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RESEARCH PAPER



## Fathers of children with a disability: health, work, and family life issues

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### ABSTRACT

**Purpose:** Fathers in families raising children with disabilities are under-researched. Fathers' perspectives can be better accommodated in childhood disability services that operate on a family-centred paradigm if their perspectives are understood. This study aimed to investigate the perspectives of fathers on caring and family life, work, and health.

**Methods:** A mixed-methods design with an online questionnaire included open-ended questions and three instruments: Depression Anxiety Stress Scales (DASS); Health Promoting Activities Scale (HPAS-M); Fathers of Children with Developmental Challenges (FCDC) Scale.

**Results:** Fathers ( $n = 33$ ) reported high depressive (58%), anxiety (37%), and stress symptoms (61%). Fathers reported low participation in health-promoting activity with less than weekly: planning health activities (58%); solo physical activity (26%); social activity (3%); time relaxing (16%). Sixty-four percent worked full-time, although work was reported to be challenged by family responsibilities. Fathers described directly caring for their children although service interactions were low and delegated to mothers.

**Conclusions:** Fathers in this study reported stress, mental health issues, and low participation in healthy activity. Fathers experienced challenges related to career progression and job choices due to family responsibilities. Providing individualised and responsive support to fathers of a child with a disability would better support the family unit.

### ARTICLE HISTORY

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### KEYWORDS

Fathers; disabled children; mental health; health promotion; professional-family relations; caregivers

### ► IMPLICATIONS FOR REHABILITATION

- Fathers of children with a disability in this study experienced high mental health symptoms.
- Fathers were involved with their child's care at home but had low service interactions suggesting that service providers need to discover new ways to better engage fathers.
- Fathers experienced challenges to participation in paid work secondary to care responsibilities for their child with a disability and resulting needs of their family.
- Services that better support fathers are important to promote better health and wellbeing and support families.

## Introduction

Families are the primary source of support, enablement, and participation for a child with a disability and parents shoulder many responsibilities. Family systems theory has long postulated that all members of a family are influenced and influential on each other [1], such that fathers experience responsive changes in their daily activities, roles, and routines when parenting a child with a disability [2]. Further, several models predict outcomes such as stress among parents of children with a disability [3,4]. Other models such as the Resiliency Model of Family Stress, Adjustment, and Adaptation and the Global Focus Model, predict family vulnerability when raising a child/ren with disability [5].

Parental health and wellbeing have substantial benefits for children including better daily support and health [6]. Across early intervention and other community services for young people with a disability, family-centred services are considered best practice [7,8]. Family-centred practice (FCP) focuses on a professional and

family partnership that prioritises family life, needs, and choices as the driver in planning intervention and promoting family help-seeking, resource, and capacity building to meet needs around childhood disability [7]. Family-centred practice aims to build on family strengths and assist families to develop their own formal and informal resources. Therefore, understanding the needs of family members is key to providing appropriate support to families. Central tenets of FCP include: (i) a trustworthy, respectful, and open relationship and partnership with families; (ii) parental involvement and choice in goal setting; and (iii) shared informed decision making regarding the child's plan and intervention [9]. Therefore, communication with parents is fundamental to partnerships from an FCP perspective.

Research indicates that mothers and fathers have significantly different roles in families affected by childhood disability. Mothers are most often the primary carer dedicating more time to child care [10,11]; are more stressed [12,13]; experience greater mental health disparity [14–16]; are more likely to participate in research

[17] and in available programs aimed at the management of disability-related issues [18,19]. Whilst there is a large body of literature delineating the experiences, health, and wellbeing of mothers, there is a relative lack of research that specifically focuses on fathers [20]. A recent scoping review of fathers in the context of childhood neurodisability located 54 studies with parents as participants, although only nine studies (10%) included only fathers with low sample sizes [20]. The review concluded that fathers were under-represented in research and that more studies with fathers were needed to better understand their involvement and contribution. Fathering perspectives and involvement in the long-term care of children with serious medical conditions are also poorly represented in the literature. A narrative review of 35 papers about the role of fathers in the medical care of children with serious health conditions identified the positive impact of fathering involvement on the child, partner, and family [21]. Only eleven papers (31%) included only fathers as participants. The review had a similar conclusion as Bogossian et al. [20], and that is that more studies of all designs, focused solely on fathers, are warranted.

Although fathers are under-represented in the peer-reviewed research literature that focuses on parenting children with disabilities, there is some emerging evidence about fathers' health, role, and the impact of fathering a child with additional care needs. Recent evidence suggests that fathers experience substantial levels of psychological distress [14]. A cross-sectional survey comparing stress, coping, and life satisfaction between fathers ( $n = 206$ ) of children with and without disabilities determined that fathers of a child with a disability experienced higher parenting and health stress, and more daily problems than the comparison group [22]. Recent research highlights the stress experienced by fathers related to challenging behaviour and higher care needs [23] and the impact of the "spill over effect" among parents of children with a disability where high stress experienced by one partner (mother or father), increases the other partner's stress, and in turn, reduces family cohesion [24].

Research also suggests that fathers' involvement in family life can enhance marital satisfaction, overall family functioning, including the child with a disability, and decrease caregiver strain amongst mothers [25]. In a study that conducted a narrative analysis on the biographical experiences of nineteen fathers of children with disabilities who published their experiences and memoirs in a book, fathering occupations (chosen activities) were found to be valued, important to fathers and centred around co-created activities with their child, advocacy and shared family responsibilities [2].

Collectively, current research suggests that mothers' and fathers' needs are different, including those related to the care of their child with a disability, service access, and use. Parents are critical partners in FCP if there is to be an optimum benefit to children and their families [7]. This study aimed to investigate fathers' health, work, family life, and experiences with the services provided to their child with a disability.

### Research questions

1. What is the subjective mental health status of fathers?
2. What activities/occupations are associated with fathering a child with a disability?
3. What do fathers report about service systems interactions and their child's care.

4. How does fathering a child with a disability affect fathers' mental health, participation in paid work, self-care and leisure activity pursuits?

### Methods

A specifically designed and piloted online questionnaire was used for this cross-sectional embedded mixed-methods study. The single-user online questionnaire was hosted by Qualtrics Research Platform (Version December 2017; Qualtrics, 2017). Ethical approval was received from the Monash University Human Research Ethics Committee (Approval number 10957).

### Participants and recruitment

The online questionnaire was designed for fathers of a child/young person of any age who had a diagnosed disability. In this study, childhood disability refers to childhood-onset conditions that are usually lifelong and result in the need for specialised or additional care and the need for specialised disability support equipment and services. The only other inclusion criteria were that fathers could complete the questionnaire in English and father and child living in Australia. The recruitment flyer was distributed in paper and electronic format and in school newsletters. The notice stated, "Fathering a child or young person with a disability: What helps, hinders and supports you?"

The online questionnaire that could be completed in a short time frame, was one strategy to attempt to recruit a high number of fathers, given evidence about father's time limitations, disinterest in research, and health issues. Due to the reported difficulty in recruiting fathers, a two-stage process was employed. The first stage involved advertising and distributing the online questionnaire to capture as much interest as possible. The flyer was posted on social media platforms, web-based media outlets including childhood disability association websites and newsletters in three states. Paper copies were distributed to local community centres, that is, libraries, maternal child health centres, and allied health practices that served children with a disability (i.e., Cerebral Palsy Education Centre) in Melbourne, Victoria. Recruitment notices were distributed through mothers and encouraged readers to "recruit a friend," "recruit your partner." Stage 1 recruited fathers for a 4-month time period and resulted in 20 participants attempting the survey. Stage 2 involved recruitment through schools (specialised and mainstream) and recruitment of group leaders where support groups for fathers or both parents were held. For example, one father was a leader of a fathers' support group and sent the flyer to the individual emails of about 30 past attendees. Stage 2 also included a duplication of stage 1 strategies. Stage 2 recruited fathers for an 8-month-period and resulted in an additional 25 participants attempting the survey.

### Instrumentation

The initial questionnaire was piloted with two fathers: one father of a teenager with cerebral palsy; and the other father of a pre-school child with multiple disabilities. Neither father participated in the study. Items, including one scale that was considered too complex to include and other long response questions, were removed to reduce the time required to complete the survey. The final online questionnaire comprised three psychometrically sound instruments, specifically designed questions and open-ended questions for fathers to share their opinions and experiences.

Demographic data were collected, including the father's age, education, work status, marital status, family income, sleep quality, and questions about their children. Questions about the status of and barriers to participation in work, health, and leisure were asked, with open-ended windows allowing fathers to record their responses. Specifically, designed questions about the child's service system and the father's knowledge and interaction with it were also included. Open-ended questions included:

1. Is your current work scenario ideal? Why/why not?
2. How have your family needs impacted your work or career?
3. What are some examples of activities that you expected to be involved in as a father?
4. What are some of the activities that you currently engage in with your child that you did not expect to be involved in? Please list or explain here.

### **Depression Anxiety Stress Scales (DASS-21)**

The DASS-21 [26] is a 21-item self-report questionnaire that uses a 4-point Likert scale (0 = did not apply; 1 = applied to me to some degree or some of the time; 2 = applied to me to a considerable degree or a good part of the time; 3 = applied very much or most of the time) to measure symptoms of depression, anxiety and stress. The DASS has undergone extensive psychometric evaluation on a non-clinical Australian sample ( $n = 2914$ ), suggesting adequate internal consistency and reliability for each of the three scales: depression, anxiety, stress (Cronbach's  $\alpha = 0.91, 0.84$ , and  $0.90$  respectively) [26]. Further, recent findings indicate measurement and structural invariance across both male and female samples [27]. Clinical cut-off points provide an indication of normal, mild, moderate, and severe symptomology for each of the scales, though the DASS does not purport to diagnose pathological depression, anxiety, or stress.

### **Health Promoting Activities Scale – Male Version (HPAS-M)**

The HPAS [28] measures a person's estimation of the frequency with which they participate in self-selected activities that promote or maintain health and well-being. The HPAS was initially developed for mothers of children with disabilities [28]. The HPAS-M was piloted with 6 men to test suitability for males and to identify preferred male activities in the key to activities. Piloting suggested that language and activities are applicable to a male population and therefore the HPAS-M was trialled in this study. The HPAS demonstrates good internal consistency (Cronbach's  $\alpha = 0.73\text{--}0.78$ ), construct validity, and stability as an outcome measure across mothers of children with a disability [29,30] and without a disability [31].

### **Fathering Children with Developmental Challenges (FCDC) Scale**

The FCDC scale [32] measures the barriers and enablers to fathers' involvement in raising their child with developmental challenges, from the fathers' perspective. The 20-item scale provides statements related to the fathering experience, and asks respondents to rate their level of agreement along a 5-point ordinal scale ranging from Strongly Agree to Strongly Disagree. Initial psychometric evaluation indicates adequate internal consistency reliability (Cronbach's  $\alpha = 0.89$ ), content validity and construct validity. The 20 item scale purports to measure the psychological, cultural, and institutional factors proposed to contribute to stress and paternal involvement among fathers. Factor analysis on the measure yielded two sub-scales: (1) impact on parenting, and (2)

involvement with child intervention. Both subscales are valid and reliable to use as single sub-scales [32]. Higher scores indicated greater support for involvement in parenting.

### **Data management and analysis**

Data were analysed using SPSS version 24. Descriptive statistics were used to determine the characteristics of participants and to present all quantitative questions. Scales were scored according to published manuals with sub-scales calculated. Research question 1 was addressed by transforming the three sub-scale scores into representative ranges according to manual directions based on the Australian population: normal; mild; moderate; severe/extremely severe.

Qualitative data were downloaded from Qualtrics and transferred to word. Open-ended questions were analysed pragmatically and thematically implementing inductive coding [33]. Firstly, all participant data were read and re-read by two authors. Coding began with the identification of key verbatim comments (rich text) from all participants. Like concepts were highlighted with like highlighted colours. Like concepts, were coded and named. Basic themes were derived by grouping like codes, and allocating groups as codes as sub-themes. For example, "Would like less hours" and "Less hours would work better but impractical..." were similar concepts and coded the same colour. Both comments were considered representative of a family balance "code" and finally subsumed under the subtheme *Making work fit with family life*, and the overall theme *Paid work*. Trustworthiness was enhanced through structuring the data analysis process and by keeping scrupulous records (credibility and dependability) and verbatim quotes (dependability) [34,35]. Fathers' quotes and terminology were used in sub-theme creation to ensure adherence to the meaning and experience of fathers as they described in their verbatim responses [35]. Researcher bias was minimised through the presentation of direct quotes. Triangulation of both qualitative and quantitative findings further enhanced trustworthiness [35] and provides a fuller picture of the father's perspectives. Only two to three quotes considered representative of the whole group were selected to represent the themes and subthemes from all participants ( $n = 33$ ).

Qualitative data were useful to identify occupations associated with fathering a child with a disability (research questions 2 and 3) and fathering and work-life (research questions 3 and 4). Research question 4 required correlation analysis to explore further associations statistically. Spearman Rho rank correlation coefficient was utilised to determine the associations between fathering (FCDC subscale 1), mental health (DASS), and participating in a healthy activity (HPAS-M).

### **Results**

Recruitment yielded few participants given the extensive dissemination of the call to participate. The study was open and advertised through networks in stages 1 and 2 for 10 months in 2018–2019. Forty-five fathers attempted the survey and 33 participants provided sufficient responses to be included in the data analysis. The 12 fathers who provided insufficient data (questionnaire aborted after the first few questions, only sporadic answers, mainly missing data) were removed from the data set to optimise correct scoring of the three measurement tools.

Participants (see Table 1) ranged in age from 28 to 63 years and lived in five Australian states: Victoria ( $n = 19$ ); New South Wales ( $n = 11$ ); and one in Queensland, Tasmania, and Western

**Table 1.** Characteristics of father's and questionnaire responses ( $n = 33$  unless stated otherwise).

Characteristics	Participant status, $n$ (%)
Age (years), mean (SD)	45.8 years (9 years)
28–35	3 (9)
36–45	13 (39)
46–55	12 (36)
56+ years old	5 (15)
Children in family	
One	9 (27)
Two	10 (31)
Three	9 (27)
Four or more	5 (15)
Work	
Income ( $n = 31$ )	
Less than \$50 000	7 (23)
Between \$50 000 and \$80 000	8 (26)
Between \$80 000 and \$150 000	11 (36)
Greater than \$150 000	5 (15)
Work status (select all that applies)	
Full time	21 (64)
Part time	7 (21)
Full time study	1 (3)
Voluntary work	3 (9)
Unpaid home duties	7 (21)
Barriers to achieving your ideal work scenario? (select all that apply)	
My child's care needs	22 (67)
My partner works and I need to look after my child/ren	8 (24)
My partner cannot work and I am sole earner	13 (39)
My ideal work scenario requires a qualification and I do not have the time/financial flexibility to study	4 (12)
I need my workplace to be understanding of my needs, and offer flexibility with regards to hours and leave	18 (55)
I need to work close to home	11 (18)
I need to work from home	2 (6)
My health	8 (24)
The amount of leave I need to take care of my family	15 (46)
Other	5 (15)
Health	
Father diagnosed medical or health condition	
Yes	14 (42)
No	19 (58)
Depression Anxiety Stress Scale scores	
Depression subscale scores ( $n = 31$ ) mean (SD)	11.61 (SD = 9.1)
Normal	13 (42)
Mild	5 (16)
Moderate	8 (26)
Severe/extremely severe	5 (16)
Anxiety subscale scores ( $n = 30$ ) mean (SD)	6.4 (SD = 6.1)
Normal	19 (63)
Mild	1 (3)
Moderate	7 (23)
Severe/extremely severe	3 (10)
Stress subscale scores ( $n = 31$ ) mean (SD)	17.81 (SD = 8.8)
Normal	12 (39)
Mild	6 (19)
Moderate	6 (19)
Severe/extremely severe	7 (23)
Does caring impact your ability to participate in enjoyable leisure activities? ( $n = 30$ )	
Yes	29 (97)
No	1 (3)
Fathering	
What are the main activities in your role as a father? (selects item in top 3 activities)	
Day-to-day care (e.g., helping with dressing, bath time, wiping nose, feeding)	24 (73)
Working/bringing in an income	20 (61)
Cooking or preparing meals	14 (42)
Taking my child/ren on outings (e.g., museum, movies, playground)	9 (27)
Transportation to and from school or leisure activities	8 (24)
Rough and tumble play	7 (21)
Quiet activities (e.g., reading, art and craft)	4 (12)
Helping with homework	2 (6)
The Fathers of Children with Developmental Challenges (FCDC)	
FCDC Subscale 1: impact on parenting ( $n = 30$ ) mean (SD)	39.4 (SD = 9.8)

Australia. Most fathers reported being married/partnered ( $n = 29$ ), with one father divorced and one single. All fathers graduated high school and 26 fathers had tertiary degrees including 15 with higher degrees. Fathers reported high participation in

home-based and family activities and low interactions with their child's services (see [Table 1](#)).

Participants were fathers of children or young people with a range of diagnoses that were classified into disability types (i.e.,



**Table 2.** Characteristics of children as described by fathers ( $n = 33$ ).

Child	
Child's age, mean (SD) (range: 2–32 years)	8.8 years (7)
Child's education attendance	
Day care/creche	7 (21)
Local kindergarten or early learning centre	3 (9)
Local (Mainstream) primary school	5 (15)
Local (Mainstream) secondary school	2 (6)
Specialised school setting	13 (39)
Home school	1 (3)
Does not attend an education program/other	2 (6)
Child's disability type and main diagnoses (select all that apply*)	
Intellectual disability	13 (39)
Physical disability	5 (15)
Cerebral palsy	13 (39)
Behavioural disability	5 (15)
Autism spectrum disorder	12 (36)
Genetic disability/disorder	6 (18)
Sensory disability (visual/hearing)	6 (18)
Other	3 (9)
Services for child	
Do you attend meetings regarding your child's therapies? (agree)	25 (76)
FCDC reasons why do not attend therapy	
I do not have enough time due to work demands to attend therapy meetings	5 (15)
There are no regular therapy meetings	3 (9)
The therapy meetings conflict with my work hours	5 (15)
I need to be at home to care for the children when therapy meets	1 (3)
I am not really interested in the therapy meetings	0
My spouse prefers that I do not attend the therapy meetings	0
My input will not make a difference to the meetings	2 (6)
I don't understand the details of the therapy	0
My spouse handles and attends the meetings	6 (18)
Do you attend special meetings for your child's education? (agree)	1 (3)
FCDC reasons why do not attend education	
I do not have enough time due to work demands to attend education meetings	5 (15)
There are no regular education meetings	1 (3)
The education meetings conflict with my work hours	4 (12)
I need to be at home to care for the children when educators meet	1 (3)
I am not really interested in the education meetings	1 (3)
My spouse prefers that I do not attend the education meetings	0
My input will not make a difference to the meetings	0
I don't understand the details of my child's education	0
My spouse handles and attends the meetings	3 (9)
Child currently receives services under NDIS	22 (67)
Child will receive NDIS services in the future	32 (97)
My child receives occupational therapy	23 (70)
I attend occupational therapy appointments	11 (33)
My child receives physiotherapy	17 (52)
I attend physiotherapy appointments	6 (18)
My child receives speech pathology	23 (70)
I attend speech pathology appointments	9 (27)
My child receives medical services	21 (64)
I attend medical appointments	17 (52)

\*Children may have multiple diagnoses.

physical, intellectual, etc.). Fathers described conditions such as anxiety disorder, oppositional defiance disorder, and depression and these diagnoses were classified as “behavioural disability.” Two diagnoses (autism and cerebral palsy) were the most common diagnoses and all incidences are included in Table 2. Most fathers ( $n = 29$ ) described two or more diagnoses for their child (see Table 2 for characteristics of children).

Fathers reported high rates of moderate to extremely high symptoms of depression (42%), anxiety (33%), and stress (42%), and 24% cited their health as impacting their paid work. Fathers reported low participation in health-promoting activities (see Table 3).

No scales were distributed normally, resulting in the use of non-parametric statistics. Total scores representing mental health (DASS – depression, anxiety, and stress sub-scores), father self-reported participation in health-promoting activity (HPAS-M), and fathers' self-rating of support to provide care of their child with a

disability and impact (FCDC subscale 1) were correlated using Spearman Rank co-efficient. The FCDC subscale 2 (fathers' involvement in therapy) was not scored due to the high number of missing items as fathers reported low therapy attendance (see Table 1). Significant and moderate negative correlations were detected between the FCDC subscale 1 and DASS Stress ( $\rho = -0.45$ ,  $p < 0.05$ ) and DASS depression ( $\rho = -0.51$ ,  $p < 0.01$ ). Significant and moderate negative correlations were detected between HPAS-M scores and DASS anxiety ( $\rho = -0.41$ ,  $p < 0.05$ ); DASS depression ( $\rho = -0.40$ ,  $p < 0.05$ ); and DASS stress.

### Open-ended questions

Two overall themes were derived from the data with associated subthemes (see Table 4). The first theme was *Paid Work and Fathers* and this included all of the issues, ways, impacts, and successes of participation in paid work as described by the sample of

Table 3. Health promoting activity and leisure participation using the Health Promoting Activities Scale (HPAS) adapted for men ( $n = 31$ ).

Item	Example activities	Never	1–3 times a year	Once a month	2–3 times a month	Once a week	2–3 times a week	Once/more every day
Personal care tasks, planning eating/exercise/tasks for health	Purposefully planning time for healthy eating and exercise routines. Meeting with a nutrition consultant; organizing a gym membership; reading health magazines and books; searching the internet for health-related information; taking vitamins; brushing my teeth.	3	3	5	2	5	6	7
A physically active recreational pursuit that you do alone	Walking; gym program; gardening; swimming, jogging; cycling; surfing; fishing; walking dog; woodwork; cooking and preparing for a large social gathering; potting, home improvement/renovating.	9	5	5	4	4	3	1
A physically active recreational pursuit that you with others	Tennis; playing squash; walking; gym sessions with personal trainer; playing a team sport; camping; bush walking/hiking; golf; picnic and activity at a park.	10	10	2	3	2	4	0
Spiritual or rejuvenating personal time	Praying; attending bible groups; being with others to pray/worship/reflect; meditating; contemplation and meaning making alone or with others; writing in a reflective journal; blogging; mindfulness exercises; reading inspirational or self-help books; watching inspirational or self-help TV programs or YouTube videos.	13	6	4	3	2	2	1
Social activities with people who are important and supportive towards you	Going to sporting matches; going to another family's home, or entertaining another family; cultural events with family and friends; local sporting club events; going to the movies; going out to dinner; going for a drive with friends; relaxing with friends; extended family gatherings.	6	8	8	8	1	0	0
Time out for yourself to spend as you wish	Doing nothing; resting; gaming; sleeping during the day; playing musical instrument/listening to musical instrument; browsing the internet; watching TV; DIY projects; art work/crafts; woodwork/constructing for leisure.	5	10	5	3	4	4	0
A quiet, physically inactive leisure pursuit that you do alone	Watching TV; reading; computer use; listening to music; building models/table top constructions; art work/crafts; reading the newspaper; doing crosswords or Sudoku puzzles.	9	5	3	4	4	4	2
A quiet, physically inactive leisure pursuit that you do with others	Watching TV; eating a meal; going to the pub; celebrating cultural occasions (Easter); outings; BBQ with friends; playing card/other games socially; social networking via computer; gaming online.	11	8	5	5	1	1	0

Table 4. Themes, sub-themes, and example quotes from four open ended questions.

Aspect of participant's life (themes)	Sub-themes	Example quotes
Paid work and fathers	Making work fit with family life	<p>"Close to home is great, prefer to work less hours to spend more time with my family"</p> <p>"A supportive employer means I can usually 'work from home' when required."</p> <p>"I have changed between part time and full time due to my family's needs, but income is delicately balanced with what is needed to run a family"</p> <p>"I try to minimize my travel for business which has some impact on my output and networking ... Our son with CP has therapy ... [and] we have another 4 year son who has not started school so I need to work from home on those mornings to be with him while my partner takes the other son with CP for therapy. This is not ideal to work from home and take care of my son (although he is a very well behaved child) at the same time."</p>
	Not the right work life balance	<p>"Ideally I would work less but need to support family"</p> <p>"No, would love <i>love</i> to spend more time with wife and kids and assisting in caring for daughter with disability"</p> <p>"I don't have a choice but to work full time."</p> <p>"Have to work more to meet increased medical costs."</p>
	Stable and predictable work prioritised over career advancement	<p>"I am now focused on career stability and more measured progression opportunities. Due to a range of factors relating to my daughter's special needs, I took the best part of a year away from work - working in a varied role - so I could dedicate more time to family and supporting my wife. Before that I was taking large chunks of time away from work, owing to sudden hospitalisations. This certainly contributed to a loss of career momentum. I have had to readjust my goals and ambitions, particularly relating to interstate or even overseas opportunities. My daughter essentially cannot fly, and has a precise medical/ support network locally."</p> <p>"Meticulous planning; delayed professional education; limitations on career path"</p> <p>"Significantly limits my ability to take on career development opportunities. I have had to look into changing roles within my firm to help with the increased care needs of my child and to support my wife whom is struggling emotionally with the situation. My bosses perceive me differently as my priority is no longer them but my family."</p>
	Work choices affected by care commitments	<p>"Type of work and career path have not been ideal. Hours per week and flexibility have been pretty good, and work location good"</p> <p>"Have to be realistic have a child with disability and two other children"</p> <p>"I need to attend meetings at the school, therapy, doctors and as my child is only allowed to attend for 2 h each day, having an impact on my work."</p> <p>"I don't get a lot of sleep, which affects my efficacy at work, also I'm quite stressed"</p> <p>"I returned to study and changed career (from engineering to an allied health profession) to better suit my family needs. My career was very specialised, and it was likely we would need to move away (likely internationally) to progress. I stagnated for 10 years to avoid this. We have worked hard to build our support networks where we live, and moving away would be devastating."</p>
Fathering occupations	Expected fathering activities	<p>"I expected to be involved in parent teacher interviews, but not [school inclusion]meetings. Cooking, transporting, behaviour management, taking to park, playing catch, trampoline, chasing, tickling, being pretend monster/ghost etc. Helping build cubbies, fixing broken toys, playing snap, connect 4, guess who etc."</p> <p>"Personal care up to a certain age"</p> <p>"Gross-motor play, life lessons, helping him process emotion and comforting him"</p> <p>"I expected to be involved in typical fatherhood activities, learning, eye contact, meaningful physical contact, travel. I still do that, but in a modified way. I expect to be involved in all activities, where possible."</p>
	Responsibilities	<p>"Being the contact person and decision maker for all hospital, medical and pharmaceutical activities."</p> <p>"Educating, nurturing, providing"</p> <p>"Unable to move away from support of family, where if he wasn't disabled, it would be fine."</p>
	Enjoyment	<p>"Play rough and tumble. Play ball with him"</p> <p>"Obviously I didn't expect to be involved in day to day care associated with profound disability, medicine and feed preparation and administration, essentially developing core nursing skills to get through each day. My daughter and I now attend the football (thanks to the AFL's support in providing a disability spot for my daughter's chair), I didn't expect this would be routine outing."</p> <p>"Playing in the back yard, having a conversation about her day, doing arts &amp; crafts. Taking her to the park and playing on the equipment."</p> <p>"Asking about my child's day. Cuddling when she's sad or upset."</p>
	Unexpected fathering	<p>"Teaching. We always looked forward to our kids being inquisitive and able to learn. We had a child with essentially no cognitive capacity to learn."</p> <p>"Elements of speech, OT and physio to help with communication, mobility and</p>

(continued)



Table 4. Continued.

Aspect of participant's life (themes)	Sub-themes	Example quotes
		day-to-day living. All things that are required for a child with special needs. These things are never expected until you have a child with special needs. Even then, it is a learning experience every day"
		"Lifting. Total personal care of a 12 year old - bathing, dressing, feeding. Troubleshooting - trying to figure out why she is screaming as she has no language or communication (other than screaming)."
		"Once we understood what was required, I expected to be involved in all activities. It is probably the degree of help needed that is difficult to expect/comprehend in advance."
		"I didn't expect to be toilet training a child past 3, or stopping him from self-harming when I can't accommodate [his preferences]. I didn't expect an outing to the park to be so stressful, or needing an exit strategy for every scenario in case he gets overwhelmed and needing to remove him quickly."
		"Bathing the child when she is still 10 years old, selecting clothes, ensuring she has gone to the toilet prior to going to bed, toothbrushing"
		"It's hard to explain, but whenever I'm out and about with my daughter, [I am] being constantly vigilant to her needs. At birthday parties or play dates I feel I need to make sure she's not feeling overwhelmed and is safe."

fathers of children with a disability. The second theme was *Fathering Occupations* and referred to the activities, role, expected and unexpected responsibilities, and activities associated with parenting a child with a disability. Both themes had four subsumed and interrelated subthemes. See Table 4 for a description of subthemes and selected representative quotes for both overarching themes ( $n = 31$  participants).

Discussion

This study investigated the mental health, work, leisure, and care situation of fathers raising a child with a disability. Fathers reported elevated depressive (58%), anxiety (37%), and stress symptoms (61%) compared to normative rates. Almost all fathers reported that their leisure was negatively impacted by caring for their child. Eighty-five percent of fathers in the study were in paid work, although qualitative data highlighted the difficulties balancing care requirements, family time, and career progression. Fathers identified many usual fatherhood activities that they enjoyed with their children as well as a multitude of unexpected and dominating tasks required for their child's care. Unexpected tasks included toileting and dressing older children, providing more help than they expected in play and self-care, preventing self-harming or behaviour "meltdowns," and teaching their child new skills. The next sections discuss findings about fathers, mental health, children, work, and health-related activity.

Fathers and mental health

Similar to previous research, the majority of fathers in the current study reported high stress and compromised mental health. These findings agree with past Australian research that reported elevated stress and depressive symptoms among fathers of children with disability ( $n = 315$ ) [36]. Giallo et al. reported that the strongest predictors of fathers' mental health difficulties were children's behaviour problems, daily stress arising from fathers' inability to attend to their own activities (work, leisure, social), and children's care needs, and low satisfaction with the parenting role. Further, past research highlighted challenging behaviour as a predictor of stress in fathers and these findings are congruent with the current study [37].

This study identified an association between mental health and both time spent participating in a healthy activity and paternal perception of support. Better mental health was reported by fathers who also reported higher participation in a healthy activity and who perceived more support for their involvement in their child's life. Enjoyable activities such as playing with children, sharing time together, communicating, and attending events such as football were valued by fathers. These findings are congruent with Cohen et al. [37] who found that a supportive spouse protects longer-term paternal mental health.

Recent research has investigated rates of depression and other mental health conditions among fathers. Canadian research involving the administrative linkage of children with a developmental disability with their parent's health service use over 20 years (prior to 2014) [14] found that mental health issues were prevalent among mothers and fathers. Sixty percent of fathers ( $n = 22\ 376$ ) experienced a mental health diagnosis including depression (48%) and other mental health problems, (42%) [15]. The study is the largest of its kind to capture prevalence rates for mental health issues experienced by fathers. The findings are congruent with fathers' reports of symptoms of depression, anxiety, and stress in the current study and highlight the need for further research and clinical guidelines to identify and implement services to support fathers.

Interventions that improve the mental health and wellbeing of parents of children with a disability are uncommon and mostly attended by mothers [13]. A recent systematic review and meta-analysis of psychopathology among parents of children with autism included 31 studies representing 9208 parents. Only 10% of the sample were fathers and no studies were dedicated to fathers alone [16]. In the service area supporting families of children with a disability, the needs of all family members should be comprehensively included in appropriate service provision. Coupled with past research, the findings in this study suggest that specifically designed services for fathers are in demand and crucial to overall family wellbeing.

Fathers and children

Fathers in the current study described difficulty navigating the challenges of paid work, balancing family life, and meeting their own and their child's needs. Fathers expressed their prioritisation

for children (“would love *love* to spend more time with wife and kids and assisting in caring for daughter with disability”); partners (“...look into changing roles within my firm to help ...support my wife whom is struggling emotionally with the situation”); and family life (“I have changed between part time and full time due to my family’s needs”).

A recent scoping review mapped fathers’ involvement with their children (with neurodisability) from a multi-faceted perspective including the affective relationship between father and child; beliefs about the fathering role, and the nature of time and activities that occur with the child [20]. The scoping reviewed found that most research about fathers has been about their beliefs about their role and situation parenting a child with a disability, with fewer studies investigating involvement in the child’s everyday activities. The current study found that fathers highly valued direct involvement within their child’s life although few were involved in school or therapy contexts. Future research might further investigate the father involvement related to balancing work and care required by children with disabilities and paternal mental health and wellbeing.

In this study, fathers reported involvement in many activities with their children which is congruent with qualitative studies about fathering children with a disability [38–40]. Interactions with service providers were infrequent and clashed with work commitments. Past research has suggested that fathers may choose less involvement with their child with a disability [41] or feel overwhelmed, overshadowed, or “invisible” in their child’s service interactions [42,43]. Future research should investigate fathers’ ideas and preferences for involvement, as well as trialling strategies to enable fathers to be involved in their child’s care and services.

### **Fathers and work**

The fathers in the current study were highly educated professionals with 79% holding degrees. However, only 64% of fathers worked full time, family income was low, and fathers described needing to work more due to the costs of childhood disability. Fathers reported compromising careers in favour of more balanced family life. In Australia where this study was conducted, population data suggests that, after the birth of a typically developing child and in the subsequent 12 years, fathers experience little change in time spent in paid work or in household work compared to women [44]. In contrast, the fathers in the current study experienced upheaval in their work-life and reported more involvement with domestic and family duties.

More research is needed to understand the differences and disparities experienced by fathers of children with a disability. These findings resonate with past research indicating that parents of children with disabilities have different stressors, financial responsibilities, capacity to work, and patterns of time-use than parents of typically developing children [24]. Future research might identify ways that parents are able to achieve more ideal and appropriate work scenarios that enable satisfaction in working lives alongside healthy family life.

### **Fathers and health-related activity**

In the current study, 58% of fathers planned healthy eating, exercise routines or attending to their health at least once per week. However, few fathers engaged in health-related activity more than weekly: 26% participated in solo physical activity; 3% participated in social activity; 16% spent time relaxing or in personally

rejuvenating activity; 6% engaged in quiet recreational pursuits with others. These rates of low participation are on par with the low participation in health maintaining and promoting activities reported by mothers of children with a disability [28]. Future research might compare health-promoting activity between fathers with and without children with disabilities and men without children to determine important differences and ways to address the disparity.

The current study is the first to measure father’s participation in such activities with a male version of the tool piloted and trialled. Findings re-iterate the need for health coaching and a family-oriented approach for parents with little time, high stress, high family responsibilities, and a child with high care needs [45,46]. Past research has identified social supports and leisure activity as an important predictor of health-related quality of life among parents of children with Down Syndrome [47]. Future research should further investigate the relationships between health activity participation, time use, and the health of fathers including ways to promote the health of fathers.

Overall, there are several limitations in this study. The data set were limited due to the low uptake by fathers, inherent bias due to a highly educated group of fathers from mainly one state in Australia. This study implemented a two-stage recruitment strategy although low uptake supports evidence that fathers are generally difficult to recruit [17]. Father’s involvement may require more incentives or co-creation and co-design to better meet fathers’ interests and concerns.

The sample in the current study included fathers with children from a wide age range and different disabilities. Future research should ensure that the population of fathers is more homogeneous if recommendations or implications within specific age groups or disability types are of interest. Future research is needed to discover what fathers both need and want from partners, medical and disability services, and the community in order to feel satisfied and included in their child’s interaction with them. An important strategy that may increase recruitment and dissemination in future research includes partnering with fathers to co-create, analyse, interpret and disseminate research with fathers in the target group. Indeed, fathers themselves may be more successful at finding ways to recruit and collect data from other fathers.

### **Conclusion**

Fathers in this study placed a high value on direct involvement with their children and were involved with their child’s care and family life. Fathers reported difficulty balancing paid work commitments with their home life and career aspirations. They reported infrequent participation in healthy activities generally and higher rates of mental health symptoms for depression, anxiety, and stress above population averages. Fathers reported low contact with their child’s services or educational setting. Clinicians and services working within a family-centred paradigm are responsible for including fathers in the family plan. By doing so, clinicians will be building the capacity of fathers to build capacity in their own families, thereby promoting health and increasing support for all family members.

### **Disclosure statement**

No potential conflict of interest was reported by the author(s).

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## Ethical approval

This project was approved by the Monash University Human Research Ethics Committee (project number 10957), Monash University, Frankston, Australia.

## Data availability statement

No data is available for this study.

## References

- [1] Bowen M. The use of family theory in clinical practice. *Compr Psychiatry*. 1966;7(5):345–374.
- [2] Bonsall A. Fathering occupations: an analysis of narrative accounts of fathering children with special needs. *J Occup Sci*. 2014;21(4):504–518.
- [3] Raina P, O'Donnell M, Schwellnus H, et al. Caregiving process and caregiver burden: conceptual models to guide research and practice. *BMC Pediatr*. 2004;4:1.
- [4] Cuzzocrea F, Murdaca AM, Costa S, et al. Parental Stress, coping and social support in families of children with a disability. *Child Care Pract*. 2016;22(1):3–9.
- [5] Cuzzocrea F, Larcen R, Westh F. Family and parental functioning in parents of disabled children. *Nordic Psychol*. 2013;65(3):271–287.
- [6] Collins PY, Pringle B, Alexander C, et al. Global services and support for children with developmental delays and disabilities: bridging research and policy gaps. *PLoS Med*. 2017;14(9):e1002393.
- [7] Rouse L. Family-centred practice: empowerment, self-efficacy, and challenges for practitioners in early childhood education and care. *Contemp Iss Early Childhood*. 2012; 13(1):17–26.
- [8] Early Childhood Intervention Australia. The National guidelines for best practice in early childhood intervention. Preston (Australia): ECIA; 2016.
- [9] Rodger S, Keen D. Child and family-centred service provision. In: Rodger S, editor. *Occupation centred practice for children: a practical guide for occupational therapists*. Oxford (UK): Wiley Blackwell; 2010. p. 45–74.
- [10] Kaniel S, Siman-Tov A. Comparison between mothers and fathers in coping with autistic children: a multivariate model. *Euro J Special Needs Educ*. 2011;26(4):479–493.
- [11] McCann D, Bull R, Winzenberg T. The daily patterns of time use for parents of children with complex needs: a systematic review. *J Child Health Care*. 2012;16(1):26–52.
- [12] Baker K, Devine RT, Ng-Cordell E, et al. Childhood intellectual disability and parents' mental health: integrating social, psychological and genetic influences. *Br J Psych*. 2020. DOI:10.1192/bjp.2020.38.
- [13] Da Paz NS, Wallander JL. Interventions that target improvements in mental health for parents of children with autism spectrum disorders: a narrative review. *Clin Psychol Rev*. 2017;51(4):1–14.
- [14] Marquis SM, McGrail K, Hayes MJ. Mental health of parents of children with a developmental disability in British Columbia, Canada. *J Epidemiol Community Health*. 2020; 74(2):173–178.
- [15] Marquis SM, McGrail K, Hayes MJ. Mental health outcomes among parents of a child who has a developmental disability: comparing different types of developmental disability. *Disabil Health J*. 2020;13(2):100874–100878.
- [16] Schnabel A, Youssef GJ, Hallford DJ, et al. Psychopathology in parents of children with autism spectrum disorder: a systematic review and meta-analysis of prevalence. *Autism*. 2020;24(1):26–40.
- [17] Leach LS, Bennetts SK, Giallo R, et al. Recruiting fathers for parenting research using online advertising campaigns: evidence from an Australian study. *Child Care Health Dev*. 2019;45(6):871–876.
- [18] Coren E, Ramsbotham K, Gschwandtner M. Parent training interventions for parents with intellectual disability. *Cochrane Database Syst Rev*. 2018;7(7):CD007987.
- [19] Barlow J, Smailagic N, Huband N, et al. Group-based parent training programmes for improving parental psychosocial health. *Cochrane Database Syst Rev*. 2012;6:CD002020.
- [20] Bogossian A, King G, Lach LM, et al. (Unpacking) father involvement in the context of childhood neurodisability research: a scoping review. *Disabil Rehabil*. 2019;41(1): 110–124.
- [21] Swallow V, Macfadyen A, Santacroce SJ, et al. Fathers' contributions to the management of their child's long-term medical condition: a narrative review of the literature. *Health Expect*. 2012;15(2):157–175.
- [22] Darling CA, Senatore N, Strachan J. Fathers of children with disabilities: stress and life satisfaction. *Stress Health*. 2012; 28(4):269–278.
- [23] Gallagher S, Pilch M, Hannigan A. Prior depressive symptoms and persistent child problem behaviours predict future depression in parents of children with developmental disabilities: the growing up in Ireland cohort study. *Res Dev Disabil*. 2018;80:170–179.
- [24] Mitchell DB, Szczerepa A, Hauser-Cram P. Spilling over: partner parenting stress as a predictor of family cohesion in parents of adolescents with developmental disabilities. *Res Dev Disabil*. 2016;49–50:258–267.
- [25] Leung PWS. Impact of fathers' support on marital satisfaction and caregiving strain: viewpoints of mothers of persons with intellectual disability in Hong Kong. *J Policy Pract Intellectual Disabil*. 2020;17(1):51–58.
- [26] Lovibond SH, Lovibond PF. *Manual for the Depression Anxiety Stress Scales*. 2nd ed. Sydney (Australia): Psychological Foundation; 1995.
- [27] Gomez R, Summers M, Summers A, et al. Depression Anxiety Stress Scales-21: measurement and structural invariance across ratings of men and women. *Assessment*. 2014;21(4):418–426.
- [28] Bourke-Taylor H, Law M, Howie L, et al. Initial Development of the Health Promoting Activities Scale to measure the leisure participation of mothers of children with disabilities. *Am J Occup Ther*. 2012;66(1):e1–e10.
- [29] Muskett R, Bourke-Taylor H, Hewitt A. Intrarater reliability and other psychometrics of the Health Promoting Activities Scale (HPAS). *Am J Occup Ther*. 2017;71(4): 1–8.
- [30] Bourke-Taylor HM, Pallant JF, Law M, et al. Predicting mental health among mothers of school-aged children with developmental disabilities: the relative contribution of child, maternal and environmental factors. *Res Dev Disabil*. 2012;33(6):1732–1740.
- [31] Bourke-Taylor H, Lalor A, Farnworth L, et al. Further validation of the Health Promoting Activities Scale with mothers

- of typically developing children. *Aust Occup Ther J*. 2014; 61(5):308–315.
- [32] Ly AR, Goldberg WA. New measure for fathers of children with developmental challenges. *J Intellect Disabil Res*. 2014;58(5):471–484.
- [33] Clarke V, Braun V, Terry G, et al. Thematic analysis. In: Liamputtong P, editor. *Handbook of research methods in health and social sciences*. Singapore (Singapore): Springer; 2019. p. 843–860.
- [34] Curtin M, Fossey E. Appraising the trustworthiness of qualitative studies: guidelines for occupational therapists. *Austr NZ J Psych*. 2007;54(3):788–794.
- [35] Patton MJ. *Qualitative research and evaluation methods*. Thousand Oaks (CA): SAGE Publishers; 2015.
- [36] Giallo R, Seymour M, Matthews J, et al. Risk factors associated with the mental health of fathers of children with an intellectual disability in Australia. *J Intellect Disabil Res*. 2015;59(3):193–207.
- [37] Cohen SR, Zeedyk SM, Tipton LA, et al. Fathers of children with or without ID: understanding long-term psychological symptoms. *J Intellect Disabil Res*. 2016;60(4):295–307.
- [38] Donaldson SO, Elder JH, Self EH, et al. Fathers' perceptions of their roles during in-home training for children with autism. *J Child Adolesc Psychiatr Nurs*. 2011;24(4):200–207.
- [39] Cashin GH, Small SP, Solberg SM. The lived experience of fathers who have children with asthma: a phenomenological study. *J Pediatr Nurs*. 2008;23(5):372–385.
- [40] Burrell A, Ives J, Unwin G. The experiences of fathers who have offspring with autism spectrum disorder. *J Autism Dev Disord*. 2017;47(4):1135–1147.
- [41] Barros Torquato IM, de Araujo Dantas MS, de Oliveira SMD, et al. Paternal participation in caring for the child with Down Syndrome. *J Nurs UFPE*. 2013;7(1):30–38.
- [42] Bagner DM. Father's role in parent training for children with developmental delay. *J Fam Psychol*. 2013;27(4): 650–657.
- [43] Lai YC. Invisible fathers' voices about the integrated programme implemented in mainstream child care centres in Hong Kong: implications for educational change. *Educ Rev*. 2020;72(1):23–40.
- [44] Baxter J. *Fathers and work: a statistical overview*. Canberra (Australia): Australian Institute of Family Studies; 2019.
- [45] Ogourtsova T, O'Donnell M, De Souza Silva W, et al. Health coaching for parents of children with developmental disabilities: a systematic review. *Dev Med Child Neurol*. 2019; 61(11):1259–1265.
- [46] King G, Williams L, Hahn Goldberg S. Family-oriented services in pediatric rehabilitation: a scoping review and framework to promote parent and family wellness. *Child Care Health Dev*. 2017;43(3):334–347.
- [47] Marchal JP, Maurice-Stam H, Hatzmann J, et al. Health related quality of life in parents of six to eight year old children with Down syndrome. *Res Dev Disabil*. 2013; 34(11):4239–4247.