

**Assessment of Family Needs and Quality of Life in Children (0-17 years)  
with Developmental and/or Cognitive Disabilities**

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**Team Project Abstract  
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Background: Upbringing and taking care of a child with a chronic health condition or a developmental disability represents a significant and sustained challenge for many families throughout their life cycle. One of the major challenges for families is to successfully identify and access services to meet their health or educational needs. These families often find it difficult to articulate their needs through existing service providers who aren't adequately trained to provide quality services and manage the complex family setting in front of them. Previous research revealed that upbringing of a child with special needs have challenges in terms of health services that promote quality of life. Also, caregivers of children with developmental disabilities suffered the burden of coordinating and/or providing health care services and experience limitations regarding finance, health and occupational development.

Objective(s): The specific aim of this project is to identify the social, health and quality of life needs of families of children (0-17 years) with disabilities.

Determine if there are statistically significant relationship between the needs and the quality of life.

Methods: The study is a non-experimental cross sectional design, self-administered questionnaire, which was distributed in the community partner organization. The questionnaire consisted of socio-demographic, health care needs (Bailey & Simeonsson, 1988) and quality of life questions. The sample collected by availability was composed by parents or legal guardians of a child with disabilities. To conduct this study IRB approval was granted by University of Puerto Rico Medical Science Campus and data collection began in December 2017. Descriptive and chi-squares, were used to identify needs, describe QoL and compare needs by socio demographic variables (income and level of education).

Community Partner(s): A community partnership was formed with the Society of Education and Rehabilitation (SER) of Puerto Rico (PR)

Results: 32 respondents completed the questionnaire. 87.5% the respondents need more information about what their child may need in the future and on how to carry out recreational activities. Additionally, support for the parents are over 50 % on accessing opportunities to meet and talk with parents with a child with a similar condition of their child. Additional results indicate that there is a significant relationship between the condition of the child and the need report by parents.

Conclusions: The results identify more needs for information, supports and financial assistance that affects the quality of life of children with disabilities and parents. There is a need for the development of recreational activities for the families of children with developmental disabilities.