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PROFESSIONALS & RESEARCHERS IN
EARLY CHILDHOOD INTERVENTION

Research Snapshot No. 11

November, 2024

Does family quality of life get better as the years go by? A comparative mixed-methods study between early years and school-aged children with disability in Australia

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What you need to know

Many families are unprepared for the lifelong commitment of caring for a child with a disability. This journey involves continuous adaptation to new challenges. While families strive to remain positive, having a child with a disability impacts daily routines, family occupations, and overall Family Quality of Life (FQOL) more profoundly than raising a child without a disability.

The gearbox model of FQOL illustrates how factors, such as family beliefs and characteristics, and indirect predictors, like services and policies, influence FQOL over time. As these factors interact, they shape the family's evolving strengths, needs, and priorities. Slide 1 – Model FQOL.

Parents often face issues like unemployment, limited self-care, health problems, and financial stress. They must also adjust their time use, prioritising caregiving over previous occupations.Despite these challenges, many parents remain hopeful and report reasonable FQOL.

What is this research about?

This Australian study compared perspectives of family quality of life (FQOL) of parents of preschool children attending early childhood intervention services (ECIS) with parents of school-aged children with disability. It examined the relationships between disability-related services, parent occupations, and FQOL.

The main aim of this research was to investigate whether FQOL is better in the families of children in the older age group. The final overarching aim was to use the results and findings to guide policy and practice to advocate for better FQOL.

The research questions guiding this article are: (i) Are there any differences in perceived FQOL between preschool years and school-aged groups of children with disability? (ii) Are there any differences between parent occupations and services and supports received? and (iii) Does perceived FQOL get better as the child with disability gets older?

What did the researchers do?

- The researchers used a mixed methods design and conducted a two-way analysis of variance (ANOVA) for the quantitative data and a qualitative comparative analysis to compared the two groups of participants from Study 1 and Study 2.
- Study 1 were the preschool group that included children in the age group of 0–7 years receiving early childhood intervention services (ECIS); (n=72 Quant; n=12 semi-structured in-depth interviews)
- Study 2 were the school-aged group included children from the ages 8 - 18 years who were attending school. (n=50 Quant; n=12 semi-structured in-depth interviews). Both studies investigated FQOL and relationships between FQOL, parent occupations, and disability-related supports/services.
- The inclusion criteria required participants to be parents/caregivers of a ECIS child/ school-aged child with disability and caregiving on a regular basis, to have a working knowledge of English, and to provide written consent.
- Parents/caregivers who did not fit within the study definition of ‘family’ were excluded (for example, a birth father with no custody of or relationship with the child or family). The study definition of ‘family’ was that it consisted of people who considered themselves a family (whether or not related by blood or marriage), and who supported and cared for each other on a regular basis
- Tools used: The Beach Center FQOLS is a 25-item survey (BCD, 2002; Hoffman et al., 2006).
- A demographic questionnaire - included sections on age, sex, relationship to the child, diagnosis of child, languages spoken at home, educational levels of main carer and partner, duration of ECIS, type of school (special or mainstream), and annual income.
- Semi structured Interviews

What did the researchers find?

Quantitative Results

- **Demographics** - The study included 122 parents across two groups: In the ECIS group(n=72), 15.3% of children had developmental delay, 13.9% had cerebral palsy, 6.9% had Down syndrome, 26.4% had autism/ASD, 11.1% had congenital issues, 11.1% had no clear diagnosis, 6.9% had speech and language delay, and 8.3% had other diagnoses. In the school-aged group(n=50), 12% of children had cerebral palsy, 18% had Down syndrome, 46% had autism/ASD, 16% had congenital conditions, 4% had no clear diagnosis, and 4% had other diagnoses.
- **Family Quality of Life (FQOL)** - ANOVA analysis showed a significant difference in FQOL scores between groups. Parents of school-aged children (11-18 years) reported lower FQOL scores compared to parents of younger children (0-2 years).
- **Parent Occupations** - There were significant differences between parents of younger children (0-2 years) and parents of school-aged children (11-18

years). Parents of school-aged children struggled to re-engage in necessary and contracted occupations, such as work or education, and experienced significant financial difficulties. Both groups found it difficult to make time for free-time activities, like meeting friends for coffee or exercising.

Qualitative results concurred with quantitative results

- **Confirming Hardships**: Significant struggles and continuous adjustments were reported..
- **Perceived FQOL**: ECIS parents described FQOL as good/reasonable, while school-aged parents used terms like hard/dreadful.
- **Positive Outlook**: Both groups maintained a positive outlook, improving their FQOL.
- **Worries & Concerns**: School-aged parents worried about future residential care and sibling impact; ECIS parents focused on school transitions.
- **Support Impact**: Services and supports had a positive impact on FQOL in both groups. School-aged parents missed inclusive services and funding from early intervention years.
- **Occupational Impact**: Both groups struggled to return to work (Contracted occupations) as before. Caregiving remained a major occupation, affecting physical and financial well-being (Necessary occupations).
- **Chronic Health**: Many parents developed chronic health conditions during early caregiving years, which remained unaddressed.

How can you use this research?

This study is relevant for ECI practitioners, service providers, organisation managers as well as policy writers. Most importantly this study can be translated in easy language to help parents understand the importance of FQOL and the various elements of this framework so that their awareness is heightened and they can tune in better to their own well-being and their family well-being.

- This research can be used to advocate for using a family centred practice approach, measuring FQOL outcomes, and honouring strengths based and positive psychology systems when working with children and families.
- Consistent with the unified theory of FQOL (Zuna et al., 2010), findings in both studies highlighted that supports and services were important factors that impacted the FQOL of both groups.
- Individual demographics were important determinants of FQOL
- Accepting the caregiving role has a positive influence on their FQOL
- Program quality predicts implementation of best practice, which in turn impacts individual factors and in turn FQOL
- Certain times are harder for families such as the time of diagnosis, transitions and unforeseen events and these can have a detrimental impact on FQOL

Where to from here

Translating research to practice

Currently the WeCare Program, which is being implemented and and evaluation of the Now and Next program use a positive psychology framework. Both of these programs are nested in parent well-being and capacity building.

Takeaway Message

FQOL doesn't get better as the years go by, so gently making parents aware of outcomes such as the relationships between caregiving and FQOL is important to help them make informed choices for their child as well as their family as a whole.

Links to related topics

Link to Study 1 is here
Relationships between early childhood intervention services, family quality of life and parent occupations: A mixed-methods Australian study
Link to study 2 is here
Opportunities for participation, inclusion and recreation in school-aged children with disability influences parent occupations and family quality of life: A mixed-methods study

About the researchers

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Citation

Bhopti, A., Brown, T., & Lentin, P. (2022). Does family quality of life get better as the years go by? A comparative mixed-methods study between early years and school-aged children with disability in Australia. *Journal of Policy and Practice in Intellectual Disabilities*, 19(4), 379–395. https://doi.org/10.1111/jppi.12433

This Research Snapshot was prepared by Anoo Bhopti, PRECI committee member

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In the spirit of reconciliation PRECI acknowledges the Traditional Custodians of country throughout Australia and their connections to land, sea and community. We pay our respect to their Elders past and present and extend that respect to all Aboriginal and Torres Strait Islander peoples today.