

# Quality of Life Study

NEWSLETTER

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TELETHON  
**KIDS**  
INSTITUTE  
Discover. Prevent. Cure.

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,** 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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