

Quality of Life Study

NEWSLETTER

October 2020

TELETHON
KIDS
INSTITUTE
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QI-Disability

Welcome everyone! We are delighted to share with you our family newsletter exploring the quality of life of children with developmental disabilities. A BIG thank you goes out to all families who have participated in our quality of life studies. Throughout this report we refer to parents and carers as caregivers.

Study report: Functioning, participation and quality of life

- Why did we do this study?
- The goal of our research was to identify how functional skills are associated with quality of life and whether community participation was able to improve quality of life.

What did we do?



You were asked to provide information for your 5 to 18 year old child.



Information was provided about children with:

- Autism spectrum disorder,
- Cerebral palsy,
- Down syndrome or
- Rett syndrome.



Reports about:

- **functional abilities** (dependence for managing personal needs, mobility, communication, eye contact when speaking),
- **frequency of community participation and our recently developed**
- **child quality of life measure, QI-Disability** were used in this study.

Who participated?

Families



435 caregivers completed our online questionnaire



75% of the families who we contacted



12 years the average age of the children



224 boys and **211** girls



Children

- **220** fully dependent for personal needs
- **1.9/7** – average frequency of community participation score
- **69/100** – average quality of life score

What did we find?

- Children who were less **dependent for managing their personal needs** and those who made **eye contact when speaking with more ease** had **higher quality of life scores**.
- **Walking and talking abilities** were less strongly associated with **quality of life**.
- More frequent **participation in the community** was independently associated with **better child quality of life**.

What are our next steps?



We are conducting further analyses to **find other strategies that can improve child quality of life**.



We are planning how to **influence service providers with this new information, to enable easier access to support for participation for families**.

How can you contact us?

If you have any questions or feedback for our team, or would like a full copy of the paper, please contact **Dr Jenny Downs** at:

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