

Livelihood Support for Caregivers of Children with Developmental Disabilities: Findings from a Scoping Review and Stakeholder Survey

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BACKGROUND

Globally, there are 53 million children living with **developmental disabilities**, 95% of them living in low and middle-income countries (LMICs)¹. Strengthening the family environment in which children with disability are raised is fundamental to improving child welfare. However, **caregivers** face significant burden, including financial burden. Furthermore, **poverty** and disability are linked in a negative downward spiral².

Supporting **livelihoods**, i.e. the capabilities, assets (including both material and social resources) and activities required for a means of living, at both the individual and household level is key for families of children with developmental disabilities. Livelihood programmes exist in many LMIC settings. However, often their target is to improve the livelihood of the person with disability directly (i.e. adults with disability).

To our knowledge, very little is known on the role, approach and availability of programmes specifically supporting the livelihood of caregivers of children with developmental disability.

OBJECTIVE

We aimed to identify existing approaches to livelihood support for caregivers of children with developmental disabilities in low- and middle-income countries through

1. a scoping review of the published literature
2. an online survey of key-stakeholders

METHODS

Scoping review of the published literature: We utilised search terms related to a) children with developmental disability, b) caregivers, c) livelihood and d) LMICs linked by the Boolean operator AND to search MEDLINE, Embase, Global Health, Web of Science, CINAHL and PsycINFO for articles published between January 2000 and May 2021 with no limit to language of publication. We also search websites of key organisations. (2)

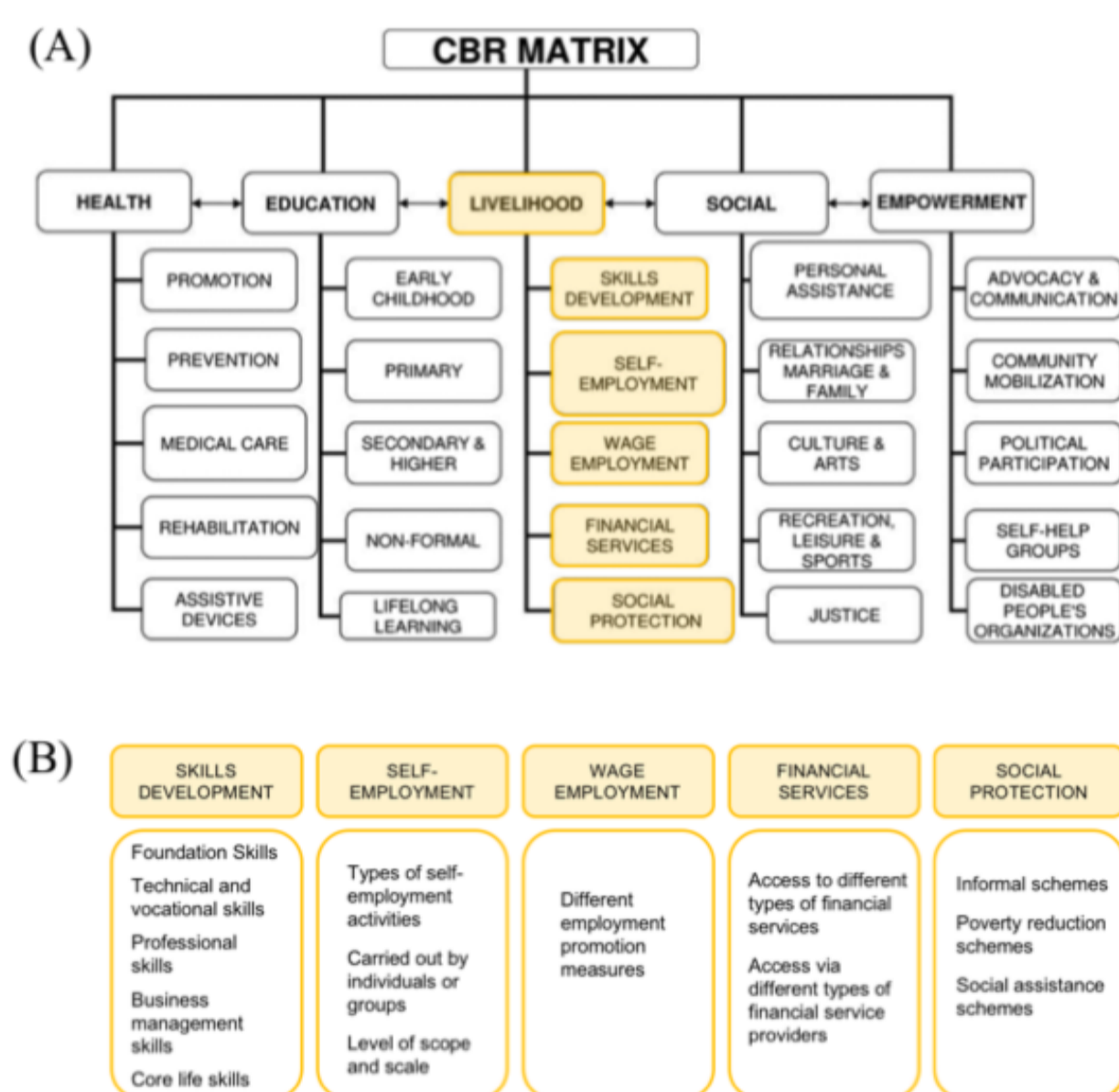


Figure 1: (A) The WHO CBR matrix, adapted from van Pletzen et al (2014)⁴ (B) Elements of the livelihood component and their core aspects

Online stakeholder survey: We utilised the WHO community-based rehabilitation (CBR) matrix³ as conceptual framework for questionnaire design. The survey was disseminated by snowballing. Informed consent was sought from all participants. We descriptively analysed the included articles and survey responses.

Ethics approval for this study was given by the London School of Hygiene and Tropical Medicine Research Ethics Committee (LSHTM Ethics ref 25187).

RESULTS: SCOPING REVIEW

We found 11 peer reviewed and 6 grey literature publications identifying specific livelihood programmes supporting caregivers of children with disabilities, largely in Sub-Saharan Africa. Studies were predominantly observational with reported outcomes measures relating to pre/post evaluation of child or parental physical or mental wellbeing. Livelihood was near to

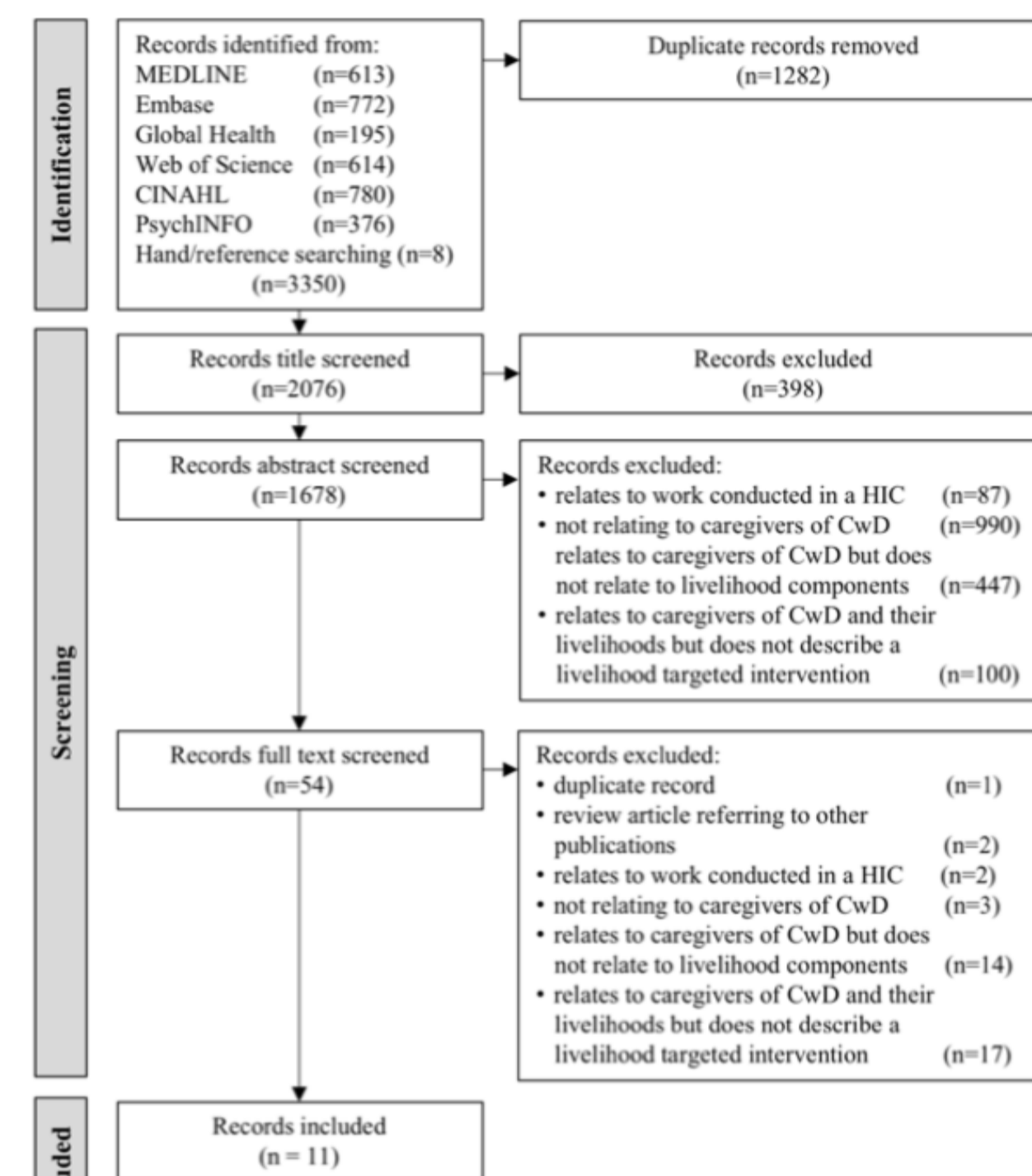


Figure 2: PRISMA-ScR flow diagram of bibliometric database search results and study inclusion process
CwD = child(ren) with disability, HIC = high-income country

always a secondary component of a wider intervention package. Where described in detail, interventions most commonly aligned with the CBR matrix livelihood components of access to social protection measures and self-employment. Self-help groups appeared to be a common intervention component aiming to effect livelihood-related change. A broad age range of the involved children with disability was reported in 3 studies (0-15 years, 2-14 years, 4-14 years). Sample size of intervention recipients, where reported, varied widely. None of the included publications presented findings from randomisation of participants.

RESULTS: SURVEY

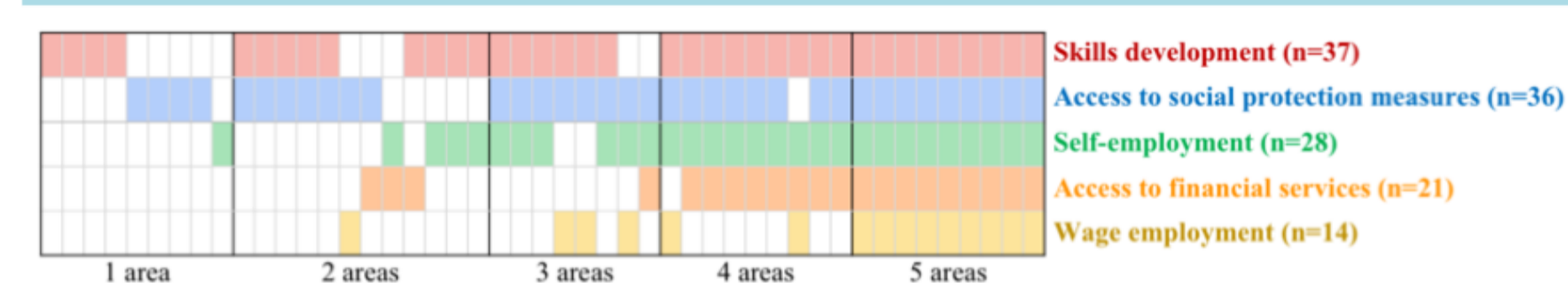


Figure 3: CBR matrix livelihood elements targeted per respondent* (*each column = one survey respondent)

Overall, 49 survey respondents reported on programmes from a 22 different countries. More than ¾ (77.8%) supported livelihood by referring to partner organizations in addition to their own work. The three most commonly targeted areas of the CBR matrix were (1) skills development (75.5%) - in particular transferrable skills such as foundation or core life skills as well as generic business skills; (2) access to social protection measures (73.5%) - in particular self-help groups and family support as well as disability benefits; and (3) self-employment (57%) - particularly new self-employment carried out at the level of income generating activities carried out by individuals or small groups.

KEY FINDINGS

- Whilst it is well documented in the published and grey literature that disability and poverty are interlinked and that caring for a child with disability places significant economic burden on the caregiver, the knowledge synthesis presented here found a **marked paucity of peer-reviewed published literature** describing interventions aiming to address this issue.
- Programmes identified through both scoping review and survey, commonly aimed to support **multiple livelihood aspects**, particularly **skills development**, access to **social protection** measures and **self-employment**; usually targeted livelihood as one component of a wider intervention; and, as indicated in survey findings, often in collaboration with **expert partners**.
- **Self-help groups** were listed in survey responses and published literature as common providers of financial services and informal measures of social protection.
- Most programmes described worked with a **broad age range** of children with disability, with none found to specifically targeting families with young children in the first 1000 days of life.
- The programmes identified here through a survey and scoping review operated in **Sub-Saharan Africa** and to a lesser extent South East Asia.
- There is a **lack of published evidence for effectiveness** of any one approach to supporting livelihood with no reported outcome measures relating specifically to livelihood found in the scoping review.

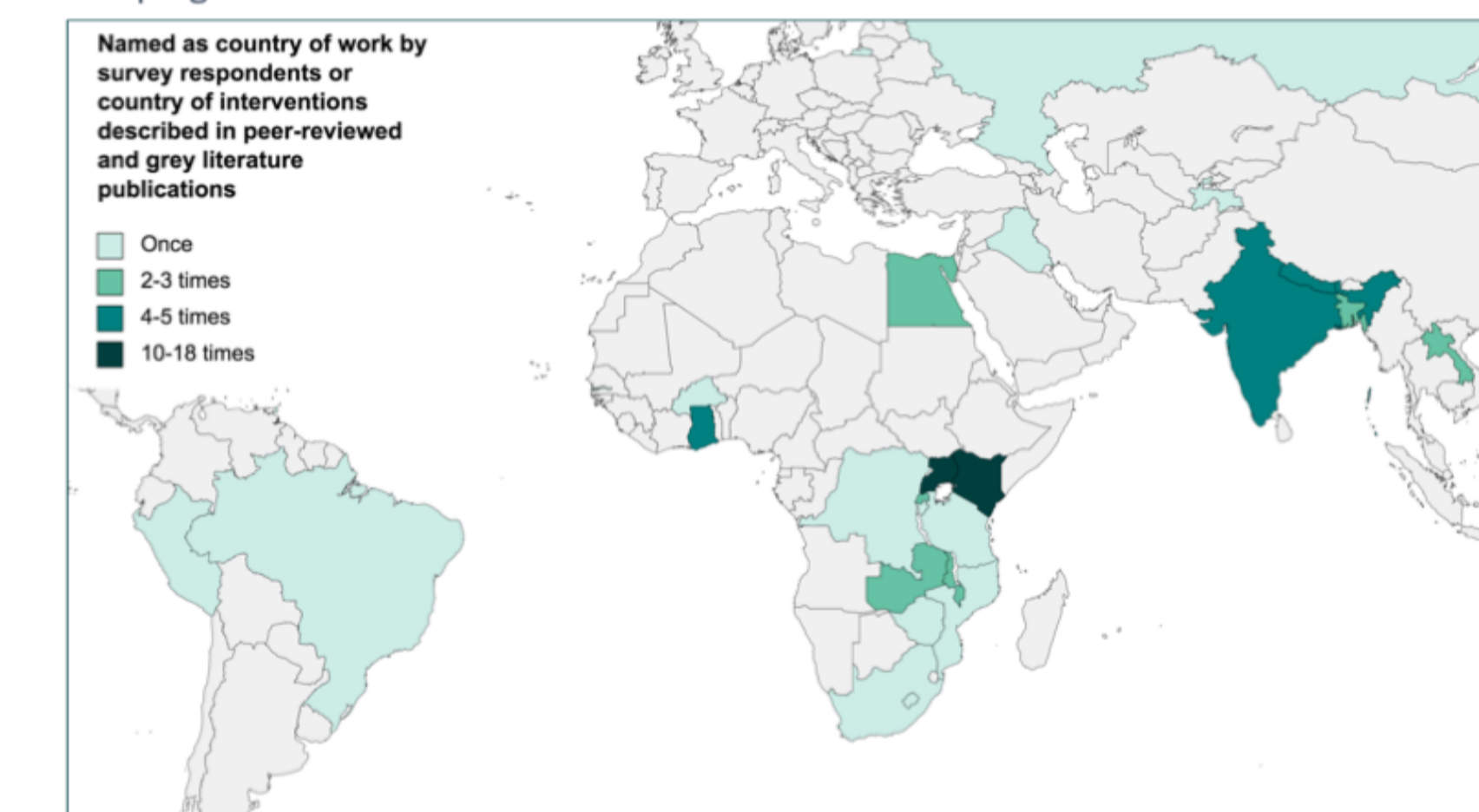


Figure 4: Global distribution of programmes identified

CONCLUSIONS

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. There is much scope for advances in policy, practice and research to tackle this important issue, with potential for substantial impact on the lives of children with disability and their families.

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All authors have declared no conflict of interest

