

International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSID) Symposium on Quality of Life in Children with Intellectual Disability.

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This symposium contained three papers from the Telethon Kids Institute in Australia focusing on the quality of life for children with intellectual disabilities. All three papers involved interviewing parents of the children (aged 6-18 years) by phone then transcribing and analysing the responses for themes related to their research questions.

The first paper by Murphy and colleagues (2016) described qualitative research that aimed to explore aspects of life that contribute to happiness and wellbeing in children with Down syndrome ($n = 17$). The research found that there were 11 domains that were important to quality of life for children with Down syndrome.

These domains were broadly grouped into three areas,

- **Daily activities:** Communication and expression, movement and physical activity, routines and predictability, independence and autonomy.
- **Health and well-being:** Physical health (e.g. fatigue, pain, respiratory issues, infections, comorbidities), behaviour and emotional wellbeing, personal value.
- **Community and environment:** Social connectedness and relationships, variety of activities, nature and outdoors, access to services.

The second paper by Epstein and colleagues (2016) investigated quality of life as a composite of life experiences for children and Autism Spectrum Disorder (ASD). The results of the thematic analyses of parent responses ($n=28$ families) were then compared to the domains from the Pediatric Quality of Life Inventory (PedsQL) in order to develop a framework for measuring quality of life in children with ASD. They found 10 domains that were applicable to children with ASD that are described below.

Health and Well-being

1. Physical health e.g., body pain, sleep, energy levels, eating, gastrointestinal health.
2. Behaviour and emotional wellbeing e.g. body language, expression, sensory stimulation, aversion, repetitive behaviour.
3. Relaxation and reassurance e.g. calming and relaxing actions, cuddling, physical contact, "down time".

Daily Activity

4. Communication and expression e.g., choice-making, sharing thoughts and feelings, non-verbal forms of expression.
5. Flexibility and routines e.g., familiar and predictable aspects of life, stopping a preferred activity with ease, topics of intense interest.
6. Leisure and recreation e.g., physical activity; "screen-time" via TV, computer, video-game; constructing with Lego; drawing; designing.
7. The natural environment e.g., time spent in nature and outdoors; contact with pets; interest in animals (e.g., park, zoo, aquarium).
8. Independence and autonomy e.g., mastery and achievement of different tasks; developing skills; learning something new.

Community Immersion and Services

9. Social desire e.g., social connectedness; shared enjoyment; social disinterest.

10. Services and associated outcomes e.g., access to supports and resources; advocacy; financial assistance.

The third paper of the symposium by Downs and colleagues (2016) used the results from the thematic analyses of the parent interviews (n = 86 families) to map quality of life domains across children with Down syndrome, Autism Spectrum Disorder with intellectual disability, cerebral palsy with intellectual disability, and Rett syndrome. They found that,

- Most quality of life domains were common across the four groups;
- Some domains were related to the child's level of functioning i.e., domains of personal value for Down syndrome; domain for independence and autonomy was not applicable for children with Rett syndrome.
- Some domains were specific to children with ASD, i.e., relaxation and reassurance; flexibility and routines; and social desire.

When Downs and colleagues (2016) compared these domains to other quality of life measures, they found that there were two new domains that were "unique" to children with intellectual disabilities. These were the domains of,

- Stability of daily routines (identified for children with Rett syndrome); and,
- The natural environment (common across all 4 groups).

Further analyses of the data and formulation of the domains into a quality of life framework revealed that,

- There needed to be systematic management of physical health;
- That a child's behaviour was a critical marker for quality of life;
- That social participation was multifaceted and that there needed to be a balance between the need for connectedness and a preference for solitary play or downtime for some children; and,

“A child's behaviour was a critical marker for quality of life...”

- Exposure to nature and animals promotes mental health and wellbeing.

The presenters concluded that the research identified specific domains that could be used as a framework to measure the quality of life of children with intellectual disabilities. This could also have the potential to more clearly identify the support needs of children with intellectual disabilities, be used as an outcome measure, and develop a tool that obtains children's views about their own quality of life.

References

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