

Research

Pathways to support: a qualitative investigation of community health workers' role in coordinating disability services in India

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Abstract

Aim To explore the roles and responsibilities of Accredited Social Health Activists (ASHAs) and Anganwadi Workers (AWWs) in providing support to people living with disability and their households.

Subject and methods The current qualitative study involves a sequential research design involving two phases of qualitative data collection. Phase one includes a brief qualitative interview with thirty-three ASHAs to map the key themes of their work in the disability sector and how they work alongside AWWs. Phase two includes in-depth interviews with seven AWWs to explore their perspectives on the services available to people with disabilities in India, including the practical, emotional, and social support they provide and how they work alongside ASHAs. Thematic analysis was undertaken to analyze the results.

Results The key responsibilities of the ASHAs were monitoring and connection, and facilitating support for practical tasks. Service mapping of AWWs identified four domains – identification and referral, service coordination, monitoring and psychosocial support. Collaborative tasks between the two cadres were identified as; health education, coordinated activities with healthcare centres, house visits, and implementation of public health programs.

Conclusion The current study provides insights into community-based disability care in India, bringing a culturally relevant perspective to global conversations about disability support services. Community health workers are an excellent resource for multidimensional care for families of people with disabilities in India. Through effectively coordinated task-shifting and task-sharing strategies, ASHAs and AWWs can work alongside each other to implement interventions to improve the lives of people with disabilities and their households in India.

Keywords Community health workers; ASHAs · Anganwadi workers · Person with disability · Collaborative tasks · India

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1 Introduction

A person with a disability is someone who has a long-term physical, mental, intellectual or sensory impairment which, in some circumstances, impacts their participation in society [1, 2]. In the existing literature on disability in India, the term "the four D's" is commonly used to describe the primary causes or categories of disability, namely: Defects at birth, which include congenital conditions leading to physical and cognitive impairments, Diseases, which refer to chronic illnesses leading to long term disabilities, Deficiencies, particularly in nutrition in children leading to disabilities, and Developmental delays where children fail to reach expected developmental milestones, often resulting in intellectual or physical impairments [3–6]. These four categories are frequently discussed together in the literature, with disability being predominantly framed as a health issue in India.

The support available for people with disabilities and their caregivers in India is often fragmented and inadequate, leaving them to face significant challenges in accessing healthcare, education, occupation, and social services [7]. People with disabilities have higher unmet health needs and require more frequent hospital visits compared to those without disabilities; however, they continue to face significant barriers to appropriate care due to negative staff attitudes, lack of awareness, absence of inclusive health facilities, lack of disability-friendly health policies, and growing mistrust in the healthcare system [8–10]. Furthermore, access to disability services remains constrained due to inadequate government funding, low awareness of available services, and the absence of community-based models of care [11]. These difficulties are compounded by poor identification and documentation systems, particularly in rural and underserved areas, due to fragmented data collection systems, inconsistent assessment tools and lack of trained assessors [5, 12]. Despite legal advancements, the absence of representative and comprehensive data on the prevalence and types of disabilities continues to critically hinder health policy development and the effectiveness of health system frameworks in India [12].

The broader structural limitations and resource constraints within the public health system in India, highlight the importance of addressing disability support at the grassroots level, where community health workers play a pivotal role. In India, there is a community health workforce consisting of around 900,000 Accredited Social Health Activists (ASHAs), governed by the Ministry of Health and Family Welfare, and more than one million Anganwadi Workers (AWWs), governed by the Ministry of Women and Child Development who provide support to these people living with disability and their households [13]. ASHA workers are female community health workers who support a population of approximately 1,000 people in their local community. ASHA workers are trained to provide education and practical support to the community on preventive healthcare, nutrition, schooling, access to drinking water, and sanitation [14]. The ASHA worker role is considered a volunteer role [15], however, their income depends on incentives earned under various schemes, typically amounting Rs 2000- Rs 8000 (approximately \$72 to \$96) per month, varying across states [16]. ASHA workers have become a household name in India, with their prominence growing significantly during the COVID-19 pandemic lockdowns when they served as vital sources of community health support and information. AWWs are involved in early screening and detection of the four D's for children aged up to six years old and in providing support and education around immunisation and services related to mother and child health care [3, 5, 14]. This support is sometimes run via the Anganwadi Centres, which are a principal hub run by AWWs for the purpose of community health action [15]. AWWs also coordinate monthly 'Health Days' in each village, providing further opportunities to promote positive healthcare [15]. Both roles were conceptualized with the understanding that women, as primary caregivers in families, are better positioned to engage with communities, particularly on issues related to maternal and child health, nutrition, and family welfare. However, despite their strategic position, they face several critical challenges, including a lack of training, overloaded responsibilities, and inadequate linkages with other resources [17].

The National Rural Health Mission (NRHM) 2005–2012 report recommends that ASHAs should coordinate their tasks with AWWs, that the two professions should be considered as a team, and that ASHAs should be 'anchored in the Anganwadi system' [15]. The NRHM 2005–2012 report also emphasises a need to plan for diversity and suggests that an initial step should be for ASHAs and AWWs to record the needs of community members and document ideas for support initiatives [15]. While these recommendations primarily address general health services, they can also be extended to disability services. However, existing studies have not adequately documented how ASHAs and AWWs collaborate specifically in the provision of disability services, leaving a critical gap in understanding their roles in this area.

Building on these recommendations, the current study addresses the gap in the coordination and documentation of disability services, which remain largely unrecorded and fragmented [7]. Mapping these pathways to care could

potentially lead to improved integration and more effective tracking of support for individuals with disabilities. The current study addresses the research question 'What are the roles and responsibilities of ASHAs and AWWs in supporting people living with disability and on which tasks do they collaborate?'. Our study analyzes the results of a qualitative survey of ASHAs and interviews with AWWs which explored their perceived roles and responsibilities in supporting community members living with a disability. With improved collaboration of service provisions, there will be potential for better monitoring and support for people living with disability in India and their households.

2 Methods

2.1 Study design

The qualitative study involves a sequential research design involving two phases of qualitative data collection, mapping out the disability services provided by ASHAs and AWWs in Kerala, India. Phase One was inductive, focused on collecting data from ASHAs. The results of the first phase guided Phase 2, which was deductive and focused on AWWs (Fig. 1). The sequential design was pragmatically influenced by feasibility constraints. ASHAs were more accessible than AWWs due to their greater availability. Consequently, data collection from ASHAs was broad, and analysis of this data informed a narrower but deeper exploration of AWWs. Iteration was a key component of this study. After Phase One data collection, preliminary themes were analyzed, and interview guides for Phase Two were revised accordingly. These iterations ensured that Phase Two focused on validating and deepening the understanding of the themes identified in Phase One.

Ethics approval was gained from the Rajagiri College of Social Sciences ethics committee and a secondary approval was granted by the University of Melbourne ethics committee. Informed consent was obtained after explaining the study's purpose, procedures, and participants' rights. Confidentiality was maintained through secure data storage and anonymization of identifying details, ensuring voluntary participation, privacy, and ethical integrity throughout the study.

2.2 Phase one

Phase One involved conducting brief interviews with ASHAs and thematically analysing the data. A qualitative interview guide was developed to explore the perceived roles and responsibilities of ASHAs, their basic demographics, and their views of working alongside AWWs. This interview guide was created by students involved in a collaborative fieldwork placement between the Rajagiri College of Social Sciences and the University of Melbourne, as mentored by the authors of this study. Examples of the questions included in the interview guide are as follows: "What does your typical day look like?" and "What activities are part of your daily routine?".

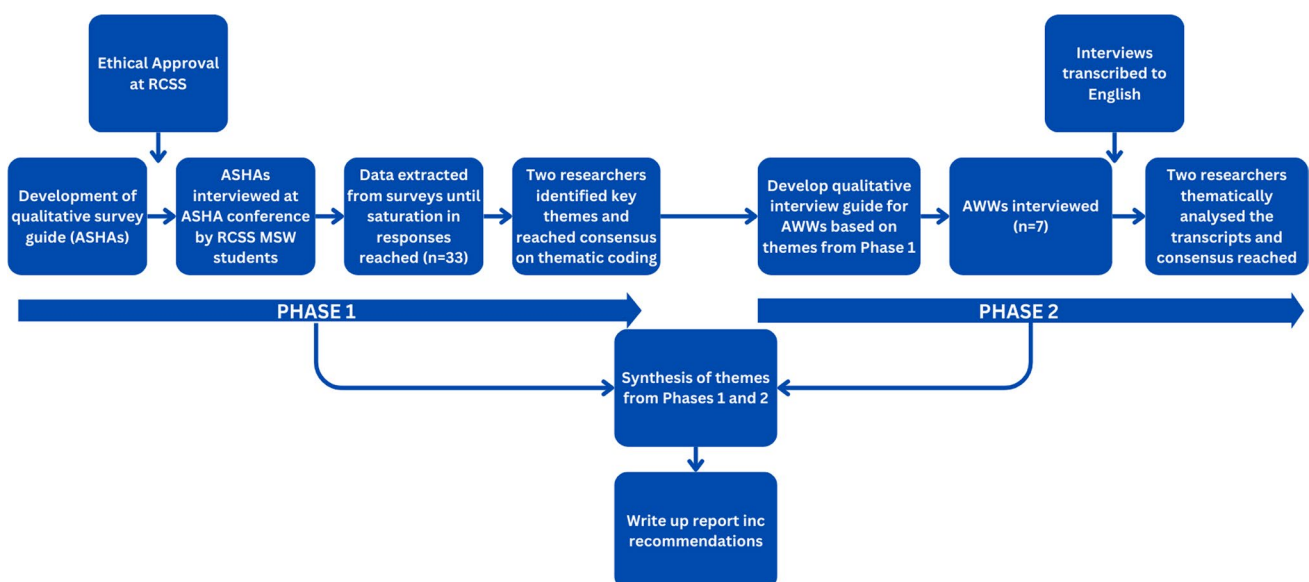


Fig. 1 Multi-phase Research Design of the Study

The interview was written in English, and then translated into Malayalam by a bilingual student researcher who then documented the verbal response back to written English. As this was a rapid data collection format, the responses were paraphrased rather than verbatim. To avoid interpreter bias, a random subset of interviews was independently reviewed by a second researcher to cross-validate summaries. The interview was conducted at a state-wide ASHA conference, in February 2023. The interview used convenience sampling to recruit 250 ASHAs drawn from a pool of 1500 ASHAs who attended the conference. All ASHAs who were in attendance at the conference were considered eligible for participation in the study. Informed verbal consent to participate in the study was gained by the student interviewers.

Interviews which were included in the analysis were selected at random. To reduce the risk of interviewer bias, 10 different student researchers completed surveys. The results of 33 ASHAs were extracted. This sample size was determined because the data being extracted had become significantly repetitive, with key themes becoming apparent. The results of Phase One were synthesized according to Braun and Clarke's reflective thematic analysis guideline [18]. A Master of Advanced Social Work trained researcher (RBP) and a Doctor of Social Work researcher (LS) individually identified key themes from the interviews and tracked them in Excel. RBP and LS then compared their coding and discussed these in detail until a consensus was reached regarding the themes and the coding to these themes. The demographics of ASHA and AWWs were also recorded to provide additional context. The results of Phase One contributed to the design of a qualitative interview guide to be used with AWWs in Phase Two.

2.3 Phase two

Phase two involved the development of a qualitative interview guide and subsequent interviews with seven AWWs. Anganwadi Workers (AWWs) were recruited through convenient sampling, targeting those actively engaged in community-based health and disability services. Although efforts were made to include a larger sample, only seven AWWs participated due to practical constraints such as their limited availability. However, the participants were taken from wider geographic settings, to ensure varied representation of contextual experiences. Despite the smaller sample size, thematic saturation was reached as no new themes emerged during the final interviews, ensuring that the data adequately captured the perspectives of this group.

The interview guide was developed by drawing upon the key themes developed in Phase One and consultations with experts in the field. The decision to use different interview guides for ASHAs and AWWs was driven by their distinct roles and the sequential research design. Although the overarching research questions remained consistent, the interview guides were tailored to capture the unique contributions and challenges experienced by each group. The questions were designed to elicit major roles and responsibilities, and systems and processes involved in disability care in the community. LS conducted the survey in April 2023. Each interview lasted 30–45 min and participant consent was audio recorded. Each interview was conducted in Malayalam and then transcribed into English for analysis by a bilingual researcher (LS). The interview guide is attached as a supplementary file (Supplementary file 1).

The AWW participants worked in different Integrated Child Development Schemes (ICDS) and represented Anganwadi centres from different districts of Kerala State (2 from Palakkad, 2 from Kottayam, 3 from Ernakulam representing diverse locations of the state). This ensured different cultural and geographical characteristics were represented. The research design reflects the existing literature which suggests that AWWs are the lead supports in the context of community disability care in India. These 7 in-depth interviews were instrumental in validating and enriching the themes identified from the ASHA interviews, ensuring a comprehensive understanding of the roles and challenges faced by both groups.

LS and RBP coded the transcribed interviews of AWWs using the NVivo software inductively. Thematic analysis was chosen for its flexibility in identifying patterns across datasets while maintaining contextual richness [18]. Text segments were able to have more than one code assigned. LS and RBP independently identified the major themes and sub-themes from Phase Two. The final themes were reached following discussion and consensus within the research team. The major themes of the study were (1) Key roles of community health workers towards disability care and (2) Collaborative tasks between the community health workers.

3 Results

3.1 Participant Characteristics

The study presents the results of a total sample of 40 community health workers (33 ASHAs and seven AWWs). Table 1 describes the demographic distribution of the community health workers—ASHAs, and AWWs interviewed in the study.

Table 1 Demographic Distribution

Demographics	ASHAs (n = 33)	AWWs (n = 7)
Mean Age	45.03	48.7
Mean work experience in years	8.9	21.8
Marital status		
Married	90.9%	100%
Widowed	6.1%	-
Unknown	3%	-
Type of family		
Nuclear family	87.9%	85.7%
Extended family	9.1%	14.3%
Joint family	3%	-
Education		
Primary	12.1%	-
Secondary	57.6%	100%
Tertiary	27.3%	-
Religion		
Christian	18.2%	28.6%
Hindu	66.7%	57.1%
Muslim	15.2%	14.2%

The mean age for ASHAs and AWWs was 45 and 48.7, respectively. The AWWs who participated in the study had, on average, 21.8 years of experience in their current role while ASHAs had generally just under nine years in their role ($n = 8.98$). Most of the community workers included in the study were married (90.9% among ASHAs and 100% among AWWs) and came from nuclear families (87.9% among ASHAs and 85.7% among AWWs). The majority of ASHAs and AWWs (66.7% and 57.1% respectively) were Hindus. All the AWWs interviewed had completed secondary education, while 12.1% of ASHAs had formal education only at the primary school level. Of the ASHAs, almost half (57.6%) had secondary education, and 27.3% had a tertiary degree.

3.2 Key roles of ASHAs

Thematic analysis found that ASHA's self-identified roles fall into two key themes (1) monitoring and connection and (2) practical support. A further breakdown of these is provided in Fig. 2.

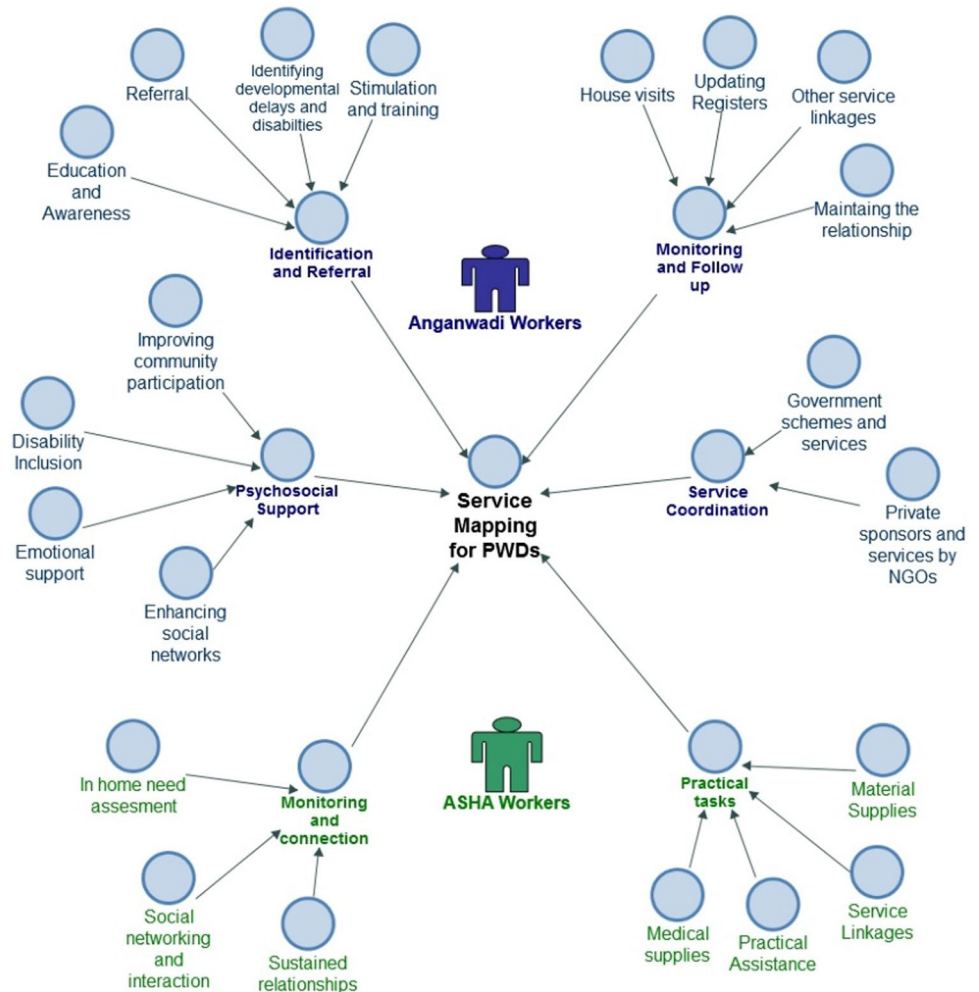
3.2.1 Monitoring and Connection

In-home assessments and social interaction were significant aspects that came up under monitoring and connection. All the ASHAs interviewed described undertaking regular follow-up visits to ensure that the families of PWDs had access to the available services. These repeated visits were identified by ASHAs as opportunities to maintain and sustain relationships with these vulnerable people. Interpersonal contact that occurs during these house visits is a useful opportunity for the caregivers to debrief and express any concerns, thus the ASHAs are also providing social interaction.

3.2.2 Practical support

Though not directly tasked with responsibilities regarding disability care, ASHAs engage in practical support for people living with disability and their families through house visits and joint programs with AWWs. ASHAs perform a variety of tasks which include the provision of medical supplies, such as medicine, air beds, and other pressure care equipment. They also assist the Junior Public Health Nurses (JPHNs) in palliative care services, facilitate pensions, and arrange for linkages to other social care schemes. ASHAs also facilitate connection to formal health services like hospitals and medical clinics, generating awareness of the services available.

Fig. 2 Service Mapping of Community Health Workers for People with Disabilities



3.3 Key roles of AWWs

The interviews with AWWs found that the disability-specific services offered by AWWs include (1) Identification and Referral, (2) Service Coordination, (3) Psychosocial Support and (4) Monitoring and Follow-up.

3.3.1 Identification and Referral

AWWs were found to be uniquely positioned to identify developmental delays and disabilities among children due to their close association with the parents. When signs of developmental delays or disabilities in children are noted, AWWs systematically observe them for a couple of weeks before speaking to their parents for further action.

"We identify disability among children based on our observation and experience. When we see something different in a kid, we don't immediately tell their parents that their kid has a disability. We observe the kid for some time and then decide to approach the parents" [51-year-old female, working as AWW for the past 20 years].

Some of the AWWs participants mentioned that they identify early signs of disability among children when they perform house visits to the mothers in their area. One of the AWWs responded:

"We identify them when we go for home visits in our area – for instance when we go for home visits, we ask the mothers some basic questions about their kids – how is your child? Is he responding correctly? Things like that. We ask them questions about the developmental milestones for each month" [39 F, with 14 years of experience, working in a rural location in Kerala].

More formal processes for early identification were done by the RBSK nurse appointed at a Primary Health Centres (PHC), who does regular assessments on children attending the Anganwadi centres for signs of developmental delays and other disabilities. Once the AWWs identify disabilities in children, they communicate this to the parents and discuss referral pathways. The AWWs make reports of these interactions which are sent back to their ICDS supervisors. They refer the parents and children either to the PHC or the nearby district hospital to confirm the type and level of disability. The AWWs also connect them with the RBSK nurse or the District Disability Rehabilitation Centres (DDRC), who provide follow-up.

“If we identify a child with a disability, we report that to our supervisor. Other than that, people from DDRC regularly call and ask for updates regarding children with disability. When we find a child with a disability, we give them their addresses, and they will look into the kind of care they need. They will assess the kind of therapy they require and assist accordingly based on the type and level of disability – physiotherapy or any other therapy” [52-year-old AWW working in the central region of Kerala, with 30 years of work experience].

3.3.2 Service coordination

The primary responsibility of an AWW concerning PWDs is to organize, facilitate and coordinate available government support services. AWWs are tasked with identifying people eligible for benefits, organizing and registering them for disability certificates, facilitating the processes and procedures for scholarships and pensions available, and raising their needs in public meetings to access assistive devices and other supportive services. Few AWWs responded.

...Also, the other services we provide are, arranging for assistive devices for people with disabilities – hearing aids for people with hearing impairment, walkers for people with locomotor disabilities and so on [39 F, with 14 years of experience, working in a rural location in Kerala].

We help these people avail those services – for instance, we help them fill in application forms... we prepare the applications for the scholarships every year.

In addition to performing their role of linking clients to government-run schemes, some AWWs responded that they connect these people to private sponsors and non-governmental organizations (NGOs) working for people living with disability.

“When we come across a private sponsor or an agency that helps them, we usually connect them to those” [49 F, working in Ernakulam].

3.3.3 Psychosocial Support

Emotional support and enhancing social networks were prominent themes that emerged from the analysis of the service delivery of AWWs for people living with disability, despite this not formally being described as a responsibility for AWWs. Consistent and frequent contact with these groups of people gives them a space to express their concerns and reduce the burden of caregiving.

“When I visit them, they usually tell me all their worries, and I try to comfort them” [AWW working in the community for the last 12 years].

All the AWWs interviewed mentioned that they frequently organize programs and activities for PWDs to improve their community participation and enhance their social networks. Analysis has shown that AWWs ensure that people living with disability are represented and included in community activities and planning meetings to meet their needs efficiently and effectively.

“Last year, there was a special gram sabha (forum for people’s participation in governance) for people living with disability. It was organized very well, and almost everyone participated in it. They raised their issues and worries during the meeting. It was a huge success. We informed them about the program, registered them, seated them and arranged for everything they needed during the session” [53 F, Christian, working as AWW for the past 25 years].

Another AWW responded about recreational and social events organized for PWDs in their area:

“We recently organized an arts festival for people with disability in our area. It was so good. Almost all the families attended that and performed something (any cultural event). We even welcomed the children from a “special school”

nearby. The programmes presented by all of them were so good. We even organized their food and snacks during the program and gave them participatory gifts. We usually organize programs like this once a year” [55 F from Kottayam with work experience of over 35 years].

3.3.4 Monitoring and follow-up

People living with disability and their caregivers are monitored on an ongoing basis by the AWWs through house visits, organized meetings and classes, planning sessions and so on. The monitoring is done through house visits and assessments at the Anganwadi Centre. Once a disability is diagnosed and confirmed, the AWWs are tasked with reporting that to the ICDS supervisor, who maintains a disability register in the Panchayat, to update the details of the people living with disability. The AWWs, when they detect and identify disability among children either when they are seen at the Anganwadi Centres or during in-house visits, will educate the parents on disability, the importance of early treatment or therapy, and the referral pathways. The AWWs will help the parents identify suitable treatment centres (if they are amenable) and assist them in contacting them. If a disability has been confirmed by a medical doctor, AWWs will help them with additional service linkages from the central government and the Panchayats.

“We identify the type of disability and help them with their needed assistance. For example, we refer them to services if they require therapy or treatment. Or if it is a child with vision impairment and they wish to send their kid to a special school, we help them organize that. If they need a pension, we arrange that. These are the services that we do” [45 F, working in Ernakulam].

3.4 Collaborative tasks between ASHAs and AWWs

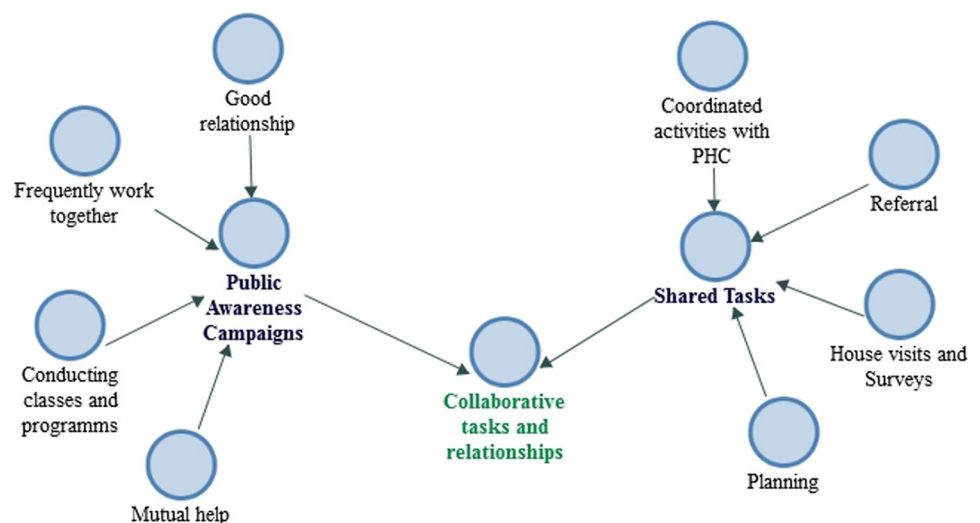
Analysis of the responses from ASHAs and AWWs found that they work collaboratively on many activities and programs related to health care implementation in the community (Fig. 3). Two themes emerged from the analysis include (1) public awareness campaigns and (2) shared tasks.

3.4.1 Public awareness campaigns

The data extracted from the ASHAs which related to their perspectives of working with AWWs found that they largely report having a good relationship with AWWs. The survey also found that ASHAs collaborate with AWWs in facilitating community awareness classes and programs related to health promotion. The ASHAs also reported that they occasionally share practical tasks such as assisting community members to apply for a pension or to receive a vaccination.

These community health workers are mediators of the health functionaries like the Primary Health Centres (PHCs)/ Family Health Centres (FHCs) and the community people. Both ASHAs and AWWs work collaboratively with the health

Fig. 3 Collaborative Tasks and Relationships Between Community Health Workers in India



care and administrative team in the community to conduct programs, organize and conduct house visits for surveys and health education and are actively involved in the coordinated activities with the PHCs.

“Since all our departments are connected and come under the Panchayat (the local self-government body), we participate in all the joint activities, surveys, and programs organized by the health department and the Panchayath” [39 F, with 14 years of experience, working in a rural location in Kerala].

3.4.2 Shared tasks

These largely related to monitoring, with both community health workers providing a degree of oversight to vulnerable community members including those living with disability and their families. Both ASHAs and AWWs participate in advocacy by attending planning meetings in the Panchayat (the local self-government bodies within each district) that address matters requiring urgent public action and procedures. The ASHAs and AWWs participate together in meetings organized at the Panchayat, raising matters relating to health in their respective wards, suggesting solutions, and working collaboratively with the administrative team in developing and implementing solutions for matters requiring public health action.

“We have Jagrata Samitis (the committee that works at the local government level in Kerala to protect women’s rights) in our ward; we meet there together. We discuss the priority actions that need to be taken in our ward and things like that during these meetings” [49 F, Hindu, working in an urban locality for the past 12 years].

“We also go for house visits together in our area”.

4 Discussion

The current study reports the findings of a qualitative analysis of the mapping of the multifaceted services provided by community health workers (ASHAs and AWWs) to the families of people living with disability in the Indian context. Service mapping identified tasks delivered collaboratively and those delivered separately. The tasks for AWWs include identification and referral of PWDs, service coordination which includes organising and facilitating various government and non-governmental schemes for PWDs, psychosocial support, and monitoring and coordination. The ASHA’s main function was frequent visits for monitoring and social interaction, and provision of practical tasks. According to our results, collaborative tasks between the two cadres included health education, coordinated activities with healthcare centres, house visits, and advocacy in the development of public health programs in the community.

There is limited evidence supporting the care services provided by community health workers for people living with disability in Indian situations. Even though the main target populations for ASHAs and AWWs are pregnant women, children, and older adults [14], the current study documents that these health workers also engage with families of people living with disability in providing practical, emotional, and social support. The findings confirmed those of other studies describing the mental health service provision roles of ASHAs [19], and the detection of childhood disability by AWWs [20, 21]. The current study findings suggest that services provided by these health workers were centred around service coordination and facilitation. However, these workers receive little formal training for engaging with people living with disability and their families [22]. This is supported by literature which suggests that conditions like disability and mental health which contribute significantly to the burden of disease are often not addressed in training programmes for community health workers in low- and middle-income countries [14, 23]. However, the direct and consistent monitoring associated with the roles of these community health workers, as evidenced by the study results, make ASHAs and AWWs important resources for the implementation of additional support interventions for the families in managing their burden levels and improving their quality of living. Coordinated efforts between these health workers have the potential to play a crucial role in the early identification, referral, and ongoing support of people living with disabilities and their families.

The study has demonstrated that community health workers involved in the care of people living with disability have the potential to guide task-sharing strategies in public health to ensure disability detection and the provision of support to families of people living with disability. Using task-sharing strategies would facilitate access to resources in low- and middle-income countries [24–26], thus strengthening family caregivers [27]. Public health campaigns on social networks have been proven effective in fostering awareness and increasing access to resources [28]. The ASHAs and AWWs can work collaboratively to support people living with disability and their families and to improve public awareness around this. Coordinated counselling and support between the cadres have been successfully implemented and tested for

maternal health outcomes [29], but have yet to be explored or tested for disability services. The ASHAs tasks appear to be more related to activities of daily living, whereas AWWs tasks are more focused on the diagnosis of disabilities and referrals. There is no clear delineation between the ASHA and AWW roles when working with people living with disability and their families but the majority of participants in this study noted that they have frequent and good communication among the community health workers network and mutually help each other, thus it can be assumed that individual service user cases are being coordinated between the assigned ASHAs and AWWs.

ASHAs and AWWs jointly organize health awareness classes for adolescent females, pregnant and lactating mothers and the general public, and the tasks are done collaboratively [14]. This crucial element of collaboration, which was evidenced in our study as well, brings together different skill sets, resulting in better community participation, and offering a more holistic and integrated approach to community health. However, the public health services in India are often disparate and lack geographical and functional coordination between different cadres of health workers [30]. Clear coordination and an equitable sharing of tasks between ASHAs and AWWs would help ensure that both cadres can effectively manage their professional responsibilities without being overburdened [31]. This further emphasizes the need for a defined care coordination system to be included in public health care management to optimize the potential without additional financial implications. Programmes and policies should provide consistent and ongoing monitoring of the needs of the families; documenting potential ideas for support initiatives, mapping the already existing services, and finally standardizing intervention models and training more professionals to work in this space [5, 14]. The aim should be to strengthen families, recognizing them as the greatest resource for caring for people with disabilities in India [27]. However, a lack of coordination at the grassroots level can result in service overlap between different cadres of community health workers and limit the effectiveness of task-sharing initiatives [32].

The current study has demonstrated the implications for the active inclusion of a care coordinator in community settings, emphasizing their role in coordinating and collaborating with community health workers to promote the development and well-being of families of people living with a disability. The development of a disability-specific cadre of health workers has been acknowledged in previous studies as well [33]. Social workers, valuable resources in community settings, contributing significantly to the overall well-being of populations are uniquely positioned to take up the role [34]. The role of social workers can focus on integrating the data from multiple sources, especially from the ASHAs and AWWs and stratifying individuals based on their condition-based needs. This involves the development of an individual care plan with a specific focus on ensuring access to condition-specific resources and linkage to services which will then be assigned to the concerned community workers (AWWs or ASHAs). The AWWs and ASHAs would further engage the stakeholders through various stakeholder engagement activities (Fig. 4). The social worker, therefore, is responsible for analysing and monitoring the care quality and intervention outcomes, and continuously strengthening the overall system. The liaison with and management of various formal and informal resources located in the geographical area and tapping them without service overlap is another major role of the social worker in the current model. This would address the structural issues of lack of training, lack of information, overlapping services, and communicative problems, and optimize the services without wastage of resources. The social worker through the ASHAs and AWWs can therefore liaise with families and government services thereby strengthening the family to care for their family members. The resource linkage function, if performed effectively, without gaps and duplications, would ensure the optimisation of the scarce resources available for the most deserving section of society.

Government leaders and policymakers should consider assigning care coordination to community health professionals like social workers to effectively utilise the already existing human resources in the community. CHWs are uniquely positioned and best suited for mainstreaming families of PWDs owing to their consistent communications and relationships with the families [35]. Developing an understanding of how they coordinate the services and resources to strengthen the families of people with disability is needed. Effective mechanisms should be put in place that would ensure the delegation of tasks to prevent workload, practice-focused training techniques to better equip them towards early identification of disability and managing caregiver burden among caregivers, and emphasising career progression chances to prevent burnout and stress of these health workers.

4.1 Limitations of the study

The study has limitations. The study was conducted in selected districts of Kerala, and while it provides insights into the experiences of CHWs in this context, the applicability of these results to other regions may be influenced by differences in regional policies and practices regarding disability care and support for community health workers. Further research in other states with varied training and resource frameworks would be necessary to draw broader conclusions.

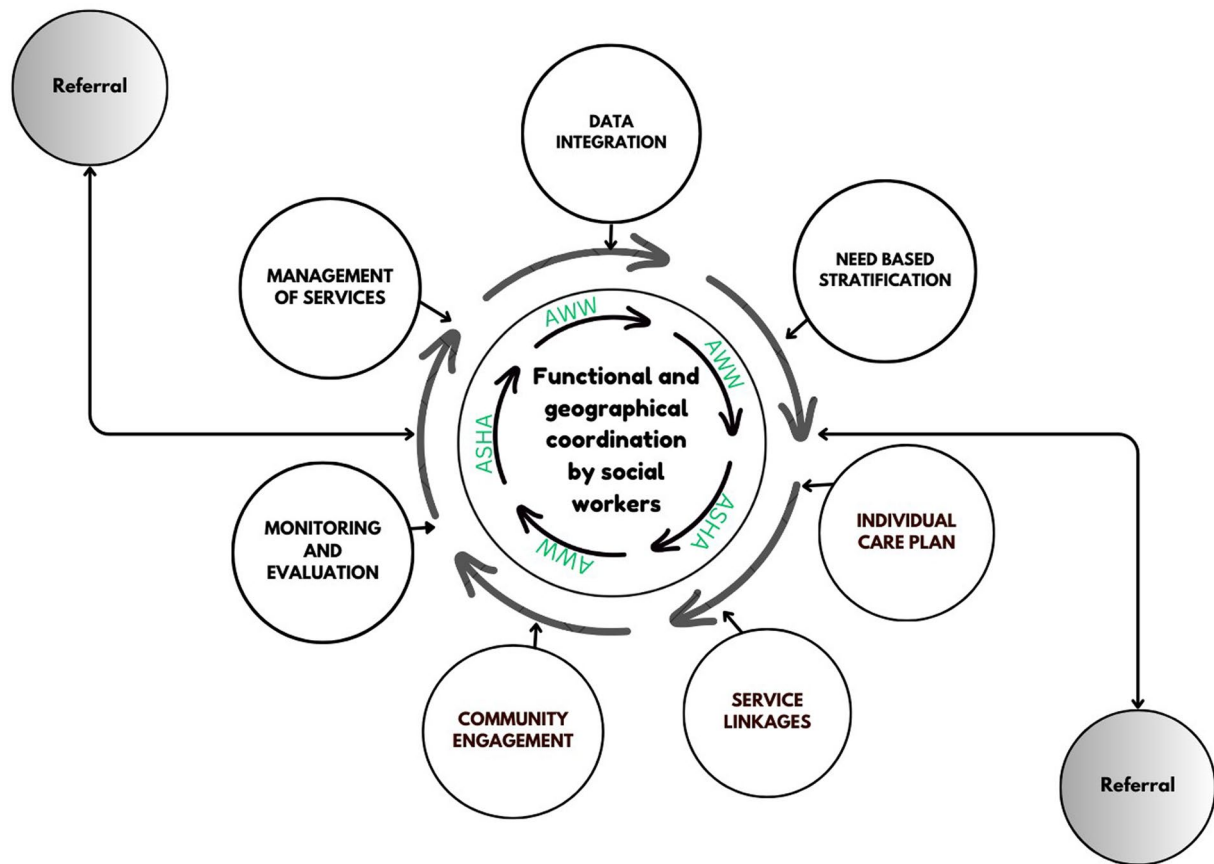


Fig. 4 Community Engagement Model for Social Workers and Community Health Workers in the Community

The methodological limitations of paraphrasing the responses of the ASHAs from the interview might have inadvertently omitted information regarding service provision and caused interviewer bias despite the use of standardized procedures. Additionally, the relatively smaller number of AWW participants compared to ASHA participants may have influenced the generalizability of the results. Larger, randomized control trials are needed to document the evidence of the effectiveness of utilising community health workers as resources for improved disability care and disability inclusion in resource-poor settings as in India.

5 Conclusions

The collaborative tasks between ASHAs and AWWs ensure comprehensive care and support for persons with disabilities and their families. While AWWs focus more on the early identification of disabilities, service coordination, and referrals, the ASHAs are primarily associated with helping with practical tasks and monitoring. ASHAs and AWWs require more clearly defined and enunciated roles that consider their skill sets at a more granular level. These skill sets should complement, but not duplicate each other. Establishing structured frameworks for collaboration and coordination can ensure smoother functioning, reduce overlap in responsibilities, and enable more effective service delivery for people with disabilities and their families.

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Data availability The data will be made available on request from the corresponding author.

Declarations

Ethics approval and consent to participate Ethics approval was gained from the Institutional Ethics Committee of Rajagiri College of Social Sciences (Reference No: RCSS/IEC/001/2023, dated February 23, 2023) and a secondary approval was granted by the University of Melbourne ethics committee. All procedures followed ethical standards set by the research committee and the 1964 Helsinki Declaration. Verbal consent was obtained from the ASHAs and the AWWs before participation and they were informed about the voluntary nature of participation. Participants were assured of confidentiality and anonymity.

Consent for publication Not Applicable as no identifying information is published.

Competing interests The authors declare no competing interests.

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