

# 学位論文抄録

Development of a Model for the Improvement and Maintenance of the Quality of  
Life of Children with Intellectual Disability in Japan  
(知的障害児の Quality of Life の向上と持続を規定する要素とその構造に関する研究)

カライ            ルウインガ  
Luyinga           Kalay

熊本大学大学院医学教育部博士課程環境社会医学専攻環境保健医学

指導教員

上田 厚 前教授  
熊本大学大学院医学教育部博士課程医学専攻環境保健医学

紹介教授

竹屋 元裕  
熊本大学大学院医学教育部博士課程医学専攻細胞病理学

## Abstract of the thesis

**Background and Purpose:** Quality of life (QOL) enhancement is an endpoint in the care of people with disability (PWD). It has been suggested that QOL should be added to the international classification of functioning, disability and health (ICF). The ICF measures health and disability in an objective way. On the other hand, QOL takes into account one's view. Studies exploring relationships between QOL and ICF-related factors have been conducted on adults with various disabilities and children with physical disability. However, we are not aware of any similar study addressing children with intellectual disability (CID). In order to fill this gap, the present study aimed at: defining the framework of an environment conducive to the well-being of CID (1<sup>st</sup> phase); describing the extent of the correlation between the CID's QOL and factors generated through the 1<sup>st</sup> phase (2<sup>nd</sup> phase) and evaluating their contribution to CID's QOL (2<sup>nd</sup> phase).

**Methods:** In the 1<sup>st</sup> phase, through a two-round Delphi survey, health professionals (HP), CID's parents and teachers responded to a thirty-one item questionnaire developed from literature review. Qualitative and quantitative data analysis procedures were used. In the 2<sup>nd</sup> phase, CID's parents responded to questionnaires measuring CID's QOL and other variables determined from the 1<sup>st</sup> phase (environment, participation and parents' QOL) as well as disability severity. Pearson's and Spearman's rho correlation analyses were used to explore correlations between CID's QOL and the other variables. Stepwise multiple regressions were performed to determine the predictors of CID's QOL.

**Results:** Seventy-one participants responded to the 1<sup>st</sup> phase. Finally, 21 items were retained. Moreover, additional domains such as participation, family members' mental health/QOL and family composition were suggested. Sixty-four parents participated to the 2<sup>nd</sup> phase. CID's QOL was significantly correlated to all the other variables but household size. Environment and participation were the only significant predictors. QOL scores were often lower than previous Japanese studies.

**Conclusions:** The present findings show that CID's QOL is of concern. QOL was related to an inherent factor (disability severity) as well as external ones (environment, participation and parents' QOL). Its predictors were environment and participation. This implies that there is a need for interventions to improve CID's QOL. These should target the disability (functional status), improve the environment and foster participation. Collaboration between HP, family and the community (teachers, public, and government) is needed to support these interventions.