

# What works to improve mental health for parents of children with disabilities?

## The question and the problem

Parents play a pivotal role in facilitating childhood development and healthcare access for children with disabilities. However, these carers need support to achieve maximum social inclusion and functioning in their communities. In addition to the usual parenting demands, parents of children with disabilities often take on complex care tasks while having to balance other aspects of family life and work commitments. As a result, they may experience additional stresses that may impact on their well-being. However, these effects may be resolved if caregivers are provided with appropriate psychological interventions.

## Recommendations

- Recommendation #1: Focus on increasing access to training interventions to alleviate psychological stress in carers.
- Recommendation #2: Provide better access to respite care to reduce the burden on family members as well as acute services as the only source of meaningful support.
- Recommendation #3: Develop contextually-appropriate and culturally-sensitive interventions that take account of the carers' socio-economic settings.
- Recommendation #4: Train local community workers and other parents with children with disabilities using community resources to provide parent training and support interventions.
- Recommendation #5: Focus on developing a good quality evidence base from LMICs to determine what works to improve the mental health outcomes of carers of children with disabilities.

“We need more research into the cultural competency of our interventions with parents of children with disabilities. Although we know that families differ across cultures, little research has examined the cultural competency of interventions.”

## Challenges

Challenge #1: There is a lack of contextually-appropriate and culturally-sensitive interventions for carers of children with disabilities in LMICs.

- Most of the interventions evaluated in LMICs have been adopted from high-income countries.
- There is a need to develop interventions that take account of the carers' cultural, language, socio-economic and community settings.

Challenge #2: Limited resources is a barrier to implementation and attendance of interventions for carers in LMICs

- There are multiple potential socio-economic barriers to implementing carer interventions.
- On the part of service providers there may be barriers such as lack of trained personnel to implement training and limited resources for use in interventions.
- On the part of the participants living in a rural area and associated difficulty with transportation, as well as lack of respite care emerge as barriers that may prevent carers from attending interventions.

Challenge #3: Respite care is often unavailable or inaccessible in LMICs

- In most LMICs government-mandated respite care is not widely available. This usually means that respite gets provided informally by other family members or support gets sought from acute services.
- Some of the barriers to respite care access include lack of respite care services, lack of information about the existing services, lack of flexibility of these services, as well as inadequate finances and transportation.

Challenge #4: Much of the carer stress comes from the stigma and cultural misconceptions associated with disability and its causes.

- Research suggests that carer stress is mediated by the cultural understandings and the meanings attached to disability.
- Negative cultural perceptions of child disability may determine the level of outside and self-stigma experienced by the parents, their experience of stress and their willingness to access support services.

Challenge #5: Female caregivers of children with disabilities are likely to experience more stress compared to other family members.

- Research suggests that mothers and grandmothers of children with disabilities may experience more stress compared to other members of the family. This is usually due to the added responsibilities and time-commitment associated with usually being the primary caregivers to the children, while having to manage other aspects of family life and work. These effects may be further exacerbated by lower socio-economic status.
- Interventions specifically targeting mothers of children with disabilities are needed to address the gendered dimensions of care work.
- Mothers and fathers are also likely to differ in the factors that contribute to their stress, with mothers being impacted more by lower socio-economic status, greater care demands and the economic implications of caring for a child with disability.

Challenge #6: High quality research on the topic coming from LMICs is lacking.

- Available studies from LMICs show some efficacy, however, are often fraught with methodological issues.
- There is a need for more good quality research from LMICs evaluating interventions for carers of children with disability.

## How did we find answers

We conducted a review of reviews, examining systematic, narrative, and other types of review evidence on the topic of access to healthcare for people with disabilities. All recommendations are based on reviews of literatures from low- and middle-income countries, as well as some reviews of literature from high-income countries where the recommendations made were transferable to low-resource settings. This evidence note is based on the findings of 2 reviews of low- and middle-income country evidence, and 4 reviews which covered literature from a range of settings.

## Evidence-informed Recommendations and Actions

Key Recommendations	Actions
<b>Focus on increasing access to training interventions to alleviate psychological stress in carers.</b>	<ul style="list-style-type: none"><li>- <i>Efficacy studies of interventions from LMICs involving components such as psychoeducation and skills training to reduce the risk of burnout or depression, improve perceptions of family functioning, nurturing positive attitudes, teaching problem-focused coping strategies, anger management, and mindfulness show some promise in alleviating carer psychological stress.</i></li><li>- <i>These components should be given consideration when designing interventions for carers of children with disabilities.</i></li><li>- <i>However, it is important for programming not to assume that all stressors experienced by families are related to being the caregivers of a child with a disability. Other factors that need to be considered are general to all families, such as poor marital and family functioning, or the need for meaningful family connections.</i></li></ul>
<b>Provide better access to respite care to reduce the burden on family members as well as acute services as the only source of meaningful support.</b>	<ul style="list-style-type: none"><li>- <i>Available research on respite care in LMICs shows potential benefits for parental stress reduction.</i></li><li>- <i>Parents of children with disabilities in LMICs are reported to struggle to access respite care compared to parents from HICs where respite care interventions are usually developed and researched.</i></li><li>- <i>Quality, not simply quantity, of respite care needs to be paid attention to when increasing access. Respite care that is most meaningful goes beyond the physical separation of parent from child. Providers need to be adequately trained to support the complex needs of children with disabilities.</i></li></ul>

<p><b>Develop contextually-appropriate and culturally-sensitive interventions that take account of the carers' socio-economic settings.</b></p>	<ul style="list-style-type: none"> <li>- <i>Majority of available research evaluating carer interventions in LMICs are adopted from developing countries. There need to be concerted efforts to develop culturally-appropriate interventions for delivery in LMICs.</i></li> <li>- <i>Culture impacts on how carers define and experience disability, and how they interact with support services.</i></li> <li>- <i>Adjust interventions to fit carer socio-economic context for more meaningful engagement.</i></li> <li>- <i>Socio-cultural factors need to be taken into account, such as lack of resources and any stigmatising views within carers' communities.</i></li> <li>- <i>Use of the carers' preferred language is essential to make intervention content meaningful, understandable and relevant.</i></li> <li>- <i>Carers' religious beliefs should be taken into account when designing interventions. It should be considered if and how the information and skills learnt during training may be incorporated into carers' religious practices, where applicable.</i></li> </ul>
<p><b>Train local community workers and other parents with children with disabilities using community resources to provide parent training and support interventions.</b></p>	<ul style="list-style-type: none"> <li>- <i>Community workers and volunteers can be trained at low-cost to implement parental training interventions, e.g. via home visits.</i></li> <li>- <i>Where other parents caring for children with disabilities can be enlisted, they should be matched based on similar needs or experiences and contact should be facilitated by a competent third party. This presents an attractive option for LMICs with relatively low intensity on resources, where services provided can be kept to a minimum, e.g., by providing some support towards the costs of telephone calls, or information technology. Services in rural areas may also look into establishing peer support networks for parents of children with disabilities.</i></li> </ul>
<p><b>Focus on developing a good quality evidence base from LMICs to determine what works to improve the mental health outcomes of carers of children with disabilities.</b></p>	<ul style="list-style-type: none"> <li>- <i>Focus on conducting high-quality primary research on the effectiveness of interventions for carers of children with disabilities to improve their mental health outcomes in LMICs.</i></li> <li>- <i>This should be followed with good quality secondary research to synthesise primary research findings from LMICs.</i></li> </ul>

## Policy priorities

Due to the lack of resources and often limited number of available psychotherapists in LMICs, policymakers need to ease the accessibility (especially for rural populations) and affordability for carers of children with disabilities to make use of interventions. Costs can be lowered by training lower-skilled community workers as well as other parents of children with disabilities. Culturally- and contextually-appropriate interventions need to be developed and mandated through collaboration between governmental departments, community-based partners and service users. A central point of access for support services, such as training and therapeutic interventions and respite care for parents of children with disabilities is needed in given administrative areas to increase accessibility.

## Conclusion

There is a lack of high-quality review evidence investigating what works for parents of children with disabilities specifically focusing on LMIC contexts. Available evidence suggests that there is a need for more and better support service provision for parents of children with disabilities. These services need to be culturally-sensitive and developed together with parents and carers of children with disabilities, and should focus on psychosocial training and respite care interventions.

## Included sources

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## GAPS & RESEARCH NEEDS

High quality primary and secondary research evidence focused on LMICs is still lacking in terms of what works for parents and caregivers of children with disabilities.

More primary research is needed to identify the active components that are effective in improving parental and caregiver mental health outcomes in LMICs.