

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

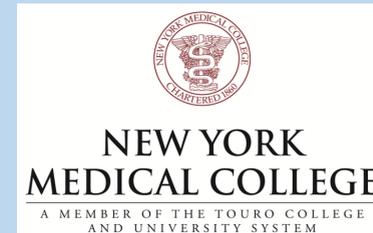


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Leadership Education in Neurodevelopmental and related Disabilities (LEND) Program

Westchester Institute for Human Development, University Center for Excellence in Developmental Disabilities and New York Medical College



Background

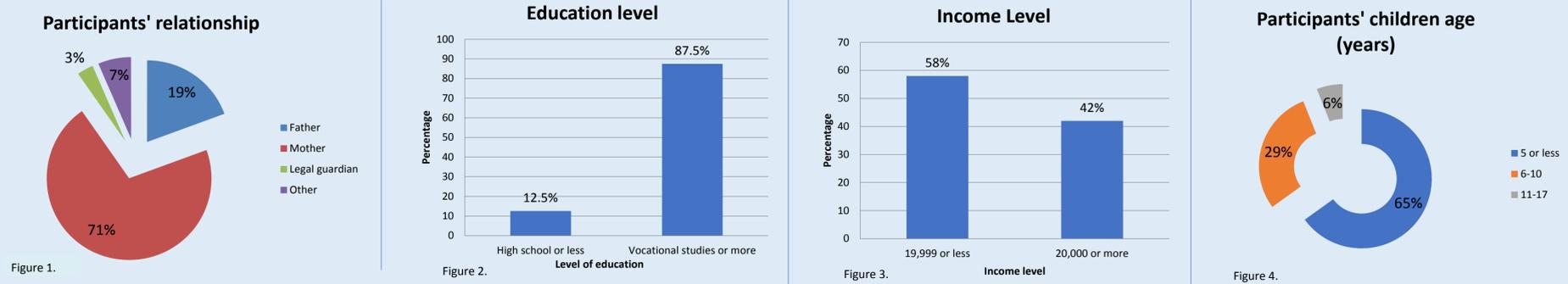
- Upbringing a child with a chronic health condition or a developmental disability represents a significant and sustained challenge for many families throughout their life cycle.
- One of the major challenges for families is to successfully identify and access services to meet their health or educational needs.
- It is often 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.
- In a study done by McManus et al. (2011), the result of the research where that upbringing of a child with needs have challenges in terms of health services that promote quality of life.
- Also, the study found that caregivers of children with developmental disabilities experience the overwhelmed task of coordinating and/or providing health care services and experience limitations in regard to finance, health and occupational development.

Objectives

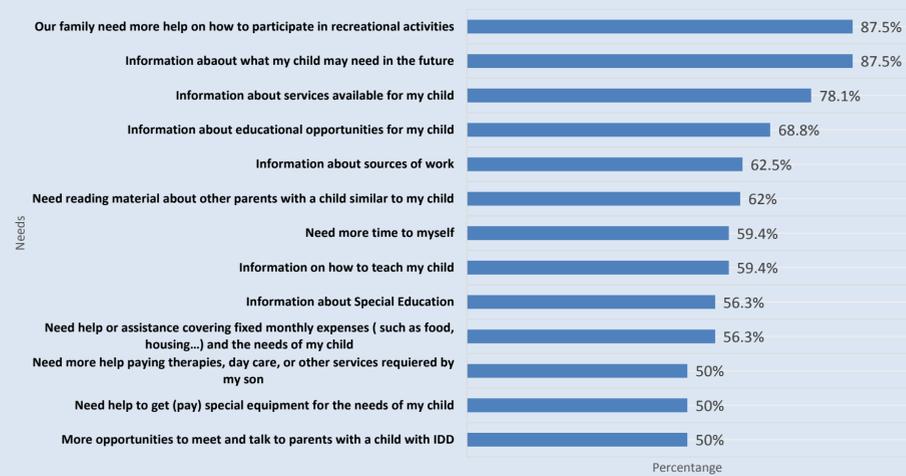
- Identify the social and health needs of families of children (0-17 years) with disabilities.
- Identify the quality of life in families of children with disabilities.
- Determine if there is a statistically significant relationship between social and health needs in families of children and the sociodemographic characteristics of the participant providing information.
- Determine if there is a statistically significant relationship between the quality of life of families with children with disabilities and the sociodemographic characteristics of the informant.

Results

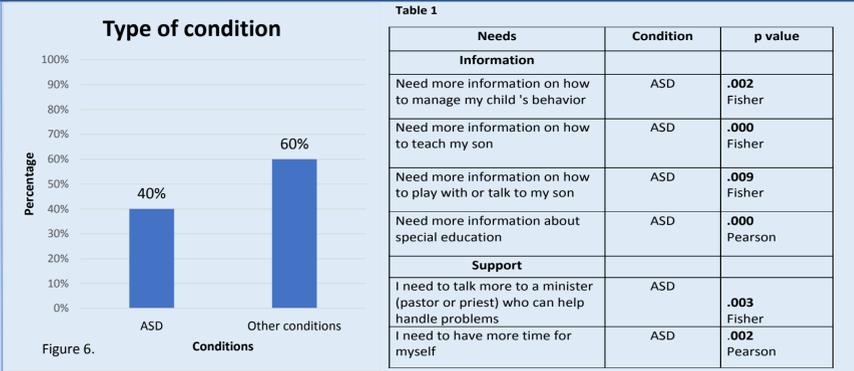
Characteristics of parents or caregivers



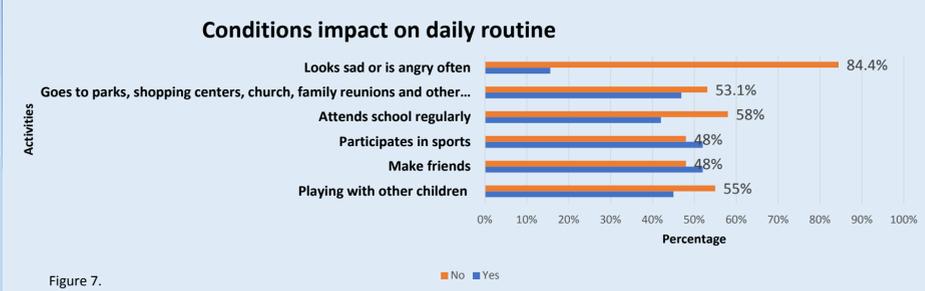
Most common needs



Type of condition



Quality of life of the child



Community Partner

- Society of Education and Rehabilitation (SER) of Puerto Rico (PR) a community base organization that provides medical, therapeutic, and educational services for people with disabilities.



Methods

- **Study design:** study is a non-experimental cross sectional design.
- **Participants:** 32 Parents of children with intellectual or developmental disabilities (0 to 17 years old) who were receiving services from our community partner participated in the study.
- **Procedure:** Contact with these families was established alongside the organization. MSC-IRB approved the study and recruitment. Project assistants were present and discussed the details of the study. Rights of all participants were safeguarded. Every family signed the informed consent.
- **Data collection:** Anonymous, self-administered questionnaire with socio-demographic, health care needs (Bailey & Simeonsson, 1988) and quality of life questions.
- **Data analysis:** Descriptive and chi-squares (p value <.05) were used to identify needs, describe QoL and compare needs by socio demographic variables (income and level of education).

Discussion

- Parents report that the most common needs are informational, support and financial assistance.
- Parents also report that the family need more help on how to participate in recreational activities, there is a relationship between the child's condition and the need reported by parents.
- The findings tell us that the condition of the child has an impact on the daily routine of both the child and the family.
- The areas in the quality of life that are most affected by having a disability are the social aspects of the child's life (peer interaction, recreational activities).
- In conclusion, results identify more need 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.