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

Eva M. Loucaides[a], Maria Zuurmond[b], Mathieu Nemerimana[c], Catherine M. Kirk[c], Rachel Lassman[d], Albert Ndayisaba[c], Tracey Smythe[b,e], Erick Baganizi[c] and Cally J. Tann[a,f,g]

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

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

➤ 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 five-years 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 no-one 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 cally.tann@lshtm.ac.uk London School of Hygiene and Tropical Medicine, Keppel Street, London WC1E 7HT, UK

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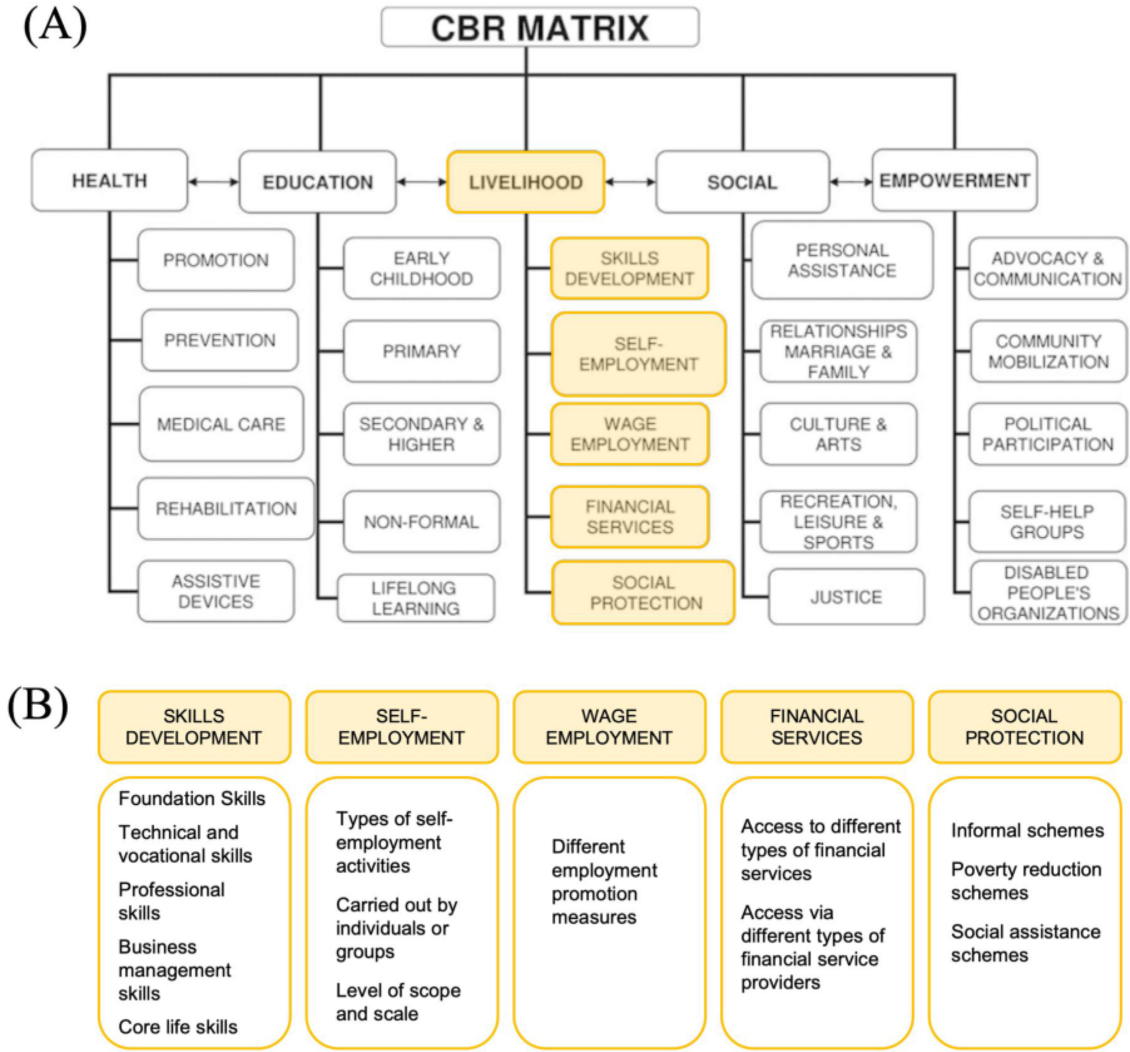


Figure 1. The WHO CBR matrix and its livelihood component. (A) Overview of the WHO CBR matrix. Adapted from World Health Organization. Community-based rehabilitation: CBR guidelines [24]. (B) Elements of the CBR matrix livelihood component and their core aspects.

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) caregivers, (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 peer-reviewed 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

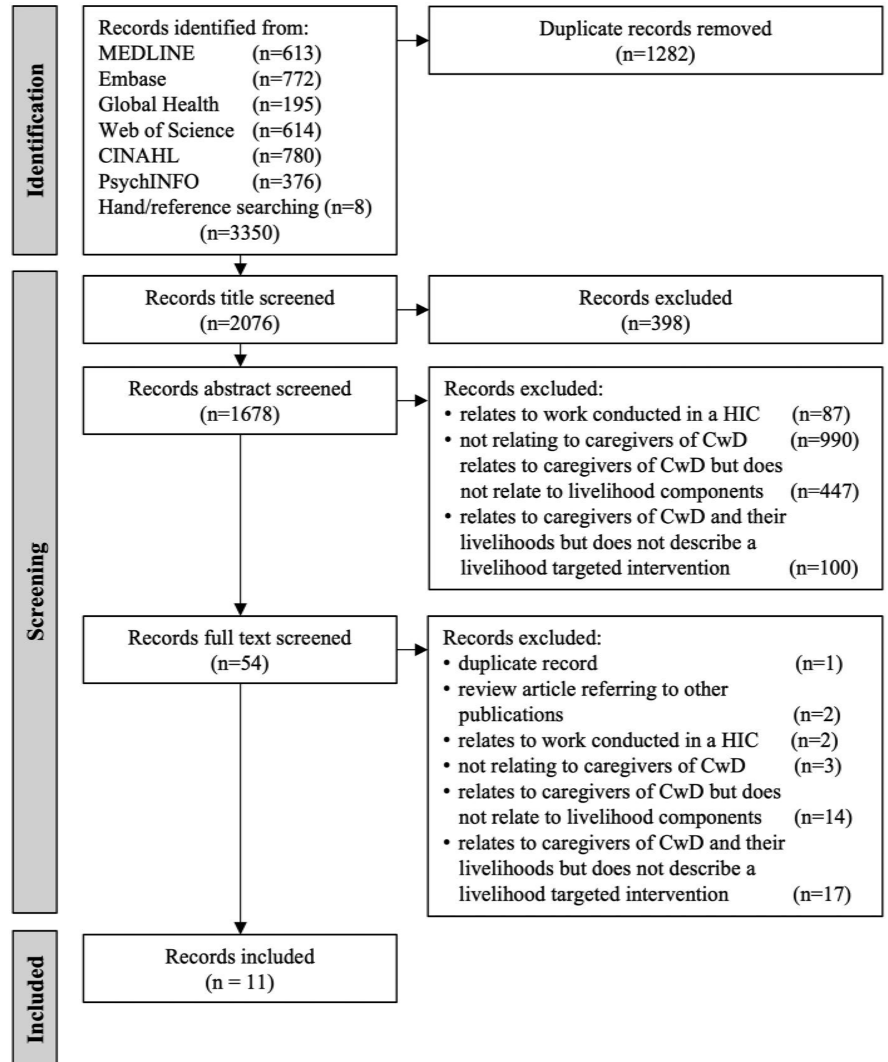


Figure 2. PRISMA-ScR flow diagram of bibliometric database search results and study inclusion process. CwD: child(ren) with disability; HIC: high-income country.

design, outcome measures, and element of the CBR matrix livelihood targeted.

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 specified the period of data collection which ranged from one month to a four-year period (Tables 1 and 2).

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].

Table 1. Summary of peer-reviewed publications included in the scoping review.

	Setting	Study design & outcome measure	Intervention: Intervention overview	Intervention livelihood content	Element(s) of the CBR matrix livelihood component targeted	Delivering organisation	Scope - Nr of participants - Timeframe	Intervention recipients: child w disability - Age - Disability - Other	Intervention recipients: caregiver
1. Bunning 2018 [29][a] 2. Bunning 2020 [30][a] 3. Gona 2020 [31][a]	Sub-Saharan Africa Kenya, rural	*Study design:* Interventional (pre-/post-evaluation) *Outcome measures:* Qualitative: Semi-structured interviews Quantitative: Sub-sections Communication Disability Profile; Multidimensional Scale of Perceived Social Support.	SHGs set up with weekly SHG meeting and 6 monthly facilitated sessions covering economic empowerment, sharing personal situations, peer support, community inclusion, access to health and education	SHGs, livelihood projects for income generation, including merry-go-round, farming, livestock rearing; access to financing and social support through SHGs; facilitated sessions on "economic empowerment" and "peer support"	Skills development; Self-employment; Access to financial service; Social protection	Public academic; SHG initiated by study team	*Nr of participants:* 11 SHG ,154 CGs *Timeframe:* work conducted and data collected from 2015 to 2018	*Age:* 0–15 years; *Disability:* "primary condition affecting body function and structure, including intellectual disability, deafness, visual impairment, autistic spectrum condition, cerebral palsy, variously associated with limitations in vision, hearing, mobility, attention, learning and the effects of seizures" *Other:* 58% not in school	*Age:* 46% 21–39 years, 52% 40+ years *Education*: 46% no formal, 23% incomplete primary *Household*: 56% 3–6 children, 25% 7–10 children
4. Aldersey 2016 [32]	Sub-Saharan Africa, DRC, urban	*Study design:* Observational (case study) *Outcome measures:* Qualitative: interviews, observations, document review	SHG providing emotional, physical, material/instrumental and informational support	Financial support to families (e.g., for medications, healthcare, funeral costs), help procuring needed equipment for improved health and daily living activities	Self-employment; Access to financial service; Social protection	SHG initiated by caregivers, collaborations with NGOs	*Nr of participants:* Not detailed *Timeframe:* Data collected over a 7 month period, SHG created in 2006	*Age:* Not detailed; *Disability:* intellectual and/or developmental disability	Not detailed
5. Bannink 2016 [33]	Sub-Saharan Africa, Uganda, urban	*Study design:* Observational (mixed methods evaluation) *Outcome measures:* Qualitative: Semi-structured interviews and focus group discussions Quantitative: Vineland Adaptive Behaviour Scales, Daily Functioning Subscales, Parental Stress Index Short Form	Descriptive study exploring parental stress and support of parents of children with spina bifida in Uganda referring to SHGs	Refers to SHGs impacting on parental livelihood "those who were members of a parent support group indicated it … helped them to learn more about … income-generating opportunities"; "parents felt the group gave them an opportunity to start income-generating activities together. They had started a rotating loan scheme, which was helping members to set up small businesses."	Self-employment; Access to financial services	SHGs initiated with the help of rehabilitation centres or community based rehabilitation initiatives	*Nr of participants:* 134 parents *Timeframe:* Data collected June 2011 to December 2014	*Age:* 4 – 14 years; *Disability:* Spina bifida; *Other:* 43% not in school	*Family member:* 78% mothers, 11% fathers, 7% grandmother *Education:* 5% no formal, 56% primary, 22% secondary
6. Masulani-Mwale 2019 [34]	Sub-Saharan Africa, Malawi, rural	*Study design:* Observational (qualitative, descriptive) *Outcome measures:* Qualitative: focus group discussions, expert consensus	Descriptive study of the development of a complex contextualised intervention	Pilots study and development of new intervention. Includes SHG formation to "address poverty issues through promotion of savings culture and small business enterprises"	Self-employment; Access to financial services	SHG initiation planned as part of the intervention	*Nr of participants:* Data presented for 14 parents Timeframe: Data collected September 2015	*Age:* Not detailed; *Disability:* intellectual disability	*Family member*: 14 mothers and fathers
7. Thapa 2017 [35]	South Asia, Nepal	*Study design:* Observational (mixed methods evaluation)	One month "intensive camp like training program" covering "pedagogy, livelihood	"parents were trained in ..livelihood earning skills and vocational training"	Skills development	SHG; Health care institution	*Nr of participants:* Data presented for 48 mothers	*Age:* 2–14 years *Disability:*	*Family member*: 48 mothers

(*continued*)

Table 1. Continued.

	Setting	Study design & outcome measure	Intervention: Intervention overview	Intervention livelihood content	Element(s) of the CBR matrix livelihood component targeted	Delivering organisation	Scope - Nr of participants - Timeframe	Intervention recipients: child w disability - Age - Disability - Other	Intervention recipients: caregiver
		Outcome measures: Quantitative: Parents: Knowledge, Attitude and Practice (KAP), "mental health" Children: Activities of Daily Living & Quality of Life	earning skills and vocational training, medical treatment, physiotherapy, speech therapy, occupational therapy, orthotics, assistive devices, hygiene & first-aid training"				*Timeframe:* "one month"	"various non-progressive developmental disorders"	
8. Narayan 2017 [36]	South Asia, India, rural	*Study design:* Observational (mixed methods evaluation) *Outcome measures*: Quantitative: Descriptive data e.g., "1372 children with development delays have shown considerable improvement in their mile stones"	Government programme for community based identification 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.	"… activities related to livelihood. Parent support was part of the overall service delivery"; "To guide parents of persons with intellectual and developmental disabilities and their family members to reach the service providers with regard to ..and welfare to meet their specific needs"	Social protection; (Skills development)	Public or national health system / governmental organisation; SHG	*Nr of participants:* "2819 children are being provided with early intervention ,..2736 parents involved" *Timeframe*: article presents data up to 2013—when programme started unclear	*Age:* Not detailed *Disability:* "intellectual and developmental disabilities"	Not detailed
9. Balasunda-ram 2007 [37]	South Asia, India, urban	*Study design*: Observational (qualitative, descriptive) *Outcome measures*: Qualitative: interviews	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"; "stalls .. sell the papier-mâché handicraft items and the spices they make."	Skills development; Self-employment; Social protection	NGO; SHG	*Nr of participants:* Not detailed *Timeframe:* 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 middle aged and older women past 50 or more"
10. Thomson 2002 [38]	Europe & Central Asia, Russia, rural	*Study design:* Observational (qualitative, descriptive) *Outcome measures:* Qualitative: Interviews. observation, document review	Descriptive study assessing the spectrum of provision for children and adults with learning Difficulties, referring to social protection provisions	"social service centres" carry 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 tickets to sanatoria," "parent support groups formed"	Social protection	Public or national health system/ governmental organisation	*Nr of participants:* Not detailed *Timeframe:* Data collected over a 7 month period in 1998	*Age :* Not detailed *Disability:* Not detailed	Not detailed
11. Kuper 2018 [39]	Latin America & Carib-bean Brazil, urban	*Study design:* Observational (case study) *Outcome measures*: Not detailed (in pilot phase at time of publication)	Carer support programmes of 10–11 sessions offered over a 3 month period covering essential care practices, such as feeding, positioning, communication, play and early stimulation, providing psychosocial support,	"the programme addresses … how parents can advocate for ..receipt of disability benefits", "aims to empower parents so they can address the driver of poor health among their children with disabilities, which include … poverty"	Social protection	Not detailed	*Nr of participants:* at the time of publication "6 parent groups" *Timeframe:* Not detailed	*Age:* not detailed *Disability:* Congenital Zika Syndrome	Not detailed

(*continued*)

Table 1. Continued.

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

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.
[a]All 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-posting 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 wage-employment 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.

Table 2. Summary of grey literature publications included in the scoping review.

	Setting	Element(s) of the WHO CBR matrix livelihood component targeted	Intervention	Impact measure
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 that they could create a sustainable life for themselves..", "farming, animal husbandry, poultry rearing, as well as advocacy and other initiatives"	Not detailed
CBM [41]	Ghana	Access to social protection measures	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% (however, ongoing issues with accessing fund)
Carers Worldwide [42]	India	Access to social protection measures, Access to financial services, Self-employment	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 support from our project to invest in a livelihood opportunity. They 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."	Descriptive text on programme content including participant quotes
Carers Worldwide [43]	India	Access to social protection measures, Access to financial services, Self-employment	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, have accessed the financial support available.., 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."	Descriptive text on programme content including participant quotes
Carers Worldwide [44]	Nepal	Access to financial services, Skills training, Self-employment	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 provide opportunities for respite"	Descriptive text on programme content including participant quotes
Carers Worldwide [45]	Nepal	Unclear	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 carers establish sustainable livelihood, and promoting alternative care arrangements."	Descriptive quantitative data of programme reach

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

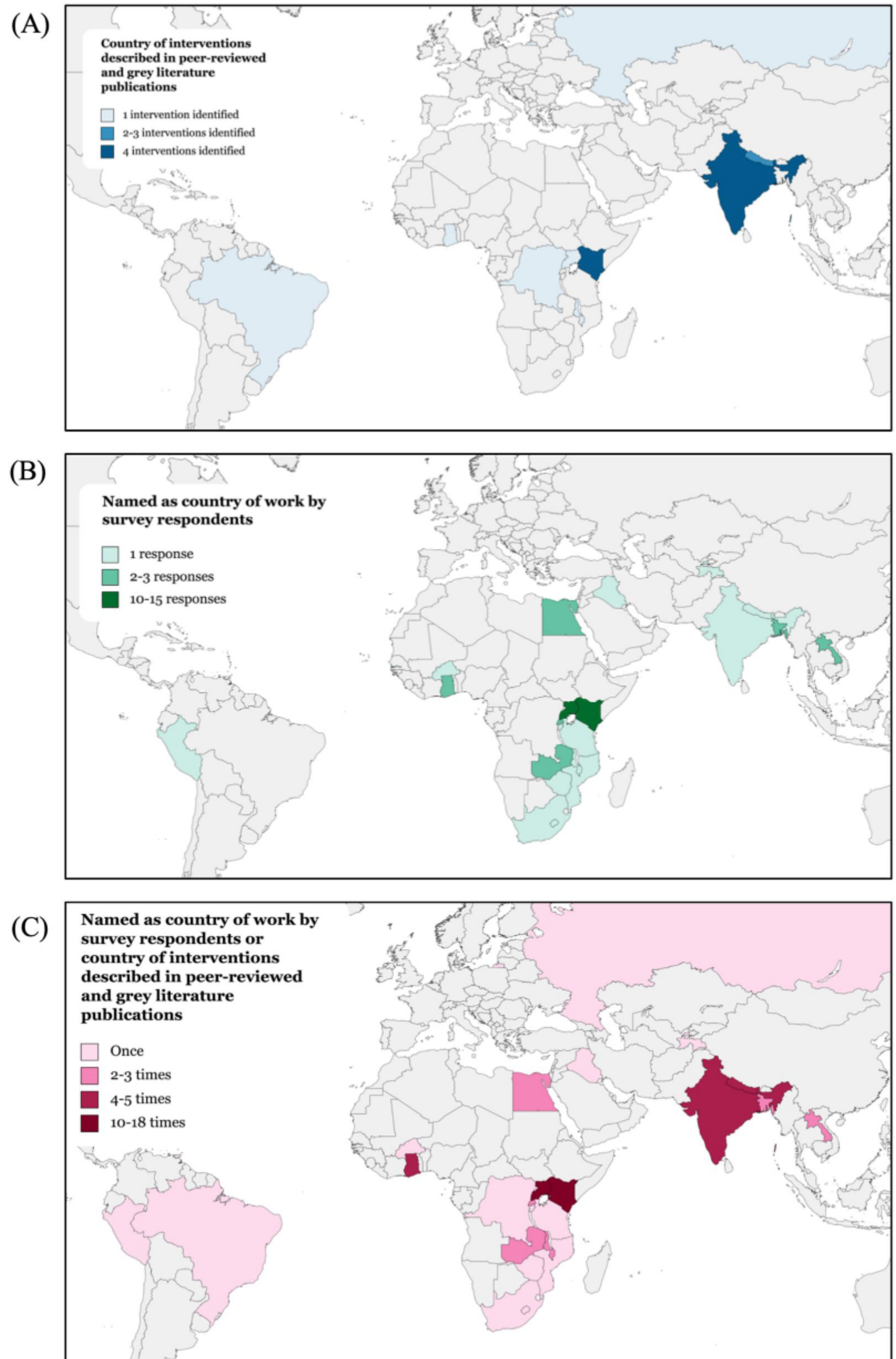


Figure 3. Global distribution of programmes identified through (A) the scoping review of published literature, (B) the online stakeholder survey, (C) the scoping review and survey combined.

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% ($n = 35$)),

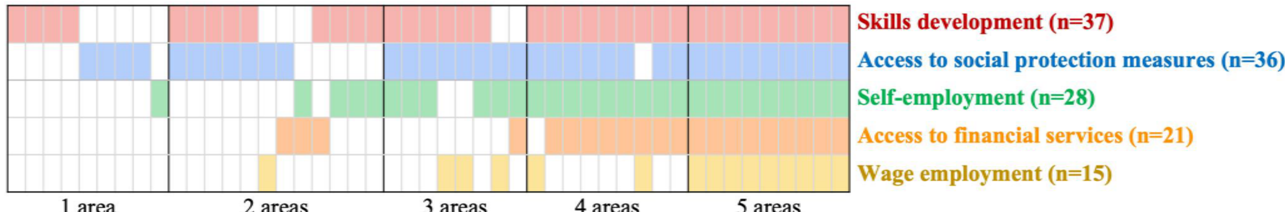


Figure 4. Element of livelihood support targeted. ($N = 47$). Columns represent one survey respondent who could indicate more than one element being targeted. Two respondents did not report on livelihood element targeted.

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,

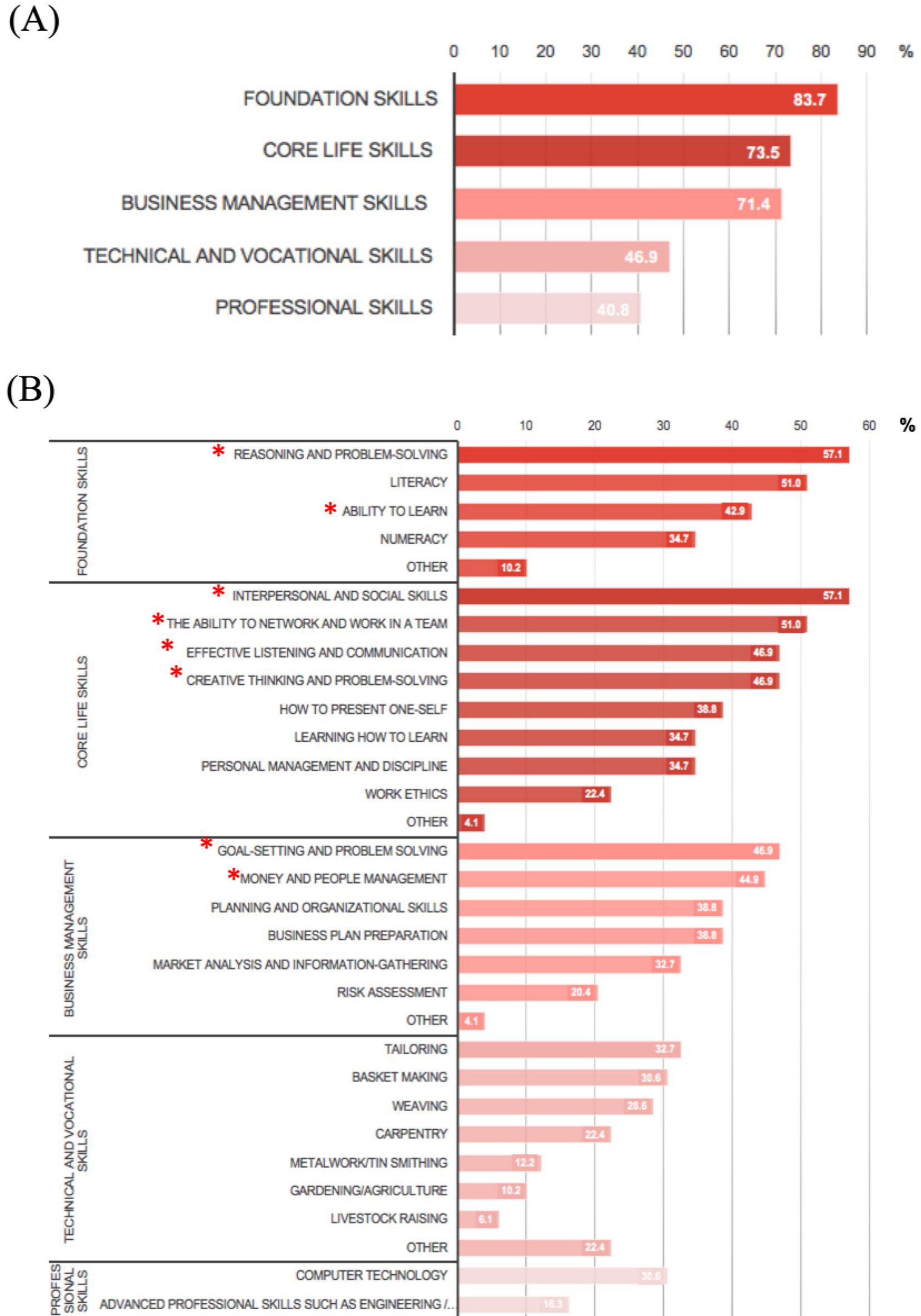
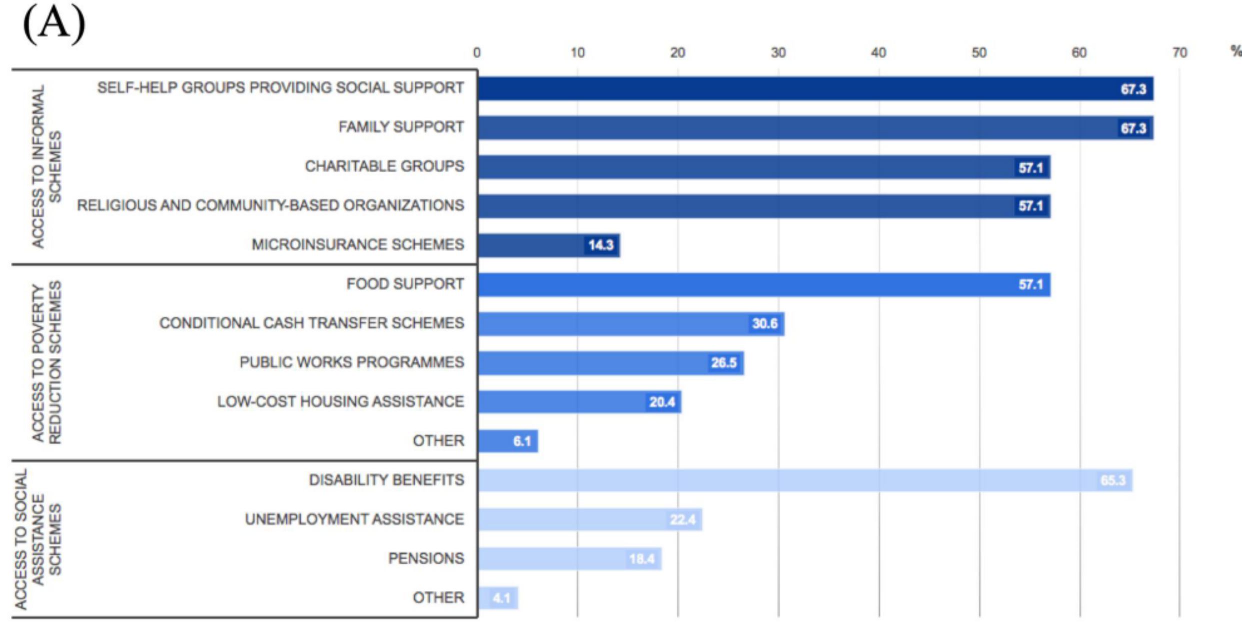


Figure 5. Livelihood support targeting skills development. ($N = 49$). (A) Element of skills development targeted. (B) Specific skills listed by respondents. * indicates skills targeted by at least 40% of programmes.

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



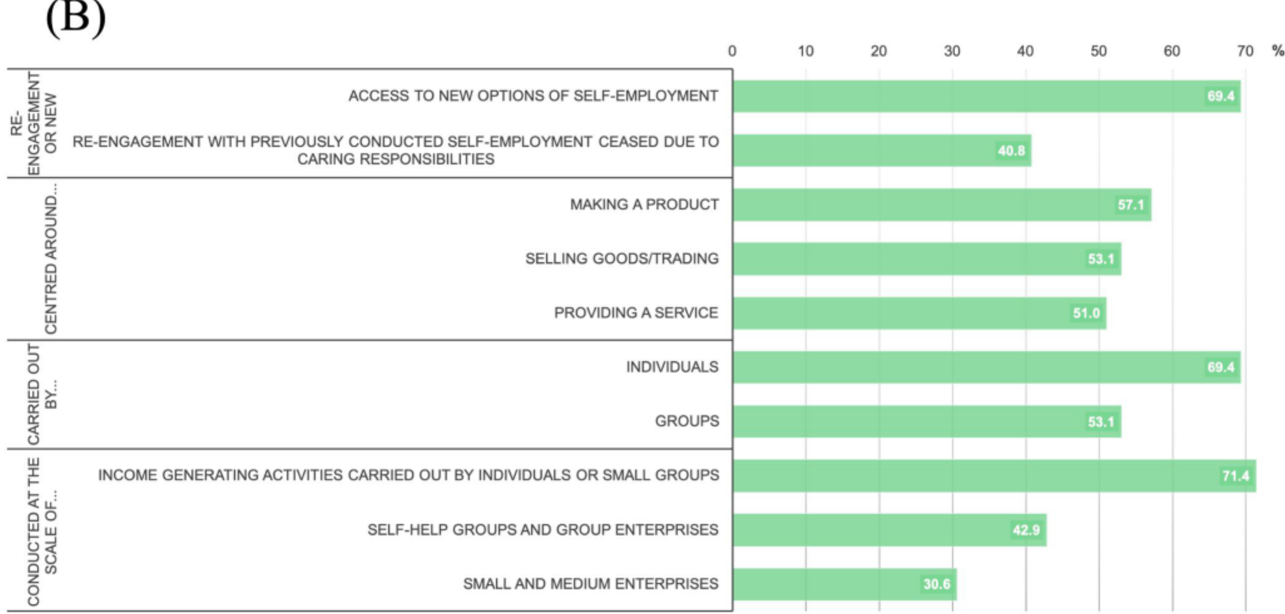


Figure 6. Livelihood support targeting (A) social protection and (B) self-employment ($N = 49$).

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-posting 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]

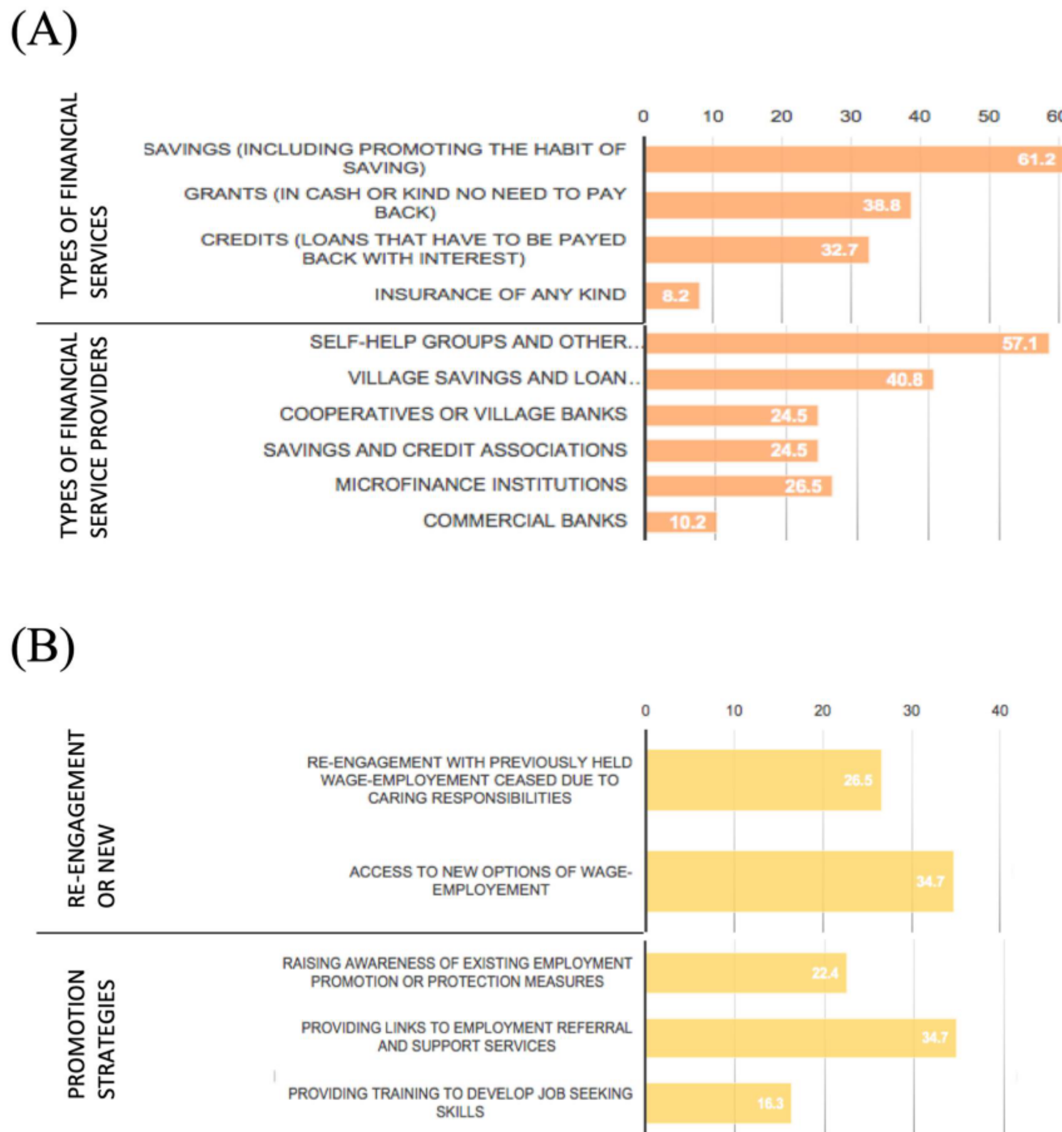


Figure 7. Livelihood support targeting (A) access to financial services and providers and (B) wage-employment ($N = 49$).

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 qualitative 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 non-random 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 yield 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.

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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

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