or interpretation, or preparation of this manuscript.

Author Contribution KP conceptualised the study and conducted the literature search. KP, SD, and DN screened articles and performed risk of bias assessments. KP led the analysis and synthesis. AH, MH, KB and CH co-supervised all stages of the project. KP drafted the manuscript with input, from AH, MH, KB, and CH. All authors reviewed and approved the final manuscript.

Data Availability No datasets were generated or analysed during the current study.

Declarations

Ethical Approval Not applicable.

Conflict of interest Authors KP, KB, CH, AH and MH have been involved in the adaptation of one of the interventions included in this systematic review (The “Baby Ubuntu” programme). This involvement did not influence the conduct, analysis, or reporting of the review, and is disclosed here in the interest of transparency.

References

Adams, M. S., Khan, N. Z., Begum, S. A., Wirz, S. L., Hesketh, T., & Pring, T. R. (2011). Feeding difficulties in children with cerebral palsy: Low-cost caregiver training in Dhaka, Bangladesh. *Child: Care, Health & Development, 38*(6), 878–888. https://doi.org/10.1111/j.1365-2214.2011.01327.x. Located at: cul.

Alibakhshi, H., Davoudi, Z., Damirchi, N., Kavian, M., Siminghalam, M. (2024). The Impact of Group Psychoeducation for Mothers of Children with Cerebral Palsy: A Randomized Controlled Trial [Research Article] [Internet]. Middle East Journal of Rehabilitation and Health Studies; 2025 [cited 2025 Jul 24]. Report No.: 12. Available from: https://brieflands.com/articles/mejrh-146484#abstract https://doi.org/10.5812/mejrh-146484

Al Imam, M. H., Jahan, I., Das, M. C., Bashar, S. M. K., Khan, A., Muhit, M., et al. (2022). SUpporting People in extreme POverty with Rehabilitation and Therapy (SUPPORT CP): A trial among families of children with cerebral palsy in Bangladesh. *Developmental Medicine and Child Neurology, 65*(6), 773–782. https://doi.org/10.1111/dmcn.15445. Located at: mdc; 36335570.

Alirahmi, M., Kikhavani, S., & Soleimannejad, H. (2023). Compare the effectiveness of two treatments, behavioral activation and acceptance and commitment therapy, on depression and mental rumination in mothers of children with cerebral palsy in Ilam city. *Journal of Education and Health Promotion, 13*(1), 260. https://doi.org/10.4103/jehp.jehp_1720_23

Anderson, M., Elliott, E. J., & Zurynski, Y. A. (2013). Australian families living with rare disease: Experiences of diagnosis, health services use and needs for psychosocial support. *Orphanet Journal of Rare Diseases, 8*(1), 22. https://doi.org/10.1186/1750-1172-8-22

Asige, E., Saloojee, G., Wanjala, G., Andrews, C., Namaganda, L. H., Kakooza-Mwesige, A., et al. (2025a). Impact of the Akwenda Intervention Program for cerebral palsy on caregiver-perceived burden, stress, and psychosocial functioning: A cluster-randomized trial in Uganda. *Developmental Medicine & Child Neurology*. https://doi.org/10.1111/dmcn.16368

Asige, E., Saloojee, G., Andrews, C., Namaganda, L. H., Kakooza-Mwesige, A., Damiano, D. L., et al. (2025b). Functioning and activity outcomes of the Akwenda intervention program for children and young adults with cerebral palsy in Uganda: A cluster-randomized trial. *Developmental Medicine and Child Neurology, 67*(1), 87–98. https://doi.org/10.1111/dmcn.16007

Atilgan, E. D., & Tuncer, A. (2021) The effects of breathing exercises in mothers of children with special health care needs: A randomized controlled trial. *Journal of Back and Musculoskeletal Rehabilitation, 34*(5), 795–804. https://doi.org/10.3233/BMR-200327. Located at: Embase; 635988369.

Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review, 84*(2), 191–215. https://doi.org/10.1037/0033-295X.84.2.191

Bellin, M. H., Osteen, P., Heffernan, C., Levy, J. M., & Snyder-Vogel, M. E. (2011). Parent and health care professional perspectives on Family-centered Care for children with Special Health Care Needs: Are we on the same page? *Health & Social Work, 36*(4), 281–290. https://doi.org/10.1093/hsw/36.4.281

Bjornstad, G., Cuffe-Fuller, B., Ukoumunne, O. C., Fredlund, M., McDonald, A., Wilkinson, K., et al. (2021). Healthy Parent Carers: Feasibility randomised controlled trial of a peer-led group-based health promotion intervention for parent carers of disabled children. *Pilot and Feasibility Studies, 7*(1), 144. https://doi.org/10.1186/s40814-021-00881-5

Borek, A. J., McDonald, B., Fredlund, M., Bjornstad, G., Logan, S., & Morris, C. (2018). Healthy parent carers programme: Development and feasibility of a novel group-based health-promotion intervention. *BMC Public Health, 18*(1), 270. https://doi.org/10.1186/s12889-018-5168-4

Borenstein, M., Hedges, L. V., Higgins, J. P. T., Rothstein, H. R. (2009). Introduction to meta-analysis. Nachdr. Chichester: Wiley; 2009. 421 p.

Bourke-Taylor, H. M., Jane, F., & Peat, J. (2019). Healthy Mothers Healthy Families Workshop Intervention: A preliminary investigation of healthy lifestyle changes for mothers of a child with a disability. *Journal of Autism and Developmental Disorders, 49*(3), 935–949. https://doi.org/10.1007/s10803-018-3789-1

Branjerdporn, N., Benfer, K., Crawford, E., Ziviani, J., Boyd, R. N., & Sakzewski, L. (2022). Efficacy of early interventions with active parent implementation in low-and-middle-income countries for young children with cerebral palsy to improve child development and parent mental health outcomes: A systematic review. *Disability and Rehabilitation, 44*(23), 6969–6983. https://doi.org/10.1080/09638288.2021.1989063. Located at: 34647839.

Campbell, M., McKenzie, J. E., Sowden, A., Katikireddi, S. V., Brennan, S. E., Ellis, S., et al. (2020). Synthesis without meta-analysis (SWiM) in systematic reviews: Reporting guideline. *BMJ (Clinical Research Ed.), 368*, l6890. https://doi.org/10.1136/bmj.l6890

Campbell, D., Milne, J., Garg, P., Tomsic, G., Ong, N., & Silove, N. (2021). Parents' and service providers' experiences of accessing health services from an Intellectual Disability Health Team. *Journal of Primary Care & Community Health, 12*, 21501327211014068. https://doi.org/10.1177/21501327211014068

Chakraborti, M., Gitimoghaddam, M., McKellin, W. H., Miller, A. R., & Collet, J. P. (2021). Understanding the implications of peer support for families of children with neurodevelopmental and intellectual disabilities: A scoping review. *Frontiers in Public Health, 9*, 719640. https://doi.org/10.3389/fpubh.2021.719640

Cohen, J. (1988). Statistical power analysis for the behavioral sciences. 2nd ed. Hillsdale, N.J: L. Erlbaum Associates; 1988. 567 p.

Cohn, L. N., Pechlivanoglou, P., Lee, Y., Mahant, S., Orkin, J., Marson, A., et al. (2020). Health outcomes of parents of children with chronic illness: A systematic review and meta-analysis. *The Journal of Pediatrics, 218*, 166-177.e2. https://doi.org/10.1016/j.jpeds.2019.10.068

Davis, E., Shelly, A., Waters, E., Boyd, R., Cook, K., & Davern, M. (2010). The impact of caring for a child with cerebral palsy: Quality of life for mothers and fathers [corrected] [published erratum appears in CHILD CARE HEALTH DEV 2010 Mar;36(2):300]. *Child: Care, Health & Development, 36*(1), 63–73. https://doi.org/10.1111/j.1365-2214.2009.00989.x

Dempsey, I., Keen, D., Pennell, D., O'Reilly, J., & Neilands, J. (2009). Parent stress, parenting competence and family-centered support to young children with an intellectual or developmental disability. *Research in Developmental Disabilities, 30*(3), 558–566. https://doi.org/10.1016/j.ridd.2008.08.005

Dlamini, M. D., Chang, Y. J., & Nguyen, T. T. B. (2023). Caregivers' experiences of having a child with cerebral palsy. A meta-synthesis. *Journal of Pediatric Nursing, 73*, 157–168. https://doi.org/10.1016/j.pedn.2023.08.026

Donald, K. A., Samia, P., Kakooza-Mwesige, A., & Bearden, D. (2014). Pediatric cerebral palsy in Africa: A systematic review. *Seminars in Pediatric Neurology, 21*(1), 30–35. https://doi.org/10.1016/j.spen.2014.01.001

Eo, Y. S. (2017). Effects of an empowerment program on the burden of mothers having a child with Cerebral Palsy. *Journal of Korean Academy of Nursing, 35*(1), 154–164. https://doi.org/10.4040/jkan.2005.35.1.154

Fung, B. K., Ho, S. M., Fung, A. S., Leung, E. Y., Chow, S. P., Ip, W. Y., et al. (2011). The development of a strength-focused mutual support group for caretakers of children with cerebral palsy. East Asian archives of psychiatry : official journal of the Hong Kong College of Psychiatrists = Dong Ya jing shen ke xue zhi : Xianggang jing shen ke yi xue yuan qi kan. 2011 Jun;21(2):64–72. Located at: mdc; 21838209.

Gokcin Eminel, A., Kahraman, T., & Genc, A. (2021). Physical workload during caregiving activities and related factors among the caregivers of children with cerebral palsy. *Irish Journal of Medical Science, 190*(2), 701–709. https://doi.org/10.1007/s11845-020-02337-w. Located at: 32789552.

Guillamón, N., Nieto, R., Pousada, M., Redolar, D., Muñoz, E., Hernández, E., et al. (2013). Quality of life and mental health among parents of children with cerebral palsy: The influence of self-efficacy and coping strategies. *Journal of Clinical Nursing, 22*(11–12), 1579–1590. https://doi.org/10.1111/jocn.12124

H M. Decolonizing healthcare innovation low-cost solutions from low-income countries [Internet]. Routledge; 2023. Available from: https://www.routledge.com/Decolonizing-Healthcare-Innovation-Low-Cost-Solutions-from-Low-Income-Countries/Harris/p/book/9781032284958

Hammarberg, K., Sartore, G., Cann, W., & Fisher, J. R. W. (2014). Barriers and promoters of participation in facilitated peer support groups for carers of children with special needs. *Scandinavian Journal of Caring Sciences, 28*(4), 775–783. https://doi.org/10.1111/scs.12110

Harniess, P. A., Gibbs, D., Bezemer, J., & Purna Basu, A. (2022). Parental engagement in early intervention for infants with cerebral palsy—A realist synthesis. *Child: Care, Health and Development, 48*(3), 359–377. https://doi.org/10.1111/cch.12916

Harris, M., Weisberger, E., Silver, D., & Macinko, J. (2015). 'They hear "Africa" and they think that there can't be any good services' – Perceived context in cross-national learning: A qualitative study of the barriers to Reverse Innovation. *Global Health, 11*(1), Article 45. https://doi.org/10.1186/s12992-015-0130-z

Hashem, S. F., & Abd El Aziz, M. A. (2018). The effect of an educational intervention for improving Mothers' care for their children with cerebral palsy. *International Journal of Nursing Didactics*. https://doi.org/10.15520/ijnd.v8i04.2126

He, C., Evans, N., Graham, H., & Milner, K. (2024). Group-based caregiver support interventions for children living with disabilities in low-and-middle-income countries: Narrative review and analysis of content, outcomes, and implementation factors. *Journal of Global Health, 14*, 04055. https://doi.org/10.7189/jogh.14.04055

Higgins, J. P. T., Green, S., (editors). Cochrane Handbook for Systematic Reviews of Interventions [Internet]. Version 5.1.0. 2011 [cited 2024 Feb 29]. Available from: https://training.cochrane.org/handbook/current/chapter-05

Hoffmann, T. C., Glasziou, P. P., Boutron, I., Milne, R., Perera, R., Moher, D., et al. (2014). Better reporting of interventions: Template for intervention description and replication (TIDieR) checklist and guide. *BMJ (Clinical Research Ed.), 348*, g1687. https://doi.org/10.1136/bmj.g1687

Hollung, S. J., Bakken, I. J., Vik, T., Lydersen, S., Wiik, R., Aaberg, K. M., et al. (2020). Comorbidities in cerebral palsy: A patient registry study. *Developmental Medicine & Child Neurology., 62*(1), 97–103. https://doi.org/10.1111/dmcn.14307

Horwood, L., Li, P., Mok, E., Oskoui, M., Shevell, M., & Constantin, E. (2019). Behavioral difficulties, sleep problems, and nighttime pain in children with Cerebral Palsy. *Research in Developmental Disabilities, 95*, 103500. https://doi.org/10.1016/j.ridd.2019.103500

Irwin, L., Jesmont, C., & Basu, A. (2019). A systematic review and meta-analysis of the effectiveness of interventions to improve psychological wellbeing in the parents of children with cerebral palsy. *Research in Developmental Disabilities, 95*, 103511. https://doi.org/10.1016/j.ridd.2019.103511

Jindal, P., MacDermid, J. C., Rosenbaum, P., DiRezze, B., & Narayan, A. (2018). Perspectives on rehabilitation of children with cerebral palsy: Exploring a cross-cultural view of parents from India and Canada using the International Classification of Functioning, Disability and Health. *Disability and Rehabilitation, 40*(23), 2745–2755. https://doi.org/10.1080/09638288.2017.1356383

Karim, T., Muhit, M., Jahan, I., Galea, C., Morgan, C., Smithers-Sheedy, H., et al. (2021). Outcome of community-based early intervention and rehabilitation for children with cerebral palsy in rural Bangladesh: A quasi-experimental study. *Brain Sciences, 11*(9), 1189. https://doi.org/10.3390/brainsci11091189

Kiernan, G., Courtney, E., Ryan, K., McQuillan, R., & Guerin, S. (2020). Parents' experiences of services for their child with a life-limiting neurodevelopmental disability. *Children's Health Care, 49*(2), 134–152. https://doi.org/10.1080/02739615.2019.1605608

King, G., King, S., Rosenbaum, P., & Goffin, R. (1999). Family-centered caregiving and well-being of parents of children with disabilities: Linking process with outcome. *Journal of Pediatric Psychology, 24*(1), 41–53. https://doi.org/10.1093/jpepsy/24.1.41

Koren, P. E., DeChillo, N., & Friesen, B. J. (1992). Measuring empowerment in families whose children have emotional disabilities: A brief questionnaire. *Rehabilitation Psychology, 37*(4), 305–321. https://doi.org/10.1037/h0079106

Kuhlthau, K. A., Bloom, S., Van Cleave, J., Knapp, A. A., Romm, D., Klatka, K., et al. (2011). Evidence for family-centered care for children with special health care needs: A systematic review. *Academic Pediatrics, 11*(2), 136-143.e8. https://doi.org/10.1016/j.acap.2010.12.014

Kumurenzi, A., Richardson, J., Thabane, L., Kagwiza, J., Urimubenshi, G., Hamilton, L., et al. (2023). Effectiveness of interventions by non-professional community-level workers or family caregivers to improve outcomes for physical impairments or disabilities in low resource settings: Systematic review of task-sharing strategies. *Human Resources for Health, 21*(1), 48. https://doi.org/10.1186/s12960-023-00831-7

Kuo, D. Z., Houtrow, A. J., Arango, P., Kuhlthau, K. A., Simmons, J. M., & Neff, J. M. (2012). Family-centered care: Current applications and future directions in pediatric health care. *Maternal and Child Health Journal, 16*(2), 297–305. https://doi.org/10.1007/s10995-011-0751-7

Leader, G., Mooney, A., Chen, J. L., Whelan, S., Naughton, K., Maher, L., et al. (2022). The co-occurrence of autism spectrum disorder and cerebral palsy and associated comorbid conditions in children and adolescents. *Developmental Neurorehabilitation, 25*(5), 289–297. https://doi.org/10.1080/17518423.2021.2011456

Liptak, G. S., Orlando, M., Yingling, J. T., Theurer-Kaufman, K. L., Malay, D. P., Tompkins, L. A., et al. (2006). Satisfaction with Primary Health Care received by families of children with Developmental Disabilities. *Journal of Pediatric Health Care, 20*(4), 245–252. https://doi.org/10.1016/j.pedhc.2005.12.008

Lord, C., Rapley, T., Marcroft, C., Pearse, J., & Basu, A. (2018). Determinants of parent-delivered therapy interventions in children with cerebral palsy: A qualitative synthesis and checklist. *Child: Care, Health and Development, 44*(5), 659–669. https://doi.org/10.1111/cch.12592

McCann, D., Bull, R., & Winzenberg, T. (2012). The daily patterns of time use for parents of children with complex needs: A systematic review. *Journal of Child Health Care, 16*(1), 26–52. https://doi.org/10.1177/1367493511420186

McCarthy, E., & Guerin, S. (2022). Family-centred care in early intervention: A systematic review of the processes and outcomes of family-centred care and impacting factors. *Child: Care, Health and Development, 48*(1), 1–32. https://doi.org/10.1111/cch.12901

McConachie, H., Huq, S., Munir, S., Ferdous, S., Zaman, S., & Khan, N. Z. (2000). A randomized controlled trial of alternative modes of service provision to young children with cerebral palsy in Bangladesh. *Journal of Pediatrics, 137*(6), 769–776. https://doi.org/10.1067/mpd.2000.110135. Located at: cul.

McDowell, N. (2021). Power is knowledge: Empowering parents of children with cerebral visual impairment. *Disability & Society, 36*(4), 596–617. https://doi.org/10.1080/09687599.2020.1751586

McGlinchey, C., Harniess, P., Borek, A. J., Garrood, A., McDonald, A., Boyle, F., et al. (2024). What aspects of health and wellbeing are most important to parent carers of children with disabilities? *Health Expectations, 27*(3), e14085. https://doi.org/10.1111/hex.14085

McHugh, C., Bailey, S., Shilling, V., & Morris, C. (2013). Meeting the information needs of families of children with chronic health conditions. *Physical & Occupational Therapy in Pediatrics, 33*(3), 265–270. https://doi.org/10.3109/01942638.2013.799628

McIntyre, S., Goldsmith, S., Webb, A., Ehlinger, V., Hollung, S. J., McConnell, K., et al. (2022). Global prevalence of cerebral palsy: A systematic analysis. *Developmental Medicine & Child Neurology, 64*(12), 1494–1506. https://doi.org/10.1111/dmcn.15346

McKenzie, J. E., Brennan, S. E. Chapter 12: Synthesizing and presenting findings using other methods. In: Cochrane Handbook for Systematic Reviews of Interventions [Internet]. Cochrane; 2024 [cited 2025 May 26]. (Version 6.5). Available from: https://training.cochrane.org/handbook/current/chapter-12

McMillan, L. J., McCarthy, M. C., Muscara, F., Anderson, V. A., Walser, R. D., O'Neill, J., et al. (2020). Feasibility and acceptability of an online acceptance and commitment therapy group for parents caring for a child with cerebral palsy. *Journal of Family Studies, 28*(4), 1338–1354. https://doi.org/10.1080/13229400.2020.1822198. Located at: psyh; 2020-77035-001.

Melendez-Torres, Gj., Sutcliffe, K., Burchett, H. E. D., Rees, R., & Thomas, J. (2019). Developing and testing intervention theory by incorporating a views synthesis into a qualitative comparative analysis of intervention effectiveness. *Research Synthesis Methods, 10*(3), 389–397. https://doi.org/10.1002/jrsm.1341

Miller L., Imms C., Cross A., Pozniak K., O'Connor B., Martens R., et al. Impact of ENVISAGE-Families workshops on outcomes for caregivers of children with neurodisabilities. Dev Med Child Neurol. 2023;35th Annual Meeting of the European Academy of Childhood Disability, EACD 2023. Ljubljana Slovenia.65(Supplement 2):19–20. https://doi.org/10.1111/dmcn.15594

Mirza, M., Krischer, A., Stolley, M., Magaña, S., & Martin, M. (2018). Review of parental activation interventions for parents of children with special health care needs. *Child: Care, Health and Development, 44*(3), 401–426. https://doi.org/10.1111/cch.12554

Mlinda, S. J., Leyna, G. H., & Massawe, A. (2018). The effect of a practical nutrition education programme on feeding skills of caregivers of children with cerebral palsy at Muhimbili National Hospital, in Tanzania. *Child: Care, Health & Development, 44*(3), 452–461. https://doi.org/10.1111/cch.12553. Located at: cul.

Morris, S. B., & DeShon, R. P. (2002). Combining effect size estimates in meta-analysis with repeated measures and independent-groups designs. *Psychological Methods, 7*(1), 105–125. https://doi.org/10.1037/1082-989X.7.1.105

Morris, C., Janssens, A., Tomlinson, R., Williams, J., & Logan, S. (2013). Towards a definition of neurodisability: A Delphi survey. *Developmental Medicine & Child Neurology, 55*(12), 1103–1108. https://doi.org/10.1111/dmcn.12218

Muthukaruppan, S. S., Cameron, C., Campbell, Z., Krishna, D., Moineddin, R., Bharathwaj, A., et al. (2022). Impact of a family-centred early intervention programme in South India on caregivers of children with developmental delays. *Disability & Rehabilitation, 44*(11), 2410–2419. https://doi.org/10.1080/09638288.2020.1836046. Located at: cul.

Nagel, K., Robinson, S. J., & Rosenbaum, P. (2008). Pediatric healthcare quality: A novel approach to lifelong child health research. *Journal of Healthcare Quality, 30*(2), 31–36. https://doi.org/10.1111/j.1945-1474.2008.tb01132.x

Nanyunja, C., Sadoo, S., Kohli-Lynch, M., Nalugya, R., Nyonyintono, J., Muhumuza, A., et al. (2022). Early care and support for young children with developmental disabilities and their caregivers in Uganda: The Baby Ubuntu feasibility trial. Frontiers in Pediatrics [Internet]. 2022 [cited 2024 Jan 31];10. Available from: https://www.frontiersin.org/articles/https://doi.org/10.3389/fped.2022.981976

National Institute for Health and Care Excellence (NICE). Cerebral palsy in under 25s: assessment and management (NG62). 2017. Report No.

Nobakht, Z., Rassafiani, M., Hosseini, S. A., & Hosseinzadeh, S. (2020) A web-based daily care training to improve the quality of life of mothers of children with cerebral palsy: A randomized controlled trial. *Research in developmental disabilities, 105*, 103731. https://doi.org/10.1016/j.ridd.2020.103731. Located at: mdc; 32659699.

Novak-Pavlic, M., Rosenbaum, P., Gazzi Macedo, L., Di Rezze, B., Yong, J., Noori, A., et al. (2022). Effectiveness of interventions to promote physical, psychological, and socioeconomic well-being outcomes of parents of children with neurodevelopmental disabilities: Protocol for a systematic review. *JMIR Research Protocols, 11*(7), e38686. https://doi.org/10.2196/38686

Nygård, C., & Clancy, A. (2018). Unsung heroes, flying blind-A metasynthesis of parents' experiences of caring for children with special health-care needs at home. *Journal of Clinical Nursing, 27*(15–16), 3179–3196. https://doi.org/10.1111/jocn.14512

Olusanya, B. O., Smythe, T., Ogbo, F. A., Nair, M. K. C., Scher, M., & Davis, A. C. (2023). Global prevalence of developmental disabilities in children and adolescents: A systematic umbrella review. *Frontiers in Public Health, 11*, 1122009. https://doi.org/10.3389/fpubh.2023.1122009

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., et al. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *BMJ, 29*, n71. https://doi.org/10.1136/bmj.n71

Pavone, P., Gulizia, C., Le Pira, A., Greco, F., Parisi, P., Di Cara, G., et al. (2021). Cerebral palsy and epilepsy in children: Clinical perspectives on a common comorbidity. *Children, 8*(1), 1. https://doi.org/10.3390/children8010016

Påhlman, M., Gillberg, C., & Himmelmann, K. (2021). Autism and Attention-Deficit/Hyperactivity Disorder in children with Cerebral Palsy: High prevalence rates in a population-based study. *Developmental Medicine & Child Neurology, 63*(3), 320–327. https://doi.org/10.1111/dmcn.14736

Pilon, B. H., & Smith, K. A. (1985). A parent group for the Hispanic parents of children with severe cerebral palsy. Children's Health Care, 14(2), 96–102. https://doi.org/10.1207/s15326888chc1402_5. Located at: psyh; 1986-28207-001.

Poojari, D. P., Umakanth, S., Maiya, G. A., Rao, B. K., Khurana, S., Kumaran, D. S., et al. (2024). Effect of family-centered care interventions on well-being of caregivers of children with cerebral palsy: A systematic review. *F1000Research, 12*, 790. https://doi.org/10.12688/f1000research.133314.2

Pousada, M., Guillamón, N., Hernández-Encuentra, E., Muñoz, E., Redolar, D., Boixadós, M., et al. (2013). Impact of caring for a child with cerebral palsy on the quality of life of parents: A systematic review of the literature. *Journal of Developmental and Physical Disabilities, 25*(5), 545–577. https://doi.org/10.1007/s10882-013-9332-6

Prest, K., Wilson, E., Vassiliadou, I., Ali, S., Lakhanpaul, M., Morris, C., et al. (2024a). 'There was nothing, just absolute darkness': Understanding the needs of those caring for children and young people with complex neurodisability in a diverse UK context: A qualitative exploration in the ENCOMPASS study. *Child: Care, Health & Development, 50*(4), 1–12. https://doi.org/10.1111/cch.13303. Located at: cul.

Prest, K., Harden, A., Heys, M., Hurt, C. (2024b). Group programmes to improve the skills, confidence and wellbeing of caregivers of children with neurodisability: a systematic review protocol [report] [Internet]. City, University of London; 2024 Nov [cited 2026 Mar 15]. Report No. Available from: https://city.figshare.com/articles/report/Group_programmes_to_improve_the_skills_confidence_and_wellbeing_of_caregivers_of_children_with_neurodisability_a_systematic_review_protocol/27679881/1 https://doi.org/10.25383/city.27679881.v1

Rauchenzauner, M., Schiller, K., Honold, M., Baldissera, I., Biedermann, R., Tschiderer, B., et al. (2021). Visual impairment and functional classification in children with Cerebral Palsy. *Neuropediatrics, 52*(5), 383–389. https://doi.org/10.1055/s-0040-1722679

Reichow, B., Kogan, C., Barbui, C., Maggin, D., Salomone, E., Smith, I. C., et al. (2024). Caregiver skills training for caregivers of individuals with neurodevelopmental disorders: A systematic review and meta-analysis. *Developmental Medicine & Child Neurology*. https://doi.org/10.1111/dmcn.15764

Rosenbaum, P. (2007). A report: The definition and classification of Cerebral Palsy April 2006. *Developmental Medicine & Child Neurology, 49*(s109), 8–14. https://doi.org/10.1111/j.1469-8749.2007.tb12610.x

Rosenbaum, P., & Gorter, J. W. (2012). The ‘F-words’ in childhood disability: I swear this is how we should think! *Child: Care, Health and Development, 38*(4), 457–463. https://doi.org/10.1111/j.1365-2214.2011.01338.x

Rosenbaum, P., King, S., Law, M., King, G., & Evans, J. (1998). Family-Centred Service: A Conceptual Framework and Research Review. Physical & Occupational Therapy In Pediatrics, 18(1), 1–20. https://doi.org/10.1080/J006v18n01_01Family-Centred

Rosenbaum, P. L., & Novak-Pavlic, M. (2021). Parenting a child with a neurodevelopmental disorder. *Current Developmental Disorders Reports, 8*(4), 212–218. https://doi.org/10.1007/s40474-021-00240-2

Salomone, E., Ferrante, C., Salandin, A., Ferrara, F., Torchio, E., Foletti, G., et al. (2022). Acceptability and feasibility of the World Health Organization’s Caregiver Skills Training implemented in the Italian National Health System. *Autism : The International Journal of Research and Practice, 26*(4), 859–874. https://doi.org/10.1177/13623613211035228

Scherer, N., Verhey, I., & Kuper, H. (2019). Depression and anxiety in parents of children with intellectual and developmental disabilities: A systematic review and meta-analysis. *PLoS ONE, 14*(7), e0219888. https://doi.org/10.1371/journal.pone.0219888

Schünemann, H., Brożek, J., Guyatt, G., Oxman, A., editor. GRADE Handbook for Grading Quality of Evidence and Strength of Recommendations [Internet]. 2013 [cited 2025 Aug 8]. Available from: guidelinedevelopment.org/handbook

Shevell, M., Oskoui, M., Wood, E., Kirton, A., Van Rensburg, E., Buckley, D., et al. (2019). Family-centred health care for children with cerebral palsy. *Developmental Medicine and Child Neurology, 61*(1), 62–68. https://doi.org/10.1111/dmcn.14053

Shilling, V., Morris, C., Thompson-Coon, J., Ukoumunne, O., Rogers, M., & Logan, S. (2013). Peer support for parents of children with chronic disabling conditions: A systematic review of quantitative and qualitative studies. *Developmental Medicine and Child Neurology, 55*(7), 602–609. https://doi.org/10.1111/dmcn.12091

Smythe, T., Reichenberger, V., Pinzón, E. M., Hurtado, I. C., Rubiano, L., & Kuper, H. (2023). The feasibility of establishing parent support groups for children with congenital Zika syndrome and their families: A mixed-methods study. *Wellcome Open Res, 6*, 158. https://doi.org/10.12688/wellcomeopenres.16839.3

Sterne, J. A., Hernán, M. A., Reeves, B. C., Savović, J., Berkman, N. D., Viswanathan, M., et al. (2016). ROBINS-I: A tool for assessing risk of bias in non-randomised studies of interventions. *BMJ (Clinical Research Ed.), 355*, i4919. https://doi.org/10.1136/bmj.i4919

Sterne, J. A. C., Savović, J., Page, M. J., Elbers, R. G., Blencowe, N. S., Boutron, I., et al. (2019). RoB 2: A revised tool for assessing risk of bias in randomised trials. *BMJ (Clinical Research Ed.), 366*, l4898. https://doi.org/10.1136/bmj.l4898

Tann, C. J., Kohli-Lynch, M., Nalugya, R., Sadoo, S., Martin, K., Lassman, R., et al. (2021). Surviving and thriving. *Infants & Young Children, 34*(1), 17–32. https://doi.org/10.1097/IYC.0000000000000182

Tekola, B., Girma, F., Kinfe, M., Abdurahman, R., Tesfaye, M., Yenus, Z., et al. (2020). Adapting and pre-testing the World Health Organization's Caregiver Skills Training programme for autism and other developmental disorders in a very low-resource setting: Findings from Ethiopia. *Autism, 24*(1), 51–63. https://doi.org/10.1177/1362361319848532

Terwiel, M., Alsem, M. W., Siebes, R. C., Bieleman, K., Verhoef, M., & Ketelaar, M. (2017). Family-centred service: Differences in what parents of children with cerebral palsy rate important. *Child: Care, Health and Development, 43*(5), 663–669. https://doi.org/10.1111/cch.12460

The King's Fund. The NHS in a nutshell [Internet]. 2024 [cited 2024 Jan 31]. Available from: https://www.kingsfund.org.uk/projects/nhs-in-a-nutshell

Thomas, J., Graziosi, S., Brunton, J., Ghouze, Z., O'Driscoll, P., Bond, M., et al. (2023). *EPPI-Reviewer: Advanced software for systematic reviews, maps and evidence synthesis*. UCL Social Research Institute, University College London.

Vadivelan, K., Sekar, P., Sruthi, S. S., & Gopichandran, V. (2020). Burden of caregivers of children with cerebral palsy: An intersectional analysis of gender, poverty, stigma, and public policy. *BMC Public Health, 20*(1), 645–645. https://doi.org/10.1186/s12889-020-08808-0

van Aswegen, T., Myezwa, H., Potterton, J., & Stewart, A. (2019). The effect of the Hambisela programme on stress levels and quality of life of primary caregivers of children with cerebral palsy: A pilot study. *South African Journal of Physiotherapy, 75*(1), 461. https://doi.org/10.4102/sajp.v75i1.461

Wan, X., Wang, W., Liu, J., & Tong, T. (2014). Estimating the sample mean and standard deviation from the sample size, median, range and/or interquartile range. *BMC Medical Research Methodology, 14*(1), 135. https://doi.org/10.1186/1471-2288-14-135

Whittingham, K., Wee, D., & Boyd, R. (2011). Systematic review of the efficacy of parenting interventions for children with cerebral palsy. *Child: Care, Health and Development, 37*(4), 475–483. https://doi.org/10.1111/j.1365-2214.2011.01212.x

World Health Organization (2007). PEPFAR, UNAIDS. Task shifting : rational redistribution of tasks among health workforce teams : global recommendations and guidelines. 88.

Yılmaz, H., Erkin, G., & Nalbant, L. (2013). Depression and anxiety levels in mothers of children with cerebral palsy: A controlled study. *European Journal of Physical and Rehabilitation Medicine., 9*, 49.

Zhao, Y., Hagel, C., Tweheyo, R., Sirili, N., Gathara, D., & English, M. (2021). Task-sharing to support paediatric and child health service delivery in low- and middle-income countries: Current practice and a scoping review of emerging opportunities. *Human Resources for Health, 19*, 95. https://doi.org/10.1186/s12960-021-00637-5

Zuurmond, M., O'Banion, D., Gladstone, M., Carsamar, S., Kerac, M., Baltussen, M., et al. (2018). Evaluating the impact of a community-based parent training programme for children with cerebral palsy in Ghana. *PLoS ONE, 13*(9), e0202096. https://doi.org/10.1371/journal.pone.0202096

Zuurmond, M., Nyante, G., Baltussen, M., Seeley, J., Abanga, J., Shakespeare, T., et al. (2019). A support programme for caregivers of children with disabilities in Ghana: Understanding the impact on the wellbeing of caregivers. Child: Care, Health & Development, 45(1), 45–53. https://doi.org/10.1111/cch.12618

Authors and Affiliations

Kirsten Prest[1,2] · **Kirsten Barnicot**[1] · **Stewart Drew**[4] · **Catherine Hurt**[1] · **David Nicklin**[1,3] · **Angela Harden**[1] · **Michelle Heys**[2,4]

✉ Kirsten Prest
kirsten.prest@citystgeorges.ac.uk

Kirsten Barnicot
Kirsten.Barnicot@citystgeorges.ac.uk

Stewart Drew
stewartdrew1908@aol.com

Catherine Hurt
Catherine.Hurt.1@citystgeorges.ac.uk

David Nicklin
d.nicklin@nhs.net

Angela Harden
Angela.Harden@citystgeorges.ac.uk

Michelle Heys
m.heys@ucl.ac.uk

[1] School of Health and Medical Sciences, City St Georges, University of London, London, UK

[2] Specialist Children's and Young People's services, Newham, East London NHS Foundation Trust, London, UK

[3] Musculoskeletal Service, Old Nurses Home, Whittington Hospital, London, UK

[4] UCL Great Ormond Street Institute for Child Health, University College London, London, UK