**Quality of Life, Coping Skills and Mental Distress among Parents of Disabled Children in Selected Districts in Nepal- A Pilot Study of an Evidence Based Manual for Home Visitors in Rural Communities**

**Date: 2013**

**Background**

There are clear deficiencies in research in the conditions of families with children with disability in LMIC countries. The study examined the quality of life, coping skills, burden and mental health stress in parents having a child with Neuro-developmental disability (NDD) in four districts of rural Nepal.

**Methods**

Home visitors from Self Help Group for Cerebral Palsy (SGCP) have performed case finding in four districts in Nepal: Main caregivers of children, 2-10 years old with NDD. These have been interviewed in their own home by a Nepali psychologist and a mental health nurse. They have been using a structured interview in addition to standardized tools like World Health Organization Quality of Life Questionnaire which has been used in several studies in Nepal, the General Health Questionnaire 12 which would enable comparison with results from other rural settings in Nepal, level of stigma (Jacoby Scale) in addition to information on level of function, participation and physical illnesses in the child (using the 10 Disability questionnaire, GMFS). Further perceived burden and effects of the disabled child on the child itself and the family have been included.

**Results**

The general impression from the interviewers in field (a psychiatric nurse and psychologist) is that these mothers situation is often very difficult with a high level of stress and mental health problems. Stigma is also a considerable problem. Sadly there are no or very limited possibilities for mental health services and counseling help locally. There have therefore already been started a discussion in Nepal how this should affect future help targeting this group and how mental health and counseling could be integrated in the curriculum and training of personnel working with this vulnerable group. The general impression based on the field experience is that interventions towards the children would be much more effective if the intervention also would involve a special focus on helping the parents, and especially mothers, to cope better psychologically.

**Conclusions**

Interventions towards the children would be much more effective if the intervention also would involve a special focus on helping the parents, and especially mothers, to cope better psychologically.

**Keywords:** coping skills; disabled children; mental distress; parents; quality of life.