

What is the evidence for utilising community resources to detect and support children with disabilities?

The question and the problem

Children with developmental disabilities have the greatest risk of poor development in the early crucial years. There is a substantial difference between the comprehension of early childhood development and the implementation of intervention services for children with disabilities in High-Income and Low-and-Middle Income countries (LMIC). The grave lack of trained health professionals (particularly in far and remote regions) is limiting service provision for intervention services, and support for families whose children have disabilities. Medical models of service provision at health facilities, patchy community follow-up, limited expertise among community health workers around disability and lack of acceptance of disability, leaves families isolated and unsupported. Consequently, the child's disability is poorly understood, support to the family is fragmented, leading to exclusion and poor development. This brief aims to understand the evidence for utilising community resources to detect and support children with disabilities.

Recommendations

- Recommendation #1: Integrate disability into childhood services that is inclusive of different sectors e.g. education
- Recommendation #2: Expand access to therapy and intervention service resources in communities
- Recommendation #3: Develop and validate appropriate screening tools for disabilities in LMICs
- Recommendation #4: Developmental surveillance in children should be routine, regular and early
- Recommendation #5: Engage families and non-specialist community resources to improve awareness and identify, support and promote acceptance for children with disabilities

Challenges

Challenge #1: Childhood Disability is not yet a Global health priority

- The Convention on the Rights of Persons with Disabilities (CRPD) states that all children with disabilities have the right to develop “to the maximum extent possible”. These guidelines recognize the importance of focusing not only on the child’s health condition or impairment, but also on the influence of the environment as the cause of underdevelopment and exclusion. Recent [reports](#) reiterate the urgent need for investments in early intervention for children with disabilities, particularly in LMIC.
- There is an urgent need to prioritise early childhood development for the beneficiaries of global child survival initiatives who have disabilities, especially in low-income and middle-income countries

Challenge #2: The burden of poor development is higher than estimated in children, taking into account additional risk factors

- Children with developmental disabilities have the greatest risk of poor development in their early years. Therefore, prioritising the needs of children with developmental disabilities is an important complement for efforts to reduce preventable childhood disability and mortality.
- Greater political prioritisation is core to scale-up, as are policies that afford families time and financial resources to provide nurturing care for young children in the community. National programmes with contextual adaptations for far and remote areas are needed, so programs can be utilised more by families in the region.
- All sectors, particularly education, and social and child protection, must play a role to meet the holistic needs of young children, since disability does not exist in a vacuum.

Challenge #3: There is presently poor community resources to facilitate earlier recognition and identification of needs for children with disabilities.

- A limited number of culturally sensitive developmental screening tools are found to be validated for children aged <5 years in low- and middle-income countries. Parents usually were the first to recognise potential delays or needs. Therefore, investments to raise parental awareness of developmental disabilities and other family needs could be beneficial.
- The engagement of community health workers (CHWs) has emerged as a very promising strategy for addressing the persistent disparities in the delivery of intervention services for disability. Conducting surveillance and screening for developmental delay and timely referral by community practitioners has been shown to support more children to be diagnosed early.

Challenge #4: Childhood disability services are often non-existent or limited in LMICs

- In many countries programmes and services targeting young children are often inadequate to meet their developmental needs, and when available they are often costly, not inclusive and located in urban areas.
- Lack of integration between various government departments renders the family unsupported and much time is lost in paperwork for registration. Integrated access to mainstream services such as health care and education therefore plays a significant role in determining child health, development and inclusion in LMICs.
- Overall there is an insufficient number of service providers with sufficient knowledge of and skills in disability and very few in community facilities are formally trained to identify children with disabilities early and within time for preventative support.
- Children with disabilities often miss out on essential vaccinations and basic treatment for common childhood illness, referral mechanisms are disjointed, children are often lost in the system, and there is no single window system for disability intervention service.

How did we find answers

This evidence brief examined evidence in the form of systematic, scoping, narrative and other forms of review on the topic of utilising community resources for utilisation of services to detect and support children with disabilities. A literature search was conducted in five databases Pubmed, Cochrane, Research Gate, Science Direct and Global Health, from January 1 1950 to 31st December 2021, using indexed mesh terms. The search mostly revealed data from high income countries, where disability is more researched. Specifically, information from eleven reviews from LMICs on the topic was used for the evidence in this brief. All recommendations and actions were derived from the included studies and additional references consulted.

Evidence-informed Recommendations and Actions

Key Recommendations	Actions
Integrate disability into all systems and services for children	<ul style="list-style-type: none">- <i>Initiate, expand and strengthen intervention services for disability in primary, secondary, and tertiary healthcare levels e.g. by providing trained workforce, routine developmental screening and accessible services.</i>- <i>Stronger leadership from practitioners, governments, and international organizations to prioritize regular childhood developmental surveillance for possible delays and disabilities, and to pursue early referral for intervention.</i>- <i>Bridging research and policy gaps in local services for supporting children with developmental delays and disabilities.</i>
Access to childhood resources in the community	<ul style="list-style-type: none">- <i>Adequate health care, nutrition, stimulation and a positive environment at home and in the community to enable children and their parents to strengthen developmental outcomes.</i>
Adapt screening tools for disability in LMICs	<ul style="list-style-type: none">- <i>Enhancing awareness and knowledge among health professional's awareness about most at-risk of delay</i>- <i>Revising existing screening tools in different ethnic and cultural settings and subsequent validation</i>
Routine and timely developmental surveillance in children	<ul style="list-style-type: none">- <i>Ensuring nationwide routine developmental surveillance programmes in LMICs using culturally sensitive tools to identify and treat developmental delay as early as possible.</i>- <i>Developmental screening at the time of routine immunisation schedule has been identified as an approach to integrate within an existing successful public health programme in LMICs. This timing would be both cost-effective, maximise response rates and limit missing children being diagnosed.</i>
Family and community resources	<ul style="list-style-type: none">- <i>Sensitize primary medical providers to the needs of these children to ensure they receive adequate preventive and curative health care alongside behavioral, social, and educational interventions.</i>- <i>Training community practitioners to support families and facilitate communication among schools, social services, and health-care personnel for coordination on care and support.</i>- <i>Normalise topics around disability and enhance acceptance for a range of neuro-diversity in children</i>- <i>Establish local resource groups for families in the community including people with disabilities, families of children with disabilities, rehabilitation service providers, community health workers, etc.</i>- <i>Actions should also be targeted towards educating and empowering parents to detect, and advocate on behalf of their children</i>- <i>Involvement of local disability organizations, parent groups and disabled people themselves will strengthen community service provision and utilization of services.</i>

Policy priorities

Governments must urgently prioritise the needs of children with developmental disabilities in global child development initiatives; it is vital to complement this with community resource strengthening for identification, referral and support services. Countries need to scale up local community efforts to prioritise consideration for children under 5 years with developmental disabilities and to contribute to accelerating progress towards the 2030 SDGs. This brief calls for emergent leadership from practitioners, governments, and community organizations to prioritize regular childhood developmental surveillance for possible delays and disabilities, and to support families in their communities.

Conclusion

A global and national unified strategy can narrow the gap between early identification, access, and utilization of intervention services by the increasing population of children with delays and disabilities. In LMIC countries, in addition, a renewed emphasis on a local approach with community resources will enable optimal development of the children and promote inclusion. In general, there is a lack of review evidence from low- and middle-income countries around the evidence for utilising Community Resources to detect and support children with disabilities. Available evidence shows that specific programs for early childhood development need to be established at the community level to strengthen local capacity by training personnel, encourage families to utilise services, empower other caregivers, all to promote positive and sustained inclusion of children.

Acknowledgements

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GAPS & RESEARCH NEEDS

Evidence presented in this review is limited due to dearth of findings from LMICs.

Recommendations from HIC are not without some limitations, when applied to resource-scarce settings. Article screening and data extraction were performed individually, introducing the potential for bias. Future studies should use rigorous protocols to minimize bias. More studies are also needed from low resource settings to generate transferrable evidence on how to utilise the value of community resources for families whose children have disabilities.