

Maternal and new-born care practices among disabled women, and their attendance in community groups in rural Makwanpur, Nepal

Introduction

An estimated 15% of the world's population has a disability, and between 2% to 4% of these have a severe disability [1, 2]. People with disabilities experience worse educational and labour market outcomes, and are more likely to be poor than persons without disabilities [3]. Disability is difficult to measure; disabled people are often difficult to find, and it is difficult to compare studies if they have not used uniform criteria for the identification and classification of disability [4]. People are disabled by their impairment, in combination with the social contexts in which they live. This interaction between their impairment and surrounding attitudinal and environmental barriers hinders their full and effective participation in society on an equal basis with others [5].

MIRA and University College London Institute of Global Health partnered with the Leonard Cheshire Centre for Disability and Inclusive Development Centre at University College London, to describe the disability and maternal health status of women who had been part of a cluster randomised controlled trial. This trial

tested the effectiveness of participatory women's groups on new-born mortality, and found a 30% reduction in mortality in clusters receiving women's groups [6].

Using qualitative and quantitative methods, we conducted research to describe the type and severity of disability of married women in the study area, describe their participation in community groups and analyse associations between maternal and new-born care behaviours and disability. We also spoke to health workers and field researchers about their experience with disabled women in rural Makwanpur.



Key Findings

- In Makwanpur, a hilly district of central Nepal, from a study of 13,687 married women of reproductive age, we found that 3,930 (29%) had a mild, moderate or severe disability with 806 (6%) having severe or very severe disabilities. Disability is therefore more prevalent than realised in rural Nepal in women of reproductive age.
- The number of children per woman was similar between disabled and non-disabled women (3.4 children per woman during the period of survey). This is a striking finding as there is a misconception in the literature that disabled women are sexually inactive or uninterested in having children.
- We found some differences between women with different types of disabilities in the access to maternal and new-born health services. Programmes that target women with specific disabilities may be particularly effective in improving access.
- Severely disabled women were more likely to be poorer and illiterate than non-disabled women, and those with sensory impairments, multiple disabilities or epilepsy are less likely to go to school than non-disabled women.
- Interestingly, disabled women were less likely than non-disabled women to see a traditional healer if they had an illness or complication during their pregnancy or delivery. This is surprising as some disabled women felt a divine spirit had caused their disability, and had sought treatment from healers for their disability.
- Low proportions of disabled and non-disabled women delivered in health facilities. Mildly disabled women were slightly more likely to deliver in a health institution, but further research is needed to clarify why this is the case.
- The disabled women in our study had both positive and negative interactions with health personnel, but significantly, these were rarely directly linked to their disability. Their concerns were similar to non-disabled women.
- Health workers reported problems communicating with disabled women, and expressed concern about limited access to facility care at delivery.
- Immediate breastfeeding and feeding of colostrum is recommended. Overall, 30% of women discarded colostrum in our study population. Very severely disabled women were more likely to discard colostrum and delay breastfeeding than non-disabled women. Of disabled women, those with multiple disabilities tended to delay breastfeeding.
- Clean delivery kits (CDK) promote clean delivery care and prevent infection. There were no differences between disabled and non-disabled women, apart from very severely disabled who were less likely to use a CDK.
- Most women delivered at home. International guidelines suggest that new-born babies should not be bathed

within 24 hours of delivery. We found no difference between disabled and non-disabled women regarding time of bathing their new-born, except for women with sensory disabilities who tended to bathe their baby earlier.

- Women with all types of disability and levels of severity attended women's groups in the same proportion as non-disabled women. Many disabled women not in maternal and new-born care groups were in savings groups, and face similar barriers as non-disabled women – family support, poverty, and distance to meeting place.
- Family support for mothers is particularly important to enable good care behaviours and timely care seeking. Where families were supportive, disabled women did not feel isolated, and were more able to participate in community activities.
- Compared with non-disabled women the risk of new-born mortality is increased among women with severe disabilities, but not among women with less severe types of disability. There were very small numbers of new-born deaths and therefore this finding needs to be interpreted with caution.



Overall, we found few differences between the maternal health of disabled and non-disabled women. Access to maternal and new-born health services for disabled women is more complex and nuanced than we originally thought. It is important that as maternal and new-born health improves in Nepal, disabled women are not left behind. It is also important to conduct research with unmarried disabled women to understand their reproductive health needs. Identification and monitoring of the health care access of all disabled women is necessary to track improvements.

Recommendations

- Additional attention should be paid to disability in national household surveys such as the Demographic and Health Surveys and National Census.
- Tools be developed to help civil society actively include disabled women in participatory groups and local decision-making, and to challenge stereotypes about disabled women
- Medical and nursing training curricula should be updated to include teaching on the needs of disabled women
- Our research used data from a previous study of married women of reproductive age. Further research should focus on the needs of unmarried, disabled women who may have different access to care, and different experiences.

References

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About the Cross-Cutting Disability Research Programme (CCDRP)

The CCDRP is a three year research programme on disability and development funded by the UK Department for International Development (DFID). Based at the Leonard Cheshire Disability and Inclusive Development Centre, Department of Epidemiology, University College London (UCL), the goal of this project has been to generate new understanding of the links between disability and global poverty in mainstream development and health areas where little attention has previously been directed towards persons with disability: maternal and child health, water and sanitation, and agriculture, as well as to better understand issues of access to mental health services in peri-urban communities. Research has been concentrated in five countries: Kenya, Zambia, Uganda, India and Nepal. The programme is also supporting a number of other stakeholders, including disabled people's organisations and local academic institutions to mainstream disability and development research.

The overarching aim of this research has been to contribute to an increase in the effective and sustained social and economic inclusion of disabled people in international development and global health initiatives through the generation of evidence-based research, as well as the capacity building of a range of partners to strengthen mutual understanding around disability inclusion.

For more information about this research, contact ccdrp@ucl.ac.uk

This research has been funded by UKAID from the UK Government. However the views expressed do not necessarily reflect the UK Government's official policies.

