

**DISABILITY LOAD ON HOUSEHOLDS HOSTING CHILDREN
WITH DEAFBLINDNESS IN IGANGA, MAYUGE AND JINJA
DISTRICTS, UGANDA**

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DECLARATION


This is my original work and has not been presented for a degree in any other University.

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ABSTRACT

Unlike in the developed world, there is little documented information about children with deafblindness (CWDB) and, virtually no research has been done in Uganda regarding all aspects of deafblindness. Therefore, little is known about the disability load borne by the household and its effect on the quality of life and the educational development of the children. The purpose of the study was to determine the nature of the disability load in the household hosting CWDB and the resulting impact on the members. The specific objectives were to dimensionalise the disability load, find the effects on the quality of life, the impact on the schooling path, investigate gender differences and generate a conceptual framework for improving schooling outcomes. The building of this conceptual framework was guided by other relevant existing theories. The approach of the inquiry was qualitative, using the Grounded Theory design which is appropriate for examining complex phenomenon. The method of inquiry was systematic, intended to carry out data collection procedure and analysis using constant questioning and comparison. A sample of five households was purposively selected. From every household, between four to five participants were selected to give a total of 23 participants. They were selected because they had borne the disability load by raising and living with CWDB. Two instruments were used, namely, in-depth interviews as well as observational guide. A pilot study to test the instruments, check the use of resources and increase familiarity with the procedure for inquiry was undertaken. Permission to carry out data collection was sought from the national and district authorities. Each interview was preceded by clarification of the aim of the interview and promise of confidentiality. Individual members of the household were interviewed in depth. The information was recorded using a tape recorder, while observing accompanying behavior. Internal and communication validity were ensured by constant questioning, comparison and theoretical sampling. Reliability in Grounded Theory approach was brought about by the development of concepts which were rigorously worked out to form categories. Concepts formed in this way last long and are therefore reliable. Immediately after each interview, the recorded information was transcribed. Data analysis included open, axial and selective coding. The study established that household members while hosting CWDB, experienced disability load of many dimensions, with the emotional one being the greatest. The disability load had a severe impact on the quality of life in the households as well as the schooling path of the children. The gender difference on the impact on the schooling path was detected but was not significant. The final outcome of the inquiry was a conceptual framework grounded in the data. The framework has been named the **Disability Load Conceptual Framework**. It is recommended that policies be developed to guide practical intervention into the socio-economic lives of household members in order to improve the schooling path of the children.