**ORIGINAL ARTICLE** 



OPEN ACCESS Check for updates

# Livelihood support for caregivers of children with developmental disabilities: findings from a scoping review and stakeholder survey

Eva M. Loucaides<sup>a</sup> (D), Maria Zuurmond<sup>b</sup>, Mathieu Nemerimana<sup>c</sup>, Catherine M. Kirk<sup>c</sup>, Rachel Lassman<sup>d</sup>, Albert Ndayisaba<sup>c</sup>, Tracey Smythe<sup>b,e</sup> (D), Erick Baganizi<sup>c</sup> and Cally J. Tann<sup>a,f,g</sup> (D)

<sup>a</sup>Centre for Maternal, Adolescent, Reproductive and Child Health (MARCH Centre), London School of Hygiene & Tropical Medicine, London, UK; <sup>b</sup>International Centre for Evidence in Disability, London School of Hygiene & Tropical Medicine, London, UK; <sup>c</sup>Maternal and Child Health Programme, Partners in Health/Inshuti Mu Buzima (PIH/IMB), Kigali, Rwanda; <sup>d</sup>Kyaninga Child Development Centre, Fort Portal, Uganda; <sup>e</sup>Division of Physiotherapy, Department of Health and Rehabilitation Sciences, Stellenbosch University, Cape Town, South Africa; <sup>f</sup>Social Aspects of Care Programme, MRC/UVRI & LSHTM Uganda Research Unit, Entebbe, Uganda; <sup>g</sup>Neonatal Medicine, University College London Hospitals NHS Trust, London, UK

#### ABSTRACT

**Purpose:** Poverty amongst families with a child with disability adversely impacts child and family quality of life. We aimed to identify existing approaches to livelihood support for caregivers of children with developmental disabilities in low- and middle-income countries.

**Methods:** This mixed-method study incorporated a scoping literature review and online stakeholder survey. We utilised the World Health Organization community-based rehabilitation (CBR) matrix as a guiding framework for knowledge synthesis and descriptively analysed the included articles and survey responses. **Results:** We included 11 peer-reviewed publications, 6 grey literature articles, and 49 survey responses from stakeholders working in 22 countries. Identified programmes reported direct and indirect strategies for livelihood support targeting multiple elements of the CBR matrix; particularly skills development, access to social protection measures, and self-employment; frequently in collaboration with specialist partners, and as one component of a wider intervention. Self-help groups were also common. No publications examined effectiveness of livelihood support approaches in mitigating poverty, with most describing observational studies at small scale.

**Conclusion:** Whilst stakeholders describe a variety of direct and indirect approaches to livelihood support for caregivers of children with disabilities, there is a lack of published literature on content, process, and impact to inform future programme development and delivery.

# ► IMPLICATIONS FOR REHABILITATION

- Disability and poverty are interlinked, but little is known on approaches to livelihood support for caregivers of children with developmental disabilities in low- and middle-income countries.
- Stakeholders report direct and indirect strategies for livelihood support targeting multiple livelihood elements; particularly skills development, access to social protection measures and self-employment; frequently in collaboration with specialist partners, and as one component of a wider intervention.
- Improved reporting of livelihood targeted activities inclusive of evaluation of feasibility, acceptability
  and impact would support wider implementation of effective livelihood programmes for caregivers of
  children with disability.

# Introduction

Globally, there are an estimated 53 million children, under fiveyears of age, living with developmental disabilities, with approximately 95% living in low- and middle-income countries (LMICs) [1]. In Sub-Saharan Africa, the number of affected children is reported to have increased by more than 70% between 1990 and 2016 [1]. It is increasingly understood that poverty and disability are interlinked and can exacerbate each other [2–5] and this has been shown to also be true for childhood disability [6–8]. Supporting livelihood, defined as the capabilities, assets, and activities required for a means of living [9], is crucial for families of children with developmental disabilities, if we are to "leave noone behind" as part of the Global Strategy's "survive, thrive and transform" agenda [10].

Childhood developmental disabilities are chronic conditions that emerge during the period of early child development and cause impairments in the child's physical, cognitive, or behavioural development [11,12]. Children with developmental disabilities frequently have complex needs, including suboptimal nutrition, health, educational attainment, and quality of life [13–15]. Meeting these needs commonly falls to the children's

CONTACT Cally Tann a cally.tann@lshtm.ac.uk Dundon School of Hygiene and Tropical Medicine, Keppel Street, London WC1E 7HT, UK Supplemental data for this article can be accessed online at https://doi.org/10.1080/09638288.2022.2160018.

© 2022 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.

## **ARTICLE HISTORY**

Received 12 May 2022 Revised 12 December 2022 Accepted 13 December 2022

#### **KEYWORDS**

Livelihood; intervention; child disability; caregiver; low- and middle-income countries

This is an Open Access article distributed under the terms of the Creative Commons Attribution License (http://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

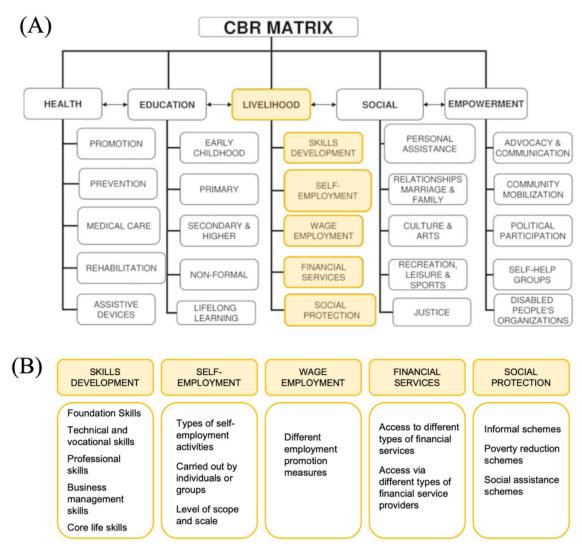


Figure 1. The WHO CBR matrix and its livelihood component. (A) Overview of the WHO CBR matrix. Adapted from World Health Organization. Community-based rehabilitation: CBR guidelines [24]. (B) Elements of the CBR matrix livelihood component and their core aspects.

primary caregivers, which can be parents, other family members or anyone with caring responsibilities for a child with developmental disability, a large proportion of whom will be women. In LMICs, medical, educational, and social services for children with disabilities and their families may be lacking or affected by limited health care budgets and workforce shortages [16]. As a result, the need to involve, support, and empower families is central to many interventions aimed at maximising health, well-being, and quality of life of children with developmental disability.

Financial challenges for caregivers include direct costs such as financing assistive devices, medications, rehabilitation, and other health-related treatment, as well as paying for transport to access care distant from the family home [4,17]. In addition, indirect costs occur due to loss of productivity, i.e., loss of opportunity to engage in income generating activities due to caring commitments [5]. A lack of financial support from family members or spouses, with many families being single parent households, may further compound financial challenges [5,18]. In particular, fathers' absence from the family unit is not uncommon [19,20]. Unfortunately, families frequently experience social isolation, contributed to by stigma and discrimination, which adds complex hurdles to overcoming poverty [17,21–23]. The World Health Organization's Community Based Rehabilitation (CBR) guidelines [24] emphasise the need to support households and families looking after a person with disability. The CBR matrix (Figure 1) is a framework developed to create uniformity in programmes and highlight the different sectors and elements that encompass the CBR strategy [24]. Whilst it can provide a useful framework for programme development and delivery, this must be implemented in a way that is flexible and sensitive to diverse local cultural contexts [25] with its limitations as a generalised, non-locally driven approach recognised.

The CBR matrix acknowledges the multi-dimensional nature of support needed and includes livelihood alongside health, education, social, and empowerment components. Within the livelihood component specifically, there are five elements: skills development, self-employment, wage employment, financial services, and social protection (Figure 1(A)), each with sub-sections or core aspects referred to in CBR guidelines on the livelihood component [24] (Figure 1(B)).

Livelihood programmes exist in many LMIC settings, however, these usually target adults with the aim of improving the livelihood of the person with disability directly [24], such as vocational rehabilitation to support individuals to access, maintain or return to employment. Less is known on the role, approach, and effectiveness of programmes to specifically support the livelihood of caregivers of children with disabilities. Indeed, a preliminary search of MEDLINE, the Cochrane Database of Systematic Reviews and JBI Evidence Synthesis revealed no current, or underway, systematic or scoping reviews on programmes specifically targeting caregivers of children with disability. In response to this information gap, we aimed to identify existing approaches to supporting the livelihood of caregivers of children with developmental disabilities in LMICs. The specific objective of the research was to conduct a scoping review of the literature and online survey of stakeholders working with families of children with developmental disabilities, to examine the role, approach and evidence for existing livelihood support programmes.

### Methods

#### Scoping review

We conducted a scoping review of the published and grey literature in accordance with the Joanna Briggs Institute (JBI) methodology [26] with results reported in accordance with Preferred Reporting Items for Systematic Reviews and Meta-analyses extension for scoping review (PRISMA-ScR) guidance [27].

#### Search strategy & source of evidence

The search strategy (Supplemental Material) was informed by a preliminary literature review identifying relevant key terms and developed with the input of a specialist librarian. We utilised four groups of search terms linked by the Boolean operator AND related to (1) children with developmental disability, (2) care-givers, (3) livelihood, and (4) LMICs to search MEDLINE, Embase, Global Health, Web of Science, CINAHL, and PsycINFO for articles published between January 2000 and May 2021. No limit to language of publication was applied. The reference lists of all included full text articles were screened for additional studies. We searched grey literature of key international non-governmental organisations and United Nations organisations, working with children with disabilities, that were recommended by team consensus (Supplemental Material).

Articles were included if they (a) referred to work carried out in LMICs, as defined by the World Bank on the basis of per-capita gross national income [28], (b) referred to caregivers with children with developmental disabilities, and (c) referred to an intervention offered to caregivers with the aim to improve caregiver or household livelihood. In alignment with the WHO CBR guidelines [24], we defined a livelihood intervention as one that aims to help individuals and their families to secure the necessities of life and improve their economic and social situations. Publications were included where livelihood was addressed as one element of a broader intervention, as long as the livelihood component was delineated. Publications were excluded if they provided descriptive data relating to caregiver livelihood burden only with no interventional component or if they described an intervention without any livelihood-targeted component.

We considered studies of experimental and observational design as well as opinion papers, review articles, reports, and guidelines or policy documents for inclusion in this scoping review if meeting eligibility criteria.

## Screening, data extraction and data analysis

Search results were imported into EndNote20 and duplicates removed. Two reviewers (EL, MZ) parallel screened first 5% of title and abstracts and subsequently 20% of full texts of search results with >80% agreement rate as to inclusion or exclusion at each

stage of the screening process. The remaining search results were screened by the two reviewers independently with discussion in cases of uncertainty. The search and the study inclusion processes were presented in a PRISMA-ScR flow diagram. Data from eligible articles were charted using a structured data abstraction tool developed for this review. We did not critically appraise individual publications as the aim of the review was to map the scope and breadth of the studies. Data from included studies was synthesised in summary tables and mapped geographically according to location of programmes described.

## **Online stakeholder survey**

The survey questionnaire (Supplemental Material) asked participants to provide information on any livelihood support work (aligned with the elements of the CBR matrix livelihood component), as well as descriptive data on the survey participant's programme. Respondents could detail further aspects of their work in optional free text questions. The questionnaire was developed in English and piloted with the input of key-stakeholders with experience in livelihood work (parents of children with disability, allied health professionals and policy makers). Feedback indicated that no substantial changes were required and no language barriers identified.

#### Survey dissemination and administration

The online survey was disseminated by email and social media by snowball methodology. We sought input from a wide range of relevant stakeholders working with families with children with developmental disability from diverse LMIC settings and utilised professional members organisations, networks and individual contacts to initiate dissemination (Supplementary Material).

#### Survey data management and analysis

Survey data was entered by participants directly into a password protected online form or collected by email. Analysis involved descriptive statistics (frequencies and percentages) using Excel. Countries were aggregated by world region or income level as defined by the World Bank [28].

## **Ethical considerations**

Informed consent was taken with survey participants invited to read a participant information sheet at the start of the survey and checking a tick-box indicating consent before progressing to the survey questionnaire. Ethics approval for this research was given by the London School of Hygiene & Topical Medicine Research Ethics Committee (LSHTM Ethics ref 25187).

# Results

#### Findings from the scoping review

Of 2075 unique results, our search yielded only 153 publications (7.3%) that referred to caregiver livelihood (Figure 2). Only 11 of these described a targeted livelihood intervention and were therefore included [29–39] (Figure 2). A summary of the included peerreviewed publications is presented in Table 1.

Table 2 summarises the six grey literature references to specific programmes supporting the livelihood of caregivers of children with disabilities [40–45].

Scoping review findings were reported according to geographic setting, the primary recipient of livelihood support, study

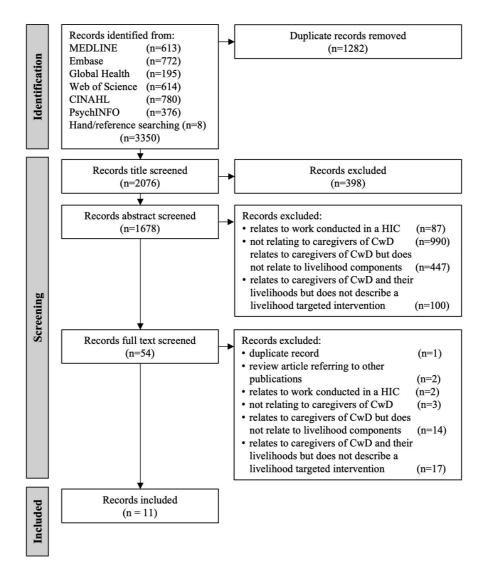


Figure 2. PRISMA-ScR flow diagram of bibliometric database search results and study inclusion process. CwD: child(ren) with disability; HIC: high-income country.

design, outcome measures, and element of the CBR matrix livelihood targeted. specified the period of data collection which ranged from one month to a four-year period (Tables 1 and 2).

# Geographic setting

Six peer-reviewed publications were from the Sub-Saharan Africa region, three from the South Asia region and one each from Europe & Central Asia and Latin America and the Caribbean (Figure 3(A)). Studies were conducted in both urban and rural settings (Table 1). Identified programmes from the grey literature were active in both Sub-Saharan Africa and South Asia (Figure 3(A)).

# **Programme recipients**

Most peer-reviewed and grey literature publications did not specify the primary and secondary recipients of described programmes in any detail, and sample size of intervention recipients, where reported, varied widely (Tables 1 and 2). Only three programmes identified in peer-reviewed publications detailed the age range of the involved children with disability (0–15 years [29–31], 2–14 years [35], and 4–14 years [33]). None focussed exclusively on children in the period of early child development (0–3 years). The timescale of any livelihood-related programme activities was rarely detailed; nine peer-reviewed publications

#### Study designs and outcome measures

Study designs were predominantly observational, relying on pre/ post evaluation if any. Evaluations commonly employed mixed methods, with qualitative outcome measures more common than quantitative measures and largely presented outcome measures related to child or parental physical or mental wellbeing. No quantitative outcome measures relating specifically to livelihood were reported, such as income level, employment status, engagement in job seeking activities or skill acquisition or access to social protection measures such as benefits. One study utilised a quantitative measure related to social support-the Multidimensional Scale of Perceived Social Support (MSPSS) [46] which assesses the perception of informal social support by friends and family-and the study's mixed methods evaluation suggested strong links between group processes relating to "handling goods and money" and "benefits to child and family" [30]. One grey literature publication reported on the level of knowledge of and access to of the Ghanaian Disability Common Fund as an outcome measure [41].

Study design & auccome messure         Intervention overview         Intervention learboot content           Study design & interventional (pre-port: control pre-port)         SHGs set up with weekly SHG         SHGs, limbhood content         SHG           Study design         SHGs set up with SHG         SHGs, limbhood prodesit on the interventional (pre-port: counting and so counting and so coal support services counting employerement, support community inclusion, through SHGs; facilitation SHS-sections communication Dualitative:         SHG				Intervention recipients:	
Study design & outcome measure         Intervention overview         Intervention livelihood coment merventional (prer-post- evaluation)         Study design         Study design         Study merver-portion families         Study merver-portion families         Study merver-portion families         Study merver-portion         Study merver-portion families         Study merver-p				intervention recipients.	
Study design & autrome measure         Intervention overview         Intervention livelihood content           Study design solution         Stids, study design interventional (per-post- evaluation)         Stids, study design interventional (per-post- evaluation)         Stids, study design interventional (per-post- evaluation)         Stids, study design intervention (per-post- evaluation)         Stids, study design intervention, provided, anning, and sold, study design; mery sport, community incluiding sensitive profile; anting personal studyon, sersition and sold, studyon, submit and excess to bealth and education is sport, and post- post study design;         Stids profile; intervention and sold, studyon, sersition sensitions are commit- empoort, community incluiding and study design;         Stids profile; intervention are sport, and proverment and informatione         Stids profile intervention and sold, studyon, sersition sensitions are commit- empoort, and prosmit and are sport to families (eg. s profile in ly and are study and sold, support to families (eg. s profile in ly and are study and sold, support to families (eg. s proverment and domination barents of children with spina are study and development for informational (meating and sold, support to families (eg. s proverment and domination barents of children with spina are study and development of and and bare babout support group discussions and and digly babeout support group discussions and and digly babe				child w dicability	
Study design & autome measure         Intervention overview         Intervention invelves SIG         Rest study weekly SIG         SIG         Rest study weekly SIG         SIG         Rest study weekly SIG         SIG         Rest study stations, peak more and weekly SIG         SIG         Rest study stations, peak more and weekly SIG         SIG         Rest study stations, peak more and weekly SIG         SIG         Rest study stations, peak more and weekly SIG         SIG         Rest study stations, peak more and weekly SIG         SIG         Rest study stations, peak more and weekly SIG         SIG         Rest study stations, peak more and weekly SIG         SIG         Rest study stations, peak more and weekly SIG         SIG         Rest study stations, peak study stations, study stations, a study statins, a st			Scone	und w disability - Arre	
outcome measure         Intervention overview         Intervention livelihood content sequation)         Intervention livelihood projects for merry go-rund, faming, access to baining personal stuations, pert semi-structured interviews         SHS         Intervention livelihood content merry go-rund, faming, access to baining personal stuations, pert sub-sections communication         SHS         Provident and merry go-rund, faming, access to health and education         Sections to merry go-rund, faming, access to health and education         Sections to merry go-rund, faming, access to merry go-rund, faming, and access to health and education         Sections to merry go-rund, faming, access to merry go-rund, faming, and access to health and education         Sections to merry go-rund, faming, access to merry go-rund, faming, access to bail acceleration         Sections to merry go-rund, faming, access to merry go-rund, faming, access to bail acceleration         Sections to merry go-rund, faming, access to merry go-rund, faming, access to access to health and education         Sections to merry go-rund, faming, access to merry go-rund, faming, access to merry go-rund, faming, access to bail acceleration         Sections to merry go-rund, faming, access to merry go-rund, faming, access to merry go-rund, faming, access to merry go-rund, faming, access to metro acceleration         Section           Study design         Study design         Study design         faming faming faming, faming faming faming to mediated to the faming faming faming to mediated to the faming faming faming faming faming faming to adminative         faming faming faming faming to mediated to the faming to adming faming faming faming faming faming faming faming to study design	Element(s) of the CBR matrix		- Nr of participants	- Disability	Intervention recipients:
Stady disgr	livelihood component targeted	Delivering organisation	- Timeframe	- Other	caregiver
Interventional (pre-foot- eduation)         meeting and 6 monthy revaluation)         incurding contrants         incurding revaluation         incurding revaluation           Outcome measures         the initiated seconds converging communitation         inancing and social support revaluation; recommic sensitructured interviews sensitructured interviews         inancing and social support revaluation; recommic sensitructured interviews           Sub-section Disability Profile; Mutidimensional Scale of Perceived Scali Support         Fee support*         and revaluation; recommic enpowerment* and "peer support*           Study degit: Mutidimensional Scale of Perceived Scali Support         Fee providing emotional, physical, financial support to families (eg. materal/finstrumental and comment review         inear support*         and revealed equipment for impower heat heat for medications, heat hore, informational support of preed acquipment for materal/finstrumental and for medications, heat hore, for medications, heat hore, informational support of preed acquipment for interviews, observations, heat hore, informational support of preed acquipment for materal/finstrumental and document review           Study degit: Observation         Step providing emotional, physical, financial support to financial support of preed actions, heat hore, document review         free support*           Study degit: Observation         Diservation (meed activity exploring preed activity with spina support oper unit for materal/finstrumental support of preed activity subport for social support of preed activity subport for social support of preed activity subport for social support of preed acticrity subport for social support of preed activity so		Public academic;	Nr of participants:	Age:	Age:
economic metry-or-round, farming- cectonic empowerment, support, community indusion, sessions on "economic support, community indusion, sessions on "economic pressions on "economic support, community indusion, sessions on "economic pressions pressions pressions on "economic pressions pressions pressions on "economic pressions pressions pressions pressions pressions on "economic pressions pressions pressions pressions pressions pressions pressions pressions pression pression pressions pressions pressions pressions pressions press		SHG initiated by study team	11 SHG ,154 CGs	0-15 years;	46% 21–39 years, 52%
Octome measures         economic empowerment, saming personal stuations, perior seni-structured interviews         Investors, realing and social support strating and social support sub-sections communication Disability Profile         Investors, realing and social support secsis to health and education access to health and education access to health and education personal support         Investors, realing and social support empowerment* and personal support           Disability Profile         Step exponding emotional, physical, here support*         Personal support           Disability Profile         Step evoluting emotional, physical, here support*         Personal support           Disability Profile         Step evoluting emotional, physical, here support*         Personal support           Disability Profile         Step evoluting emotional (case sudy)         Step evoluting emotional support to familie (egu- material/metal and bereviews observations, bernations, herbiticans, herevicuport group indicated herbiticans, herbiticans, her				Disability:	40+ years
Conditative Sensiturciured interviews Countrative         stanting personal struations, peri support, community inclusion, support, community inclusion, sessions on "econonic anowerment" and plability Profile; Muthidimensional Scale of Perevied Scal Support         financing and social support encoverment access to health and education sessions on "econonic empowerment" and plability Profile; Muthidimensional Scale of Perevied Scal Support         financing and social support encoverment" and "peer support"           Sudy design:         SHG providing enotional physical.         Financial support to families (e.g., informational support outcome messures: informational support outcome mesconestope outcome messures: information outcome messures	cial protection		Timeframe:	"primary condition affecting Education: 46% no	g Education: 46% no
Semi-structured interviews         support, community inclusion, sub-scions Communication         support, communication         through SHGs, facilitated           Sub-scions Communication Sub-scions Communication         access to health and education         essions on "economic essions on "economic apport, "peer support", "peer su			work conducted and data	body function and	formal, 23%
Quantitative         access to health and education bibility Profile: Precised Scial Support.         sessions on "acconnic empowerment" and "preer support"           Disbility Profile: Multidimensional Sciel Perceived Scial Support.         Test support         sessions on "acconnic empowerment" and "preer support"           Study design:         SHG providing emotional, physical, Financial support to families (eg., outcome mecaures:         International support to families (eg., informational support to families (eg., naterial/instrumental and outcome mecaures:           Study design:         SHG providing emotional, physical, Financial support to families (eg., informational support to families (eg., naterial/instrumental and outcome mecaures:         International (series design)           Observational (mixed methods outcome mecaures:         Becciptive study exploring informational (meted equipment for improved heath and daly uning activities         International (series design)           Outcome mecaures:         Descriptive study exploring informational (meted interviews)         Refer to High on primer for improved heath and daly uning activities           Study design:         Descriptive study exploring informatione:         Refer to High on preerise of high on promotion of studies for development for inscrites Pateral Stress           Study design:         Descriptive study of the proved beam of a complex         Percention includes SHG development of a complex           Study design:         Descriptive study of the medic storing ison streeving development consenuus         Percention includes SHG development o			collected from 2015	structure, including	incomplete primary
Sub-sections Communication Disability Profile: Multidimensional Scale of Perceived Social Support     empowerment* and "peer support"       Disability Profile: Multidimensional Scale Support     File Frondinal Informational Support to Families (e.g., Informational support       Study design:     SHG Frondinal support to families (e.g., Informational support       Diservational (cass study)     File Frondinal support to families (e.g., Informational support       Diservational (cass study)     File Frondinal support to families (e.g., Informational support       Diservational (cass study)     Pierce Scale support       Diservational (cass study)     File Frondinal support to families (e.g., Informational support       Diservational (cass study design:     File Frondinal support to families (e.g., Informational support       Diservational (cass study design:     Pierce Scale Support       Study design:     Descriptive study exploring Informational support of Pierce Pierce       Diservational (mixed methods     Pierce Study and support of Pierce Pierce       Diservational (mixed methods     Pierce Study and development for Pierce Pierce       Diservational (mixed methods     Pierce Pierce			to 2018	intellectual disability,	Household: 56% 3–6
Disblity Profile:     "peer support"       Mitidimensional Scale of Perceived Social Support.     "peer support"       Mitidimensional Scale of Perceived Social Support.     "peer support"       Displity Profile:     "peer support       Mitidimensional Scale of Social Support.     "peer support"       Displity Profile:     "peer support"       Observations:     Brito Perceived       Outcome measures:     informational support in formedications, health race, informational support       Outcome measures:     Informational support       Outcome measures:     Descriptive study exploring       Refers Solis:     Parental informational support of amilies (e.g., informational support       Outcome measures:     Descriptive study exploring       Distributive:     Descriptive study exploring       Distributive:     Prements of children with spina       Outcome measures:     Prements of children with spina       Distributive:     Prements of c				deafness, visual	children, 25%
Multidimensional Scale of Perceived Social Support.       Preceived Social Support to families (e.g., material/instrumental and observational (case study)       Preceived Social support to families (e.g., material/instrumental and outidative:         Disconter measures:       SHG providing emotional, physical, Financial support to families (e.g., material/instrumental and outidative:       Financial support to families (e.g., informational support to medications, healthcare, informational support         Dualitative:       Dualitative:       improved health and daly horument review, beenal (mked method)         Dualitative:       Descriptive study exploring       Refers to SHGs impacting on pocuming outidation         Dualitative:       Descriptive study exploring       Refers to SHGs impacting on portunity or start         Outidative:       Descriptive study of the introve exports       Parental (inveltade activities Started a liftida in Uganda refering opportunity or start         Outidative:       Descriptive study of the interverses       Parental (preceive)       Parental (preceive)         Outidative:       Descriptive study of the interverses       Parental (preceive)       Parental intervention         Study design:       Descriptive study of the interverses       Parental intervention       Parental intervention         Outidative:       Descriptive study of the interverses       Parental intervention       Parental intervention         Outintarive:       Descriptive study of the interverses				impairment, autistic	7–10 children
Study design:     Sted Social Support:       Study design:     Sted providing emotional, physical, Financial support to families (e.g., material/instrumental and costs), help procuring oublitrative:       Otcorram medications:     Sted providing emotional, physical, Financial support to families (e.g., material/instrumental and costs), help procuring oublitrative:       Outcome medications:     Informational support to families (e.g., material/instrumental and costs), help procuring oublitrative:       Outcome medications:     Descriptive study exploring       Refers to HGS     Prefers to HGS       Outcome medications:     Descriptive study exploring       Refers to HGS     Prefers to HGS       Outcome medications     Descriptive study exploring       Refers to HGS     Prefers to HGS       Outcome medications     Dustrutions       Outcome medications     Dustrutions       Outcome medications     Instructured interviews on the prefers to HGS       Outcome medications     Dustrutions       Outcome medications     Instructured interviews on the provinties' for the an opportunity to start scales, Daily Functioning       Subscales, Prendal Stress     Prendal on the study of the more about income- studies for the study of the more about income- studies for the study of the more about income- studies for the study of the more about income- studies for the study of the more about income- studies for the study of the more about income- studies for theopendine for heat to baserial on theopendines for theopendines fo				spectrum condition	
Sub-Saharan     Sub/ disigrr     SHG providing emotional, physical. Financial support to families (e.g., material/instrumental and Observational (case study)     SHG providing emotional, physical. Financial support to families (e.g., medications, beabmacanes, informational support       DRC,     Outcome messures; informational support     Immerial support to families (e.g., medications, beabmacanes, informational support       DRC,     Outcome messures; informational support     Immerial support to families (e.g., medications, beabmacanes, informational support       Sub-Saharan     Sub-Saharan     Sub-Saharan     Descriptive study exploring activities       Sub-Saharan     Sub-Sabaran     Descriptive study exploring activities     Refers to SHGs impacting on were members of a prent inproved heath and daly document mexues; Dutation;       Outcome messures;     Descriptive study exploring     Refers to SHGs impacting on were members of a prent inproved heath and daly document mexues;       Outcome messures;     Distervational (fida in Uganda refering)     Refers to SHGs impacting on were members of a prent income generating dorivities;       Outcome messures;     Outcome messures;     Distervational (fida in Uganda refering)     Improved heath and daly income apportunity to star       Outcome mesures;     Count to SHG     Distervational (trus and support document mexues;     Improved heath and aly income apportunity to star       Outcome mesures;     Count to star     Study design;     Distervational (trus and suport document to star       Adescons </td <td></td> <td></td> <td></td> <td>spectrum conuctor,</td> <td></td>				spectrum conuctor,	
Study desgr:     SHG providing emotional, physical, Financial support to families (e.g., material/instrumental and for medications, healthcare, informational support       Observational (case study)     BHG providing emotional, physical, Financial support to families (e.g., material/instrumental and for medications, healthcare, informational support       Outcome messures:     Informational support     for medications, healthcare, informational support       Outcome messures:     Informational support     for medications, healthcare, informational support of prevaluation)       Deservational (mixed methods     Descriptive study exploring     Refers to SHGs impacting on parents of children with spina       Outcome messures:     Diffida in Uganda refering     Parental livelihood "those who evaluation)       Outcome messures:     Diffida in Uganda refering     support group indicated it income-focus group discussions       Outcome messures:     Diffida in Uganda refering     support group indicated it income-focus group discussions       Outsores     Diffida in Uganda refering     support group indicated it income-focus group group indicated it income-focus group discussions       Outsores     Study design:     to SHGs     support of them to learn       Outsores     Parental Stress     support group indicated it income-focus group discussions       Outsores     Study design:     to SHGs       Outsores     Parental Stress     to subsoress       Subsorales     Parental Stres				erebiai paisy, variousiy associated with	
Study design:     SHG providing enotional, physical, Financial support to families (e.g., material/instrumental and for medications, healthcare, uncome measures:       Observational (case study)     material/instrumental and for medications, healthcare, informational support       Outcome measures:     informational support       Study design:     Descriptive study exploring       Refers vial     Refers to SHGs inpacting on parental livelihood "those who eralitative:       Outcome measures:     bifida in Uganda refering a support group indicated Qualitative:       Outcome measures:     bifida in Uganda refering a support group indicated Qualitative:       Cours group discussions     trheped them to learn       Outcome measures:     bifida in Uganda refering a support group indicated Qualitative:       Countitative:     to SHGs       Countitative:     to senstury site       Renes stores:     generating activities:       Sensi-structured interviews and     to SHGs       Qualitative:     to set up or store       Renes stores:				limitations in vision	
Study design:         SHG providing emotional, physical, financial support to families (e.g., material/instrumental and Observational (case study)         SHG providing emotional, physical, financial support to families (e.g., material/instrumental and Outcome measures:         Internal costs), help procuring informational support         Financial support to families (e.g., funeral costs), help procuring needed quipment for improved health and daily document review           Outcome measures:         Descriptive study exploring         Refers to SHGs impacting on parental stress and support of parental interling         Parental interlings           Outcome measures:         Descriptive study exploring         Refers to SHGs         Parental interlings           Outlative:         Descriptive study exploring         Refers to SHG         Parental interlings           Outlative:         Descriptive study exploring         Refers to SHG         Parental interlings           Outlative:         Distribution         to SHGs         Parental interlings         Parental interlings           Countitative:         Duantitative:         Parental interviews and to SHG         Parents of a parent to SHG         Parents of a prosenting of a contings': Countitative:           Countitative:         Duantitative:         Parents of a conting support of a conting support of a conting support of a conting subscriptive study of the index Short Form         Parents of a conting support of a conting support of a conting support of a conta coutal support of a containe' to parent of a contage				horring mobility	
Study design:     Study design:     Financial support to families (e.g., material/instrumental and outcome measures:     Informational support to families (e.g., informational (case study)       Outcome measures:     Outcome measures:     informational support     for medications, healthcare, informational support       Outcome measures:     Outcome measures:     informational support     for medications, healthcare, informational support       Outcome measures:     Duservations, interviews, observations, document review     Descriptive study exploring     Refers to SKGs impacting on parental stress and support of parental stress and support of parental inveltimod       Outcome measures:     Duservational (measures:     Duservational parental stress and support of parental stress     Parental inveltimod       Outcome measures:     Dustructured interviews and outcous group discussions     Descriptive study exploring op protunits': "parents fet the group gave them an opportunits': "parents fet the group gave undex short form       Study design:     Descriptive study of the parental intervention     Parents protein of savings cubus careins       Study design:     Descriptive stud				nearing, mobility,	
Study design:     SHG providing emotional, physical, Financial support to families (e.g., material/instrumental and for medications, healthcare, outcome measures:       Outcome measures:     informational support       Outcoment review     Descriptive study exploring       Refers to SHGs impacting on parental stress and support of parental livelihood.       Outcome measures:     Distroit univelihood.       Outcome measures:     Distroit univelihood.       Outsome measures:     Distroit up activities       Outsome measures:     Distroit up and streid       Outsome measures:     Distroit up and streid       Outsome measures:     Distroit up and streid       Outsome measures:     Distroit up and streid a tro.       Couns group discusions     parental stress       Outsome measures:     Distroit up and streid a tro.       Couns group discusions     parental stress       Couns group discusions     parental stres       Su				attention, learning and	
Study design:     SHG providing emotional, physical, Financial support to families (e.g., material/instrumental and Outcome measures:     SHG providing emotional, physical, Financial support to families (e.g., material/instrumental and Outcome measures:     SHG providing emotional, physical, Financial support to families (e.g., metrial costs), help procurring Qualitative:       Outcome measures:     Informational support     for medications, help procurring improved health and daily hiving activities       Outcoment review     Descriptive study exploring     Refers to SHGs impacting on parental stress and study design:       Outcoment review     Descriptive study exploring     Refers to SHGs impacting on parental stress       Outcome measures:     Distrome measures:     Study design:       Outcome measures:     Distrome measures:     Pinanci al strest       Outcome measures:     Distrome measures:     Study design:       Outcome measures:     Distrome measures:     Pinanci al street       Outsome measures:     Distrome measures:     Pinanci al street       Outsome measures:     Distrome more about:income- generating genotunity to start       Scales, Daily Functioning     New intervention     New intervention       Index Short Form     Distrome generating activities     Study design:       Study design:     Descriptive study of the provention (qualitative, descriptive)     Descriptive study of and development of development of a complex descriptive)       Study design: <td< td=""><td></td><td></td><td></td><td>the effects of seizures"</td><td></td></td<>				the effects of seizures"	
Study design:         SHG providing emotional, physical, Financial support to families (e.g., material/instrumental and outcome measures:         SHG providing emotional, physical, Financial support to families (e.g., material/instrumental and outcome measures:         Financial support to families (e.g., financial support for improved health and daily design:           Outcome measures:         Informational support         fineral costs), help procurring needed equipment for improved health and daily design:           Duscrent review         Descriptive study exploring         Refers to SHGs impacting on parental stress and support of parental invelsion           Outcome measures:         Duscrent review         Descriptive study exploring           Outcome measures:         Dustrome measures:         Printipe activities           Outcome measures:         Dustrome measures:         Printipe activities           Outcome measures:         Distrome measures:         Printipe activities           Coustoroup distrome         Distrome measures:				Uther: 5006 and in school	
Duroup design:         Descriptional (case study)         Descriptional support         Descriptional support           OutGome measures:         informational support         for medications, healthcare, informational support           OutGome measures:         informational support         for medications, healthcare, informational support           OutGome measures:         informational support         for medications, healthcare, informational support           OutGome measures:         Descriptive study exploring         Refers to 5HGs impacting on parental stress and support of parental inveltional measures:           OutGome measures:         Difficient in Uganda referring         parental stress and support of parental inveltional support group indicated Qualitative:           Outcome measures:         Difficient in Uganda referring         support group indicated it income-evaluation           Outcome measures:         Difficient in Uganda referring         support group indicated it income-evaluation           Outcome measures:         Difficient in Uganda referring         support group indicated it income-evaluation           Outcome measures:         Difficient in Uganda referring         support group indicated it income-evaluation           Outcome measures:         Difficient difficient in Uganda referring on poportunity to start         subscriptive           Outcome measures:         Study design:         Ditervention         structures </td <td></td> <td>CLIC initiation by provincers</td> <td>Ne of narticinants.</td> <td></td> <td>Not dotailod</td>		CLIC initiation by provincers	Ne of narticinants.		Not dotailod
Outcome measures:         Informational support         Interest costs), help procuring uner costs, help procuring unterviews, observations, informational support         Interest costs), help procuring unterviews, observations, informational support           Qualitative:         Distributions         Interviews, observations, informational support         Interviews, observations, informational support           Qualitative:         Distributions         Descriptive study exploining refers to SHGs impacting on operant of costs           Study design:         Descriptive study exploining         Refers to SHGs impacting on operant of costs           Outcome measures:         Different interviews and ocuments are solve exploining         Refers to SHGs           Qualitative:         Different interviews and observational filters with spina support of earned livelihood "those who observational filters with spina support of a parent of a truth of an upont of costs group discussions           Qualitative:         Different interviews and to SHGs         Different interviews and to SHGs           Qualitative:         Different interviews and to SHGs         Different interviews and to SHGs           Quantitative:         Different interviews and to SHG         Different interviews and to SHG           Countitative:         Diamitative:         Diamitative:         Diamitative:           Study design:         Diamitative:         Diamitative:         Diamitative:           Study design:		a muateu by caregivers,	Nr or participants:	Aye: N=+ 1-+-:1-1-	ואסר מהרקווהם
Outcome medures:         Informational support         Unreal costs, nelp procuring claiming activities           Qualitative:         improved health and daily document review         improved health and daily hing activities           Study design:         Descriptive study exploring         Refers to SHGs impacting on parental stress and support of parental inveltionod           Observational (mixed methods         parental stress and support of parental inveltionod         parental inveltionod           Outcome measures:         Difida in Uganda referring         support group indicated           Outcome measures:         Difida in Uganda referring         support group indicated           Outcome measures:         Difida in Uganda referring         support group indicated           Outcome measures:         Difida in Uganda referring         support group indicated           Outcome measures:         Difida in Uganda referring         support group indicated           Outcome measures:         Difida in Uganda referring         support group indicated           Outcome measures:         Difida in Uganda referring         support group indicated           Outcome measures:         Duality Functioning         tr helped them to learn           Scales, Daily Functioning         tr helped them to learn         tr helped them to learn           Scales, Daily Functioning         tr helped them to learn		collaborations with ingus	Not detailed	Not detailed;	
Qualitative:     Descriptive study exploring     improved health and daily invosed descriptive study descriptive study exploring       Refers to baservational (mixed methods     Descriptive study exploring     Refers to SHGs impacting on parental inveltibood "those who evaluation)       Dustrative:     Dustrative:     Descriptive study exploring     Refers to SHGs impacting on parental inveltibood "those who evaluation)       Dustrative:     Dustrative:     Dustrative:     Dustrative       Dustrative:     Dustrative:     Support group indicated out the parental inveltibood "those who parental interviews and to SHGs     Dustrative:       Dustrative:     Dustrative:     Dustrative:     Dustrative:       Dustrative:     Dustrative:     Subscieles     Parental Stress of a parent to learn the more about income-generating opportunity to start scales. Daily Functioning       Subscieles     Paily Functioning     Trhelped them to learn to started a index short Form       Nineland Adaptive Behaviour     Study design:     Descriptive study of the more about income-generating activities subscieles. Paily Functioning       Subscieles, Parental Stress     Dustrative:     Trhelped them to learn more about income-generating activities subscieles. They had started a index short form       Subscieles, Parental Stress     Daily Functioning     Trhelped them to learn more about income-generating activities subscieles. Parenta Vitice auditative:       Subscisters     Daily Functioning     Tr in	Social protection		Timeframe:	Disability:	
interviews, observations, improved heath and daily document review aduation becoment review but denoted and support of activities and denoted denoted and the denoted activities and denoted descriptive) durative. Descriptive study of the prough promotion for devolopment of a new intervention. Includes Shife descriptive) duration descriptive study descriptive study descriptive study descriptive study descriptive dualitative. Descriptive study descriptive) issues dualitative: dualitativ			Data collected over a	intellectual and/or	
document review         Inving activities           Study design:         Descriptive study exploring         Refers to SHGs impacting on parental stress and support of parental inveloped dualitative:         Inving activities           Outcome measures:         bifda in Uganda referring a support group indicated trhelped them to learn poor group indicated quantitative:         Inving activities           Courcome measures:         bifda in Uganda referring a support group indicated trhelped them to learn poor group of stress         Inving activities           Courcome measures:         bifda in Uganda referring a support group indicated trhelped them to learn to SHGs         Inving activities           Courcome measures:         bifda in Uganda referring a support group indicated trhelped them to learn treem aportincome- generating activities           Calles, Daily Functioning         rescriptive study of the under short.         Refer a group gave treem and started a income-generating activities           Study design:         Descriptive study of the descriptive)         Pilots study and development of formation.         for unstrom.           Outcome measures:         Outcome measures:         through promotion of savings could rescriptive)         for unstrom of averings for use on to averings for use on the mark under of a complex           Outcome measures:         through promotion of savings could rescriptive)         for undr			7 month period, SHG	developmental disability	
Study design:         Descriptive study exploing         Refers to 5HGs impacting on parental stress and support of parental stress and ounitative:         Descriptive study exploing         Refers to 5HGs         parental support group indicated trhelped them to learn more aboutincome- docus group discussions           Qualitative:         to 5HGs         norr about income- income about income- docus group discussions         parental stress           Quantitative:         to 5HGs         parental stress         parental stress           Quantitative:         "parents fit the group gave Vineland Adaptive Behaviour         parental stress           Vineland Adaptive Behaviour         "parents fit the group gave to stress         parental stress           Study design:         Descriptive study of the Observational (qualitative, development of a complex         parental stress is study and development of formation         parental stress           Outcome measures:         Descriptive study of the new intervention         proversions         through promotion of savings           descriptive         contrables         four stores         through promotion of savings           Study design:         Demonth "Intensive camples"         through promotion of savings			created in 2006		
Observational (mixed methods     parental stress and support of evaluation)       outcome measures:     bifidia in Uganda refering Qualitative:       Outcome measures:     bifidia in Uganda refering Qualitative:       Semi-structured interviews and focus group discussions     to SHGs       Quantitative:     to SHGs       Vineland Adaptive Behaviour Scales, Daily Functioning Subscales, Parental Stress Index Short Form     Descriptive study of the development of a complex descriptive)       Study design:     Descriptive study of the development of a complex descriptive)       Outcome measures:     forus group discussions, expert consensus		SHGs initiated with the help of Nr of participants:	of Nr of participants:	Age:	Family member: 78%
evaluation)     parents of children with spina       Outcome measures:     bifida in Uganda referring       Qualitative:     to SHGs       Semi-structured interviews and     to SHGs       Quantitative:     to SHGs       Customs     to SHGs       Semi-structured interviews and     to SHGs       Quantitative:     to SHGs       Quantitative:     to SHGs       Vineland Adaptive Behaviour     Scales, Jaily Functioning       Subscales, Parental Stress     hdevelopment of a complex       Index Short Form     Descriptive study of the       Study design:     Descriptive study of the       Observational (qualitative,     development of a complex       descriptive)     contextualised intervention       Outcome measures:     Outlative:       focus group discussions, expert consensus     Study design:		rehabilitation centres or	134 parents	4 – 14 years;	mothers, 11%
Outcome measures:     bifida in Uganda referring       Qualitative:     to SHGs       Semi-structured interviews and     focus group discussions       focus group discussions     Quantitative:       Quantitative:     to SHGs       Qualitative:     Descriptive study of the development of a complex descriptive)       Descriptive)     contextualised intervention       Outcome measures:     Qualitative,       Qualitative:     focus group discussions, expert consenus       Study design:     One month "intensive camp like		community based	Timeframe:	Disability:	fathers, 7%
Qualitative:     to SHGs       Semi-structured interviews and focus group discussions     to SHGs       Rous group discussions     doamtiative       Quantitative:     methaviour       Scales, Daily Functioning Subscales, Parental Stress Index Short Form     Descriptive study of the development of a complex development of a complex descriptive)       Study design:     Descriptive study of the development of a complex descriptive)       Outcome measures:     contextualised intervention       Qualitative:     forus group discussions, expert consensus       Study design:     One month "intensive camp like		rehabilitation initiatives	Data collected June 2011 to Spina bifida;	o Spina bifida;	grandmother
Semi-structured interviews and focus group discussions Quantitative: Vinelaes, baily Functioning Subscales, Parental Stress Index Short Form Study design: Descriptive study of the development of a complex descriptive) contextualised intervention Outcome measures: Qualitative: focus group discussions, expert consensus Study design: One month "intensive camp like			December 2014	Other:	Education:
focus group discussions Quantitative: Vineland Adaptive Behaviour Seales, Daily Functioning Subscales, Parental Stress Index Short Form Descriptive study of the Study design: Descriptive study of the development of a complex descriptive) contextualised intervention Outcome measures: Qualitative: focus group discussions, expert consensus Study design: One month "intensive camp like				43% not in school	5% no formal, 56%
Quantitative: Vineland Adaptive Behaviour Scales, Daily Functioning Subscales, Parental Stress Index Short Form Study design: Descriptive study of the development of a complex descriptive) contextualised intervention Outcome measures: focus group discussions, expert consensus Study design: One month "intensive camp like					primary,
Vineland Adaptive Behaviour Scales, Daily Functioning Subscales, Parental Stress Index Short Form Study design: Descriptive study of the Observational (qualitative, development of a complex descriptive) contextualised intervention Outcome measures: focus group discussions, expert consensus Study design: One month "intensive camp like					22% secondary
Scales, Daily Functioning Subscales, Parental Stress Index Short Form Study design: Descriptive study of the Observational (qualitative, development of a complex descriptive) contextualised intervention Outcome measures: Contextualised intervention Outcome measures: focus group discussions, expert consensus Study design: One month "intensive camp like					
Subscales, Parental Stress Index Short Form Study design: Descriptive study of the Observational (qualitative, development of a complex descriptive) contextualised intervention Outcome measures: Qualitative: focus group discussions, expert consensus Study design: One month "intensive camp like					
Index Short Form Study design: Descriptive study of the Observational (qualitative, development of a complex descriptive) contextualised intervention Outcome measures: Oualitative: focus group discussions, expert consensus Study design: One month "intensive camp like					
Study design: Descriptive study of the Study design: Descriptive) development of a complex descriptive) contextualised intervention Outcome measures: Qualitative: focus group discussions, expert consensus Study design: One month "intensive camp like					
Study design:         Descriptive study of the           Observational (qualitative,         development of a complex descriptive)           descriptive)         contextualised intervention           Outcome measures:         contextualised intervention           Qualitative:         contextualised intervention           Custome measures:         contextualised intervention           Qualitative:         contextualised intervention           Resultative:         consume           Assert consensus         cone month "intensive camp like					
Study design: Descriptive study of the Observational (qualitative, development of a complex descriptive) contextualised intervention Outcome measures: Qualitative: focus group discussions, expert consensus Study design: One month "intensive camp like		-			
Africa,         Observational (qualitative,         development of a complex         new intervention. Includes SHG           Malawi,         descriptive)         contextualised intervention         formation to "address poverty           rural         Outcome measures:         issues         issues           Qualitative:         through promotion of savings         focus group discussions,           extert consensus         enterprises"         enterprises           South Asia,         Study design:         One month "intensive camp like         fallend in         Skil		SHG initiation planned as part Nr of participants:	. Nr of participants:	Age:	Family member: 14
mauwi, descriptive) contextualed intervention to address poverty rural Outcome measures: issues issues Qualitative: through promotion of savings focus group discussions, expert consensus expert consensus enterprises" South Asia, Study design: One month "Intensive camp like "parents were trained in		of the intervention	Data presented for 14	Not detailed;	mothers and fathers
Tutal Outcome measures: Qualitative: through promotion of savings focus group discussions, expert consensus South Asia, Study design: One month "Intensive camp like "parents were trained in			parents	Uisaumiy.	
Qualitative:     Utalitative:       focus group discussions,     cuture and small business       expert consensus     enterprises"       South Asia,     Study design:       One month "Intensive camp like     "parents were trained in			limertame:	intellectual disability	
rocus group discussions, expert consensus South Asia, Study design: One month "Intensive camp like "parents were trained in			Data collected september		
expert consensus South Asia, Study design: One month "intensive camp like "parents were trained in			2015		
Study design: One month "intensive camp like "parents were trained in					
	ills development SHG;		Nr of participants:	Age:	Family member:
Nepal Observational (mixed methods training program"		Health care institution	Data presented for 48	2–14 years	48 mothers
evaluation) covering "pedagogy, livelihood			mothers	Disability:	

Intervention

Continued.	
le 1. (	
Tab	

Intervention

Study design & outcome measure Interv		Interv	Intervention overview	Intervention livelihood content	Element(s) of the CBR matrix livelihood component targeted	Delivering organisation	Scope - Nr of participants - Timeframe	child w disability - Age - Disability - Other	Intervention recipients: caregiver
Outcome messures: earning skills and vocational Quantitative: training, medical treatment, Parents: Knowledge, Attitude and physiotherapy, Practice (KAP), "mental speech therapy, orcholics, asistive health" therapy, ortholics, asistive children: devices, Activities of Daily Living & hygiene & first-aid training"	traii spei hyg	earning skills and vocationa training, medical treatment, physiotherapy, speech therapy, occupational therapy, orthotics, assistive devices, hygiene & first-aid training"	_				<i>Timeframe:</i> "one month"	"various non-progressive developmental disorders"	
Study design:         Government programme for Observational (mixed methods         Government programme for community based identification evaluation)           observational (mixed methods)         and care provision for people with disability. Training of Quantitative:         """           Outcome measures:         with disability. Training of """         """           Descriptive data         """         """           Descriptive data         (CRPs) and establishment of neighbourhood centres.         ""           development delays have         """         Services ventually owned and shown         ""           ther mile stones"         ""         ""         ""         ""	69	Government programme for community based identificatio and care provision for people with disability. Training of "Community Resource Persons (CRPs) and establishment of neighbourhood centres. Services eventually owned and managed by women's SHGs.	<b>c</b> , –	<ul> <li> activities related to livelihood. Social protection; (Skills Parent support was part of the development) overall service delivery";</li> <li>To guide parents of persons with intellectual and developmental disabilities and their family members to reach the service providers with regard toand welfare to meet their specific needs"</li> </ul>		Public or national health system / governmental organisation; SHG	<i>Nr of participants:</i> "2819 children are being provided with early intervention2736 parents involved" Timeframe: article presents data up to 2013—when programme started unclear	Age: Not detailed <i>Disability:</i> "intellectual and developmental disabilities" D	Not detailed
Study design:     Descriptive study exploring impact "They learn a skill that enables       Observational (qualitative,     of disability and poverty on the them to eam an income";       descriptive)     faith of mothers of CwD in     "earn to take responsibility       Outcome measures:     to SHGs     "table".       Qualitative:     to SHGs     "table".       Interviews     to SHGs     "table".		Descriptive study exploring impact of disability and poverty on the faith of mothers of CwD in monthly meetings referring to SHGs		They learn a skill that enables them to earn an income"; "learn to take responsibility for the management of the SHG"; "stallssell the papier-maché handicraft items and the spices they make."	Skills development; Self- employment; Social protection	NGO; SHG	<i>Nr of participants:</i> Not detailed T <i>Tmeframe:</i> Not detailed	Age: Not detailed; Disability: "children identified as mentally handicapped or children at risk for developmental delay if they did not have access to intervention services."	Family member/Age: "Mothers ranged from very young, most of them having been married between the ages of 14 and 16, to the and 16, to the or didel aged and or of or nore" of or one and of or nore" of or one and
ope & Study design:     Descriptive study assessing the "       Central Asia, Observational     spectrum of provision for sia, qualitative, descriptive)       sia, qualitative, descriptive)     children and adults with control outcome measures:       al     Outcome measures:     Difficulties, referring to social Interview.       notecrion     protection provisions       document review     document review	Descriptive study assessing the spectrum of provision for escriptive) children and adults with sures. Defindutes, referring to social fervation, protection provisions review	<u>م</u>	2	"social service centres" cany out "child and family support" and "disability support" family with CWD on at risk register receive "advice and support" and can "arrange for and collect some types of benefit directly from the offices e.g., certificates entitling them to free public transport discounts and trickets to sanatoria," "parent support qroups formed"	Social protection	Public or national health system/ governmental organisation	<i>Nr of participants:</i> Not detailed <i>Timeframe:</i> Data collected over a 7 month period in 1998	<i>Age :</i> Not detailed Dis <i>ability:</i> Not detailed 8	Not detailed
Latin America & Study design: Carer support programmes of "the Carib-bean Observational (case study) 10–11 sessions offered over a Brazil, Outcome measures: 3 month period covering urban Not detailed (in pilot phase at essential care practices, such as time of publication) feeding, positioning, communication, play and early stimulation, providing psychosocial support, psychosocial support,	Carer support programmes of I (case study)     10–11 sessions offered over a sures:       3 month period covering (in pilot phase at ublication)     3 month period covering essential care practices, such as redning, positioning, communication, providing stimulation, providing psychosocial support.	r a h as	"the	The programme addresses how Social protection parents can advocate for eceipt of disability benefits', "aims to empower parents so they can address the triver of poor health among their poor health among their condition with disabilities, which include		Not detailed	<i>Nr of participants: Age:</i> at the time of publication "6 not detailed parent groups" Dis <i>ability:</i> <i>Timeframe:</i> Congenital Z Not detailed	Age: "6 not detailed Dis <i>ability:</i> Congential Zika Syndrome	Not detailed

6 😧 E. M. LOUCAIDES ET AL.

(continued)

	Intervention recipients: child w disability	- Age	- Disability Intervention recipients:	- Other caregiver		
		Scope	- Nr of participants	- Timeframe		
Intervention				Delivering organisation		
Inte			Element(s) of the CBR matrix	Intervention livelihood content livelihood component targeted Delivering organisation		
				Intervention livelihood content		
				Intervention overview	improving connection to	and the second second second
			Study design &	outcome measure		
				Setting		

WHO: World Health Organization; CBR: community based rehabilitation; SHG: self-help group; CG: caregiver; CwD: child(ren) with disability; NGO: non-governmental organisation; DRC: Democratic Republic Congo. All three publications relate to the same study.

three publications relate to the same study

# Livelihood component of the CBR matrix targeted

Within the programmes reported, livelihood was almost always one component of a wider intervention package, and often not the primary focus. Amongst grey literature findings, the organisation Carers Worldwide stood out, with reports on multiple established programmes to support caregivers and frequent emphasis on livelihood support [42-45] (Table 2).

Self-help groups appeared to be a common intervention component aiming to effect livelihood-related change (described in several grey literature programmes [40,43-45] and in at least seven of the nine programmes described in peer-reviewed publications [20-37]). In addition, in the publications found self-help group formation initiation was commonly driven by an external body such as an INGO/NGO, governmental, or private academic organisation.

Where interventions were described in enough detail to be categorised by component of the CBR livelihood matrix, the most commonly found categories were access to social protection measures in the form of social support offered by self-help groups or sign-positing to disability benefits, and self-employment with income generating activities carried out by self-help groups or individuals supported by self-help groups. Reports on interventions falling under the categories of "access to financial services" (via self-help groups) or "skill development" were present but less frequent, and we found no description of any intervention supporting caregiver access to wageemployment in the publications included here (Tables 1 and 2).

#### Findings from the online stakeholder survey

Between 11 May and 6 July 2021, 58 survey responses were received. Of these, 50 respondents confirmed that they work with children with disability and their caregivers in a LMIC, and that their work aims to improve the livelihood of the families, meeting inclusion criteria. One respondent detailed work carried out in a high-income country and was thus excluded. The remaining 49 survey responses, representing 49 individual programmes, were further analysed. Survey respondents could indicate more than one answer for multiple questions, meaning the total pool of listed answers per question was frequently >49.

Similar to the scoping review, survey findings were reported according to geographic setting, the primary recipient of livelihood support, study design, outcome measures, and element of the CBR matrix livelihood targeted.

### Geographic setting

Survey respondents reported on programmes from a total of 22 different countries, with multiple survey participants indicating work in more than one country (Figure 3(B)). Listed countries or regions of work were predominantly in Sub-Saharan Africa (76.4% (n = 42)). The majority (94.4% (n = 50)) were from low-middle income or low-income countries (Supplemental Material).

## Programme recipients

Almost all respondents identified the child as the primary target for their programme (85.7% (n = 42)). Two-thirds (61.2% (n = 30)) described targeting the carer, or other family member. The household as a whole and/or the community were more likely to be secondary targets or were not targeted at all. However, caregiver and household empowerment, including social support between households, was mentioned by several respondents in free text answers. Some also referred to community focussed work or the need to address wider social aspects of disability, including raising awareness, stigma reduction, and promoting social inclusion.

	Cottine	Element(s) of the WHO CBR matrix livelihood		
CBM [40]	Kenya and other East Africa	Self-employment	CBM partnership with local CBR organisation SPARK "facilitated men and women with disability and the mothers of CwD to come together to form SHG, so	Not detailed
CBM [41]	Ghana	Access to social protection measures	that they could create a sustainable life for themselves", "farming, animal husbandry, poultry rearing, as well as advocacy and other initiatives" Community-based modular participatory parent training programme for children with cerebral palsy in Ghana - Getting to Know Cerebral Palsy.	Knowledge of the Ghanaian Disability Common Fund increased from 39% to 90%
Carers Worldwide [42]	India	Access to social protection measures, Access to financial services,	Illustrative showcase of assisting family with two children with disability together with partner organisation SPREAD assisting with "applying for a disabled persons ID card which entitles him to a higher pension," "received	(however, ongoing issues with accessing fund) Descriptive text on programme content including
Carers Worldwide [43]	India	Self-employment Access to social protection measures, Access to financial services, Colf and Access	support from our project to invest in a livelinood opportunity. Iney purchased a goat which has since had 3 kids. This goat-rearing enterprise is generating a good income for the family, making them financially secure." Illustrative showcase of assisting grandmother caregiver together with local partner EKTA by signposting to local carer group where she "learned about available services, facilities and provisions." "Now living in a new house, bound accompany of the facility of the super burget to the factor together with the she	participant quotes Descriptive text on programme content including
Carers Worldwide [44]	Nepal	sen-employment Access to financial services, Skills training, Self-employment	nave accessed the intartical support availables, are benefiting from the regular income K is earning from the grocery store she has set up at her home thanks to funding from the project." Jyoti Carers Group of parents of children with disability: joint savings, training in shoe production and sale of products, lobbying for community caring centre to "enable them to take it in turns to care for each other's children and	participant quotes Descriptive text on programme content including
Carers Worldwide [45]	Nepal	Unclear	provide opportunities for respite" Care for carers project in partnership with SHG for Cerebral Palsy Nepal (SGCP). Ongoing project that promotes the social, emotional, medical and economic wellbeing of carers, mostly mothers, of children with Cerebral Palsy and other neurological disorders. Local SHGs set up, health camps for carers held, counselling visits to carers groups, formation of a Carers Association, "helping	participant quotes Descriptive quantitative data of programme reach
			carers establish sustainable livelihood, and promoting alternative care	

CBM: Christian Blind Mission; SHG: self-help group; CBR: community based rehabilitation; CG: caregiver; CwD: child(ren) with disability.

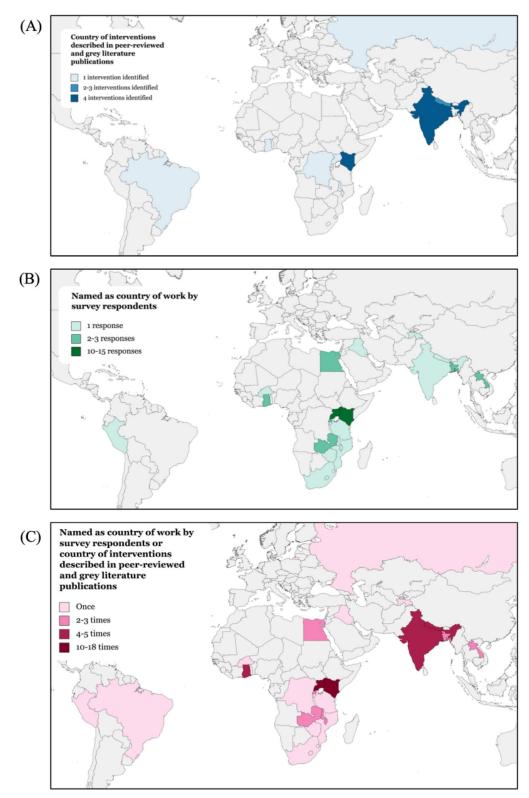


Figure 3. Global distribution of programmes identified through (A) the scoping review of published literature, (B) the online stakeholder survey, (C) the scoping review and survey combined.

The age range of children with disability, directly or indirectly involved in the respondents work, was generally broad. More than half (55.5% (n = 27) were inclusive of children 0–18 years with seven (14.2%) inclusive of young people >18 years. Only eight respondents (16%) exclusively focussed on <4 years.

### Programme delivery

Survey respondents held a variety of roles with NGO worker and Researcher most common (Supplemental Material). More than half of respondents worked for a non-governmental organisation (NGO/INGO) and a fifth for a private not-for-profit (NPO) organisation (Supplemental Material). By far the majority (77.8% (n = 35)),

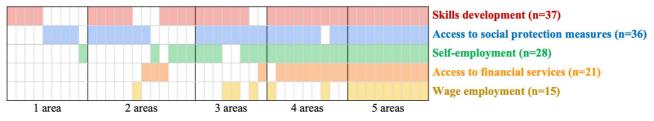


Figure 4. Element of livelihood support targeted. (N = 47). Columns represent one survey respondent who could indicate more than one element being targeted. Two respondents did not report on livelihood element targeted.

reported combining a direct approach to livelihood support with referral to a partner organisation specialising in livelihood support, reflecting a recognition of the role of specialist partners.

### Livelihood component of the CBR matrix targeted

Figure 4 shows which elements of the livelihood support component of the CBR matrix targeted by respondent's programmes. Overall, 75.5% (n = 37) indicated that their work most commonly targeted "skills development"; 73.5% (n = 36) "access to social protection measures"; 57.0% (n = 28) self-employment; 42.9% (n = 21) access to financial services; and 28.6% (n = 14) wage employment (Figure 4). No apparent trends in combination of livelihood elements targeted were seen amongst the sample of survey responses received. Organisations were as likely to work across multiple aspects of livelihood support, as to adopt a more focussed approach; 18.4% (n = 9) targeted all domains and an equal proportion targeted a single area alone (Figure 4).

*Skills development.* Skills development was the most common element of livelihood targeted within the CBR matrix amongst survey respondents (75.0%) (Figure 4). Foundation skills, such as reasoning and problem solving, and literature, were reported to be commonly targeted (83.7% (n=41) as well as core life skills (73.5% (n=36)) and business management skills (71.4% (n=35)). Targeting professional or technical and vocational skills was overall less common (Figure 5(A)). The emphasis on the generic skills development and business management more broadly (Figure 5(B)), suggests that survey respondents preferred transferable skills applicable to a wide range of livelihood activities.

**Social protection.** Access to social protection measures was supported by nearly three-quarters of survey respondents (Figure 4). Programmes more commonly promoted access to informal schemes offering social support (n = 42), than official measures of poverty reduction (n = 38) and social assistance schemes (n = 33). In our survey sample the most commonly accessed schemes were self-help groups, family support and disability benefits (Figure 6(A)). Around half promoted social protection *via* community-based organisations (charitable and religious) and food support, and a third reported use of conditional cash transfer schemes (Figure 6(A)).

Self-employment. Amongst the 49 responses, 57.1% (n = 28) promoted self-employment (Figure 4). The majority offered access to new options of self-employment (n = 34), which was more common than re-engagement with previously conducted self-employed income generation activities that had ceased due to caring responsibilities (n = 20) (Figure 6(B)). Self-employment support centred around a range of activities, including service provision, product manufacture and selling of goods and activities were more likely to be carried out by individuals (n = 34) than groups (n = 26) (Figure 6(B)). Similarly, income generating

activities carried out by individuals or small groups (35) were reported to be more commonly supported than those carried out at enterprise scale (Figure 6(B)).

Accessing financial services. Access to financial services was promoted by 42.9% (n = 21) of survey respondents (Figure 4). Programmes aimed to improve access to savings (n = 30) over grants (n = 19) or credits (n = 16) and promoting access to insurance of any kind was notably rare (n = 4). Self-help groups and other informal providers (n = 28) predominated financial service provision, followed by Village Savings and Loan Associations (VSLAs) (n = 20) (Figure 7(A)).

*Wage employment.* Less than a third (30.6% (n = 15)) of survey respondents reported supporting wage employment (Figure 4). Again, access to new options of wage employment were more common than re-engagement with employment ceased due to caring responsibilities. A third of respondents reported providing links to employment referral and support services and a quarter aimed to raise awareness of existing employment promotion or protection measures (Figure 7(B)).

*Other components.* Multiple respondents indicated supporting other needs, not immediately related to livelihood, of both the child (e.g., access to inclusive education, healthcare needs, nutrition, mobility aids) and the caregiver (e.g., parenting skills, psychosocial needs, healthcare needs). In addition, some respondents carried out advocacy and policy work through partnerships with Disabled Person's Organisation (DPOs) and governmental organisations.

# Discussion

Disability and poverty are crucially interlinked, and caring for a child with disability places significant economic burden on the family [5,17]. Whilst livelihood support aimed at caregivers was substantially reported by stakeholders, we found a marked paucity of publications in the peer-reviewed health literature relating to livelihood interventions targeting caregivers. Whilst the majority of identified programmes in our sample of scholarly and grey literature targeted multiple CBR livelihood elements, the most commonly described were skills development, access to social protection and self-employment. Self-help groups were also commonly identified, and were frequently embedded within a wider child disability intervention and supported by a partner organisation specialising in livelihood support. In general, quantitative measures of impact on outcomes relating specifically to livelihood were lacking, however, this should be framed within the recognition that CBR, as a complex multi-sectoral approach, renders assessment of attributions of impact challenging [47]. The majority of identified programmes worked with a broad age-range of children in Sub-Saharan Africa, and to a lesser extent South Asia,

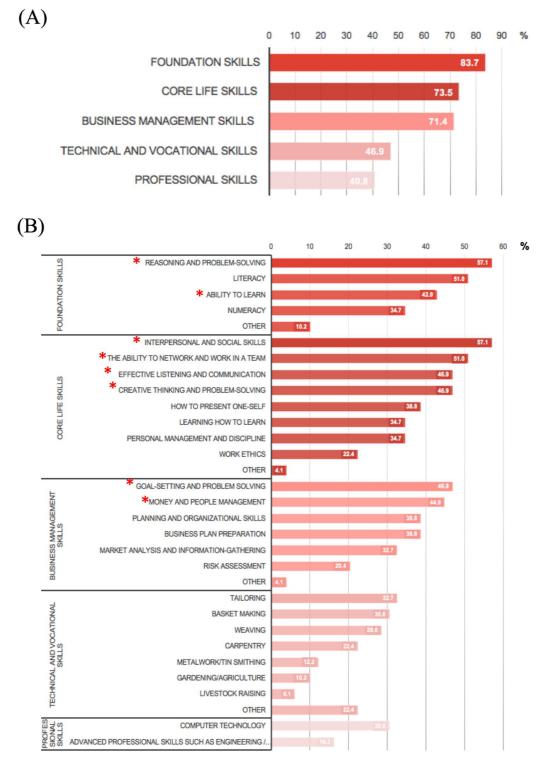
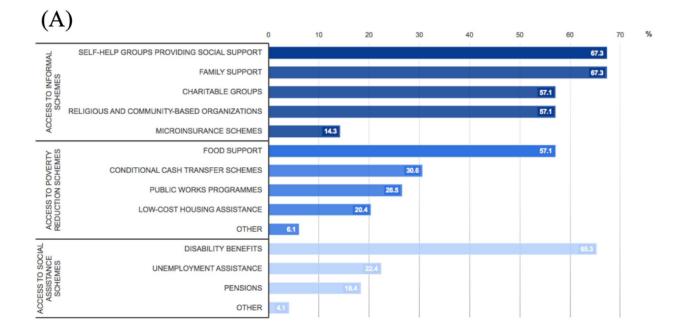


Figure 5. Livelihood support targeting skills development. (N = 49). (A) Element of skills development targeted. (B) Specific skills listed by respondents. \* indicates skills targeted by at least 40% of programmes.

and none of those identified specifically target those in the first thousand days (0–3 years).

Livelihood has many dimensions, and supporting it in the context of families with a child with disability is complicated by high care needs and costs as well as associated loss of opportunity to generate an income [5,6,16,17]. Our findings suggest that it is predominantly addressed as a component of a broader, family-centred intervention, commonly using a multi-pronged approach. Signposting to existing resources such as disability benefits or parent support groups, and collaboration with partners specialising in livelihood support, is frequently utilised to access specialised knowledge and opportunities for grants and other forms of social protection.

Access to social protection is recognised as an essential component of supporting the livelihood of marginalised and vulnerable groups. Notably, policy and advocacy reports such as the UNICEF



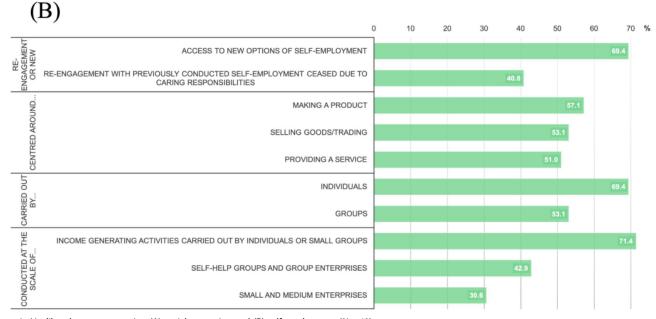


Figure 6. Livelihood support targeting (A) social protection and (B) self-employment (N = 49).

report on Inclusive Social Protection Systems for Children with Disabilities in Europe and Central Asia [48] frequently focus on access to social protection measures to improve livelihoods of families of children with disability. More global in approach, the UNICEF 2013 State of the World's Children [49] highlights the need to expand accessible social protection measures such as cash transfer programmes targeted specifically at children with disabilities and their families and states that such targeted social protection measures have been implemented in multiple countries but does not describe any programmes in more details. A recent review of social protection policies for caregivers in South Africa showed there is little research which evaluates where social protection policies are sufficient for meeting caregiver needs, with caregivers commonly not included as a vulnerable group, and subject to various barriers in accessing those policies and their benefits [50]. Whilst our study found that social protection linkages were frequently promoted and included sign-positing to disability benefits, informal measures such as social support offered by self-help groups or family was most common.

We found that livelihood support specifically targeting families with young children in the first 1000 days was rare in the literature we reviewed, and in contradiction with the recognition of this period being a crucial window of opportunity for early child development [51,52]. Livelihood support would be well-placed here; there is, for example, evidence for improved child developmental outcomes with (conditional) cash transfer schemes for families living in poverty [53]. Barriers to providing livelihood support during this period include delayed identification of disability and thus missed opportunities for early intervention [54]. Opportunities to address this include strengthening the health sector to provide early identification and referrals for early intervention services [55]

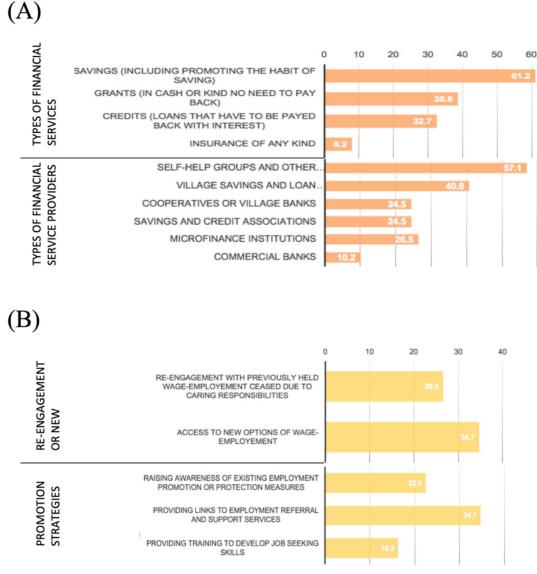


Figure 7. Livelihood support targeting (A) access to financial services and providers and (B) wage-employment (N = 49).

that are inclusive of livelihood components, such as linkages to social protection schemes. In addition, whilst children are explicitly mentioned to be included under the Convention of the Rights of Persons with Disability (CRPD), often countries do not have mechanisms for ensuring engagement of children in DPOs [56].

Self-help groups were central to many approaches to supporting caregiver livelihood described here. There is accumulating evidence for the impact of interventions delivered through self-help groups in LMICs [57] and they are an entry point for the provision of financial services and informal measures of social protection. Importantly, given that caregivers in LMIC settings are almost always female, caregiver self-help groups are an opportunity for economic empowerment inclusive of a gender lens. A systematic review has shown that women's economic self-help groups have a positive, statistically significant effect on women's economic, social, and political empowerment through, for example, increased familiarity with handling money, independence in financial decision making, solidarity, improved social networks and respect from the household and other community members [58]. A large scale impact evaluation of a women business training course in Kenya utilised randomisation and control groups to evidence an increase

in womens' income, longevity of womens' businesses as well as improvements in mental health and subjective wellbeing [59]. Also emerging from work with women's groups [58], and reflected in several of the free text survey responses we received, is the need for advocacy, community and policy level work to achieve effective and sustainable change. Furthermore, the gender lens should not just be reaching women, but engage male partners and other caregivers to care for and provide for the child with disability.

The true extent to which livelihood support is offered to caregivers of children with disability in LMICs remains unclear. Undoubtedly, the limited yield of the scoping review conducted is not representative of overall activity levels in this area. The survey described here, clearly showed that there is awareness of this important issue amongst those working with children with disability and that work is being done to address it through a variety of direct and indirect approaches. The marked lack of published evidence for effectiveness of the approaches to supporting livelihood within the health literature and related fields aligns with findings from previous reviews related more generally to childhood disability in LMIC settings. These reviews concluded that there is little to no evidence-base to inform service development, with almost no information available about family-support facilities [54,59]. Our findings also align with a general call for more and higher quality evidence on the effectiveness of interventions targeted at children with disability and their caregivers in LMICs more broadly [60–62].

To our knowledge this is the first structured approach to synthesise knowledge on livelihood support centred on families of children with disability as opposed to adults themselves with disability. The scoping review yield was restricted to publications from 2000 onwards and more peer-reviewed publications describing livelihood support as a small part of a wider package of care may not have been picked up by our search and screening strategy. Searching the literature for qualitative studies has been noted by others to be challenging [63] and likely affected our ability to identify more livelihood support programmes. Whilst we searched bibliometric databases that include gualitative literature, such as CINAHL (which is frequently regarded as one of the best databases for the qualitative literature due to its in-depth subject terms) and Web of Science (which covers arts, humanities and social sciences indexing databases), we predominantly searched databases covering health literature and this may have substantially limited our findings. The grey literature was searched in a limited way and further expansion of this search may have yielded additional findings. Whilst we had no language restriction for publications included in the scoping review, for pragmatic reasons we limited the survey to English. This, together with a nonrandom snowball sampling approach and survey completion requiring internet and email access as well as good literacy skills, might have introduce an element of selection bias and limited the vield of survey responses.

In conclusion, we have shown that whilst stakeholders describe a variety of direct and indirect approaches to livelihood support for caregivers of children with disabilities, overall, there is a lack of published and unpublished literature on content, process and impact of livelihood support, at least within the health literature and related fields. In the absence of robust evidence for improvement in livelihood-specific measures it is hard to conclude what specific approach to livelihood support in this vulnerable population will be most promising. However, given the findings here, consideration should be given to both direct and indirect strategies for livelihood support including sign-posting to existing resources and services through a range of expert partners. Provision and promotion of access to social protection measures, as well as other pro-caregivers social policies, through developing and implementing national and local level policies and implementing guidelines, should be inclusive of families with young children in the first 1000 days. Self-help groups can be an effective tool to support caregiver livelihood by providing gender-inclusive economic empowerment, and their formation and sustained operation should arguably therefore be supported. Importantly, wherever possible organisations should strive to collect monitoring, evaluation and learning data related to the livelihood of the families they work with (e.g., income level, employment status, access to benefits), to contribute to the evidence base for effective approaches. Larger scale implementation and impact research around livelihood support centred on caregivers of children with developmental disability appears warranted to improve understanding of not only what works, but also what can be effectively implemented at scale in low-income country settings.

# Acknowledgments

We thank Russell Burke, assistant librarian at the London School of Hygiene & Tropical Medicine, for assistance in developing the scoping review search strategy. We thank all professional members organisations and networks that supported survey dissemination.

## **Disclosure statement**

No potential conflict of interest was reported by the author(s).

# Funding

This work was supported by Grand Challenges Canada under grant TTS-2104-38112. EML is an Academic Clinical Fellow whose salary was funded by the UK National Institute for Health and Care Research whilst this work was conducted.

# ORCID

Eva M. Loucaides () http://orcid.org/0000-0001-8717-1045 Tracey Smythe () http://orcid.org/0000-0003-3408-7362 Cally J. Tann () http://orcid.org/0000-0003-0131-4952

# References

- [1] Olusanya BO, Davis AC, Wertlieb D, et al. Developmental disabilities among children younger than 5 years in 195 countries and territories, 1990–2016: a systematic analysis for the global burden of disease study 2016. Lancet Glob Health. 2018;6(10):e1100–e1121.
- [2] Banks LM, Kuper H, Polack S. Poverty and disability in lowand middle-income countries: a systematic review. PLoS One. 2017;12(12):e0189996.
- [3] Birenbaum A. Poverty, welfare reform, and disproportionate rates of disability among children. Ment Retard. 2002;40(3): 212–218.
- [4] Mitra S, Palmer M, Kim H, et al. Extra costs of living with a disability: a review and agenda for research. Disabil Health J. 2017;10(4):475–484.
- [5] Anderson D, Dumont S, Jacobs P, et al. The personal costs of caring for a child with a disability: a review of the literature. Public Health Rep. 2007;122(1):3–16.
- [6] Mont D. Combatting the costs of exclusion for children with disabilities and their families. New York (NY): United Nations Children's Fund (UNICEF); 2021.
- [7] World Health Organization & United Nations Children's Fund (UNICEF). Early childhood development and disability: a discussion paper. Geneva: World Health Organization; 2012.
- [8] World Health Organization & World Bank. World report on disability 2011. Geneva: World Health Organization; 2011.
- [9] Chambers R, Conway G. Sustainable rural livelihoods: practical concepts for the 21st century. Institute of Development Studies (IDS) Discussion Paper 296, Brighton: IDS; 1992.
- [10] Kuruvilla S, Bustreo F, Kuo T, et al. The global strategy for women's, children's and adolescents' health (2016-2030): a roadmap based on evidence and country experience. Bull World Health Organ. 2016;94(5):398–400.
- [11] Developmental Disabilities, Centre for Disease Control and Prevention (CDC). 2022. Available from: https://www.cdc. gov/ncbddd/developmentaldisabilities/index.html
- [12] Committee on Nervous System Disorders in Developing Countries Board on Global Health Institute of Medicine. Chapter 5: developmental disabilities. In: Neurological, psychiatric, and developmental disorders: meeting the

challenge in the developing world. Washington (DC): National Academies Press (US); 2001. p. 113–178.

- [13] Hume-Nixon M, Kuper H. The association between malnutrition and childhood disability in low-and middle-income countries: systematic review and meta-analysis of observational studies. Trop Med Int Health. 2018;23(11):1158–1175.
- [14] Ertem IO, World Health Organization. Developmental difficulties in early childhood: prevention, early identification, assessment and intervention in low-and middle-income countries: a review. Switzerland: World Health Organization; 2012. Available from: https://apps.who.int/iris/handle/10665/ 97942
- [15] Kuper H, Monteath-van Dok A, Wing K, et al. The impact of disability on the lives of children; cross-sectional data including 8,900 children with disabilities and 898,834 children without disabilities across 30 countries. PLoS One. 2014;9(9):e107300.
- [16] Thrush A, Hyder A. The neglected burden of caregiving in low- and middle-income countries. Disabil Health J. 2014; 7(3):262–272.
- [17] Hasan H, Aljunid SM, Amrizal MN. The costs of caregivers for children with disabilities that participate in Centre-Based and Home-Based Community-Based rehabilitation (CBR) programmes in the east Coast of Malaysia. Intellect Discourse. 2019;27:945–963.
- [18] Taderera C, Hall H. Challenges faced by parents of children with learning disabilities in Opuwo, Namibia. Afr J Disabil. 2017;6(1):283–210.
- [19] Bannink F, Stroeken K, Idro R, et al. Community knowledge, beliefs, attitudes, and practices towards children with spina bifida and hydrocephalus in Uganda. Int J Disabil Dev Educ. 2015;62(2):182–201.
- [20] Tigere B, Makhubele JC. The experiences of parents of children living with disabilities at Lehlaba protective workshop in Sekhukhune district of Limpopo province. Afr J Disabil. 2019;8(0):528–528.
- [21] Zuurmond M, Seeley J, Nyant GG, et al. Exploring caregiver experiences of stigma in Ghana: they insult me because of my child. Disabil Soc. 2022;37(5):827–848.
- [22] Zuurmond MA, Mahmud I, Polack S, et al. Understanding the lives of caregivers of children with cerebral palsy in rural Bangladesh: use of mixed methods. DCID. 2015;26(2): 5–21.
- [23] Nyante GG, Carpenter C. The experience of carers of children with cerebral palsy living in rural areas of Ghana who have received no rehabilitation services: a qualitative study. Child Care Health Dev. 2019; 1145(6):815–822.
- [24] World Health Organization. Community-based rehabilitation: CBR guidelines. Geneva: World Health Organization; 2010.
- [25] Iemmi V, Gibson L, Blanchet K, et al. Community-based rehabilitation for people with disabilities in low-and middle-income countries: a systematic review. Campbell Syst Rev. 2015;11(1):1–177.
- [26] Aromataris E, Munn Z, editors. JBI manual for evidence synthesis. JBI. 2020. Available from: https://synthesismanual.jbi. global
- [27] Tricco AC, Lillie E, Zarin W, et al. PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. Ann Intern Med. 2018;169(7):467–473.
- [28] Countries and Economies. The World Bank. 2022. Available from: https://data.worldbank.org/country
- [29] Bunning K, Gona J, Newton C, et al. Self-help groups for caregivers of children with developmental disabilities in

Kenya: a pathway to empowerment. J Appl Res Intellect Disabil. 2018;31(4):485.

- [30] Bunning K, Gona JK, Newton CR, et al. Empowering selfhelp groups for caregivers of children with disabilities in Kilifi, Kenya: impacts and their underlying mechanisms. PLoS One. 2020;15(3):e0229851.
- [31] Gona JK, Newton C, Hartley S, et al. Development of selfhelp groups for caregivers of children with disabilities in Kilifi, Kenya: process evaluation. Afr J Disabil. 2020;9(a650): 1–9.
- [32] Aldersey HM, Turnbull AP, Turnbull IH. Family support in Kinshasa, Democratic Republic of the Congo. J Policy Pract Intellect Disabil. 2016;13(1):23–32.
- [33] Bannink F, Idro R, van Hove G. Parental stress and support of parents of children with spina bifida in Uganda. Afr J Disabil. 2016;5(1):225.
- [34] Masulani-Mwale C, Kauye F, Gladstone M, et al. Development of a psycho-social intervention for reducing psychological distress among parents of children with intellectual disabilities in Malawi. PLoS One. 2019;14(2): e0210855.
- [35] Thapa R. Fulbari program: an integrated approach at rehabilitating and empowering the child and family of children with developmental disability in Nepal [conference abstract]. Eur J Paediatr Neurol. 2017;21(Supplement 1): e149.
- [36] Narayan J, Pratapkumar R, Reddy SP. Community managed services for persons with intellectual disability: Andhra Pradesh experience. J Intellect Disabil. 2017;21(3):248–258.
- [37] Balasundaram P. Love is not a feeling: faith and disability in the context of poverty. J Relig Disabil Health. 2007;11(2): 15–22.
- [38] Thomson K. Regional welfare system developments in Russia: community social services. Soc Policy Adm. 2002; 36(2):105–122.
- [39] Kuper H, Smythe T, Duttine A. Reflections on health promotion and disability in low and middle-income countries: case study of parent-support programmes for children with congenital Zika syndrome. IJERPH. 2018;15(3):514.
- [40] Christian Blind Mission (CBM). Disability inclusive development toolkit. 2015 [cited 2021 Aug 2]. Available from: https://www.cbm.org/news/news/news-2015/read-our-disability-inclusive-development-did-toolkit/?msclkid=e56fc6 e5b6f311eca27bcf6e6eab1cd1&cHash=cebb1b94af42f93dc 34f0cffed4de18d
- [41] Christian Blind Mission (CBM). Ghana country report: evaluating the impact of a community-based parent training programme for children with Cerebral Palsy in Ghana. 2017 [cited 2021 Aug 2]. Available from: https://www.cbm.org/fileadmin/user\_upload/Publications/Ghanacountry-reportfinal. pdf
- [42] Carers worldwide. Lifting carers and their families out of poverty; [cited 2021 Nov 2]. Available from: https://carersworldwide.org/lifting-carers-and-their-families-out-of-poverty/
- [43] Carers Worldwide. Impact report; 2019 [cited 2021 Nov 2]. Available from: https://carersworldwide.org/wp-content/ uploads/2020/02/CarersWorldwideReport2W.pdf
- [44] Carers Worldwide. Baseline study report: caring for carers of children with cerebral palsy in Nepal; 2017 [cited 2021 Nov 2]. Available from: https://carersworldwide.org/aboutus/reports-and-publications-2/