‘No one believed us: no one came to help’: caregivers' experiences of violence and abuse involving children with fetal alcohol spectrum disorder

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Abstract
Child and adolescent-to-parent violence and abuse (CAPVA) refers to abusive and violent behaviours by children towards their parents or primary caregivers. The abuse and harmful behaviours can include a full range of physical, emotional, verbal, financial, and material actions over prolonged periods of time, from childhood to young adulthood. Parents and caregivers of children with neuro-developmental conditions are vulnerable to CAPVA, and little research has been undertaken exploring the experiences of caregivers of children with fetal alcohol spectrum disorder (FASD). In Aotearoa New Zealand, 56 caregivers were interviewed using semi-structured interviews, and over half identified significant levels and impacts of CAPVA, including dealing with physical violence and frequent emotional abuse. Health and stress issues were present in all caregivers interviewed. Caregivers also identified how systemic ignorance and a lack of understanding from caring professionals led to parent blaming, a sense of shame and isolation. Yet, caregivers also showed resilience and implemented strategies of de-escalation and distraction. More specialised practice is needed in this emerging field of family violence and in how to support families with children who have FASD.

Keywords
caregivers, caring professionals, child and adolescent-to-parent violence and abuse (CAPVA), fetal alcohol spectrum disorder (FASD)
INTRODUCTION

Fetal alcohol spectrum disorder (FASD) is a lifelong neuro-developmental disability that children are born with as a consequence of prenatal alcohol exposure (Gibbs & Sherwood, 2017; Joseph et al., 2022). FASD is also listed in the DSM-5 as a mental health diagnosis, specifically noted as a lifelong neuro-behavioural disorder caused by prenatal alcohol exposure (Hagan et al., 2016). People with FASD can have challenges with emotional regulation, impulsivity, sensory and communication needs, and executive and adaptive functioning abilities (Joseph et al., 2022). People with FASD also have strengths and can live good lives with an early diagnosis and appropriate, targeted support (Pei et al., 2019). However, more often than not families who are impacted by FASD find there is little or no funded support, especially in New Zealand (Gibbs & Sherwood, 2017). Children with FASD and other neuro-developmental disabilities are likely to communicate using abuse and violence at times, which means their caregivers might face additional challenges (Fitz-Gibbon et al., 2018; Joseph et al., 2022; Newbold, 2022).

Child and adolescent-to-parent violence and abuse, or CAPVA as it is known, is where violence or abuse occurs from children to their main caregivers, and it is often unreported, under-acknowledged, and misunderstood (Holt, 2016; Moulds et al., 2016; Newbold, 2022; Williams et al., 2017). There are complex issues underpinning the issue of intent or blame of disabled children in terms of causing their caregivers harm; the topic of violence remains a taboo topic, and that abuse experienced by parents is put into the too-hard basket, in terms of support from professionals (Bonnick, 2019; Fitz-Gibbon et al., 2018; Holt, 2016).

The aim of this paper is to explore the CAPVA experiences of caregivers who parent children and young people living with FASD, to promote increased awareness and practice suggestions for caring professionals engaged in therapy or support for families with FASD. To date, there have been few empirical studies, and this paper adds a lived experience perspective from caregivers who parent children living with FASD in Aotearoa New Zealand.

LITERATURE REVIEW: DEFINING CAPVA AND HOW IT IMPACTS FAMILIES AND CAREGIVERS

Authors have noted a range of definitions of CAPVA, for example, Baker and Bonnick (2021, p. 64) tell us that CAPVA is:

a pattern of harmful, and in some cases, controlling, behaviour by children or adolescents towards parents or caregivers, where abusive behaviour can be physical, verbal, emotional,
psychological, financial, property-based or sexual. Abusive behaviour can be intentionally harmful and controlling, and/or unintentionally harmful, functioning to communicate distress, anxiety or trauma.

Others have discussed that, regardless of intent, CAPVA occurs when caregivers end up feeling threatened or harmed or controlled by their children and young people to the extent that they adjust their own lives to cope with or accommodate the abuse (Holt, 2016; Paterson et al., 2002). Regardless of whether the child or young person has a disability or special need, caregivers, including parents, grandparents, and foster or adoptive parents can feel controlled and they are often afraid (Holt, 2016; Newbold, 2023; Selwyn & Meakings, 2016; Williams et al., 2017).

The range of CAPVA includes verbal insults, hitting, spitting, meltdowns involving screaming and much damage lasting hours at times, broken windows, holes in walls, smashed technology, being chased or attacked with weapons, having money or belongings stolen, being intimidated, constant demands being made, or having false allegations made against the caregiver (Baker & Bonnick, 2021; Bonnick, 2019; Holt & Birchall, 2022). The prevalence range of CAPVA is thought to be from 5% to 21%, but for specific populations, studies have noted 46% in kinship care families and 83% in adoptive families (Fitz-Gibbon et al., 2018; Holt & Birchall, 2022; Moulds et al., 2016; O'Hara et al., 2017; Selwyn & Meakings, 2016; Toole-Anstey et al., 2023).

For neuro-disabilities, there is limited research, with one Australian survey noting that where adolescent-to-parent violence was present, 18% of the adolescents had neuro-disabilities, like autism and ADHD, but FASD was not mentioned (Fitz-Gibbon et al., 2018). Another Australian study, which drew on a large self-report study of young people, found that those with a disability of any kind were 1.3 times more likely to use violence at home than young people who did not have a disability, and 1.4 times more likely to use frequent violence than youth who did not have a disability (Fitz-Gibbon et al., 2022). Recently also, Joseph et al. (2022) completed a systemic review of aggressive behaviour and violence in children and adolescents with FASD and considered the extra vulnerabilities that children with FASD have which might increase violence to caregivers. These include struggles with emotional regulation, impulsivity, hyperactivity, executive and adaptive functioning issues, and sensory and communication difficulties (Joseph et al., 2022).

The repeated and relentless nature of CAPVA to those who have caregiver responsibilities is widely discussed in the literature, and studies have revealed significant impacts on mothers, grandparents, and adoptive and foster parents (Fitz-Gibbon et al., 2018; Holt & Birchall, 2022; Selwyn & Meakings, 2016; Williams et al., 2017). CAPVA inverts traditional ‘power’ relationships whereby caregivers feel ashamed, disempowered, and unable to take control of the situations they are facing (Bonnick, 2019; Murphy-Edwards & van Heugten, 2018; Williams et al., 2017). Caregivers often find themselves blamed for their inability to reduce the violence by caring professionals who, while well-meaning, fail to understand the lived reality of families facing daily CAPVA (Baker & Bonnick, 2021; Bonnick, 2019; Newbold, 2022; Selwyn & Meakings, 2016). Studies have reported on the trauma, isolation, mental health, and physical harms that caregivers face (Baker & Bonnick, 2021; Holt, 2016) and also that they often feel isolated and are unable to ask for or find help and support (O’Hara et al., 2017). One study in New Zealand, which focused on frequent property damage by children to their parents, as a distinct form of CAPVA, noted serious impacts not just of a financial nature but parents talked of trauma, fear, avoidance behaviours, and emotional numbing — and that these often got more intense as abuse is repeated over time (Murphy-Edwards & van Heugten, 2018). Selwyn and Meakings’ (2016) study of adoptive parents experiencing CAPVA in the United Kingdom noted parents feeling ashamed, isolated, and experiencing a sense of failure in their parenting capacities. Fitz-Gibbon et al. (2018) surveyed 120 caregivers in Australia who had been abused by their adolescent child, and there were numerous stories of parents’ work being impacted, relationship breakdowns, loss of natural supports, and living in constant fear and stress. Holt and Birchall’s study of 27 grandparents impacted by CAPVA reported that grandparent caregivers were impacted by suicidal thoughts, depression, and anxiety (Holt & Birchall, 2022).
Dilemmas for parents and caregivers

While some definitions highlight the intentional or controlling nature of CAPVA (Baker & Bonnick, 2021; Bonnick, 2019; O’Hara et al., 2017), for caregivers who parent children with a range of neuro-developmental disabilities like autism, or FASD, or ADHD, the intent issue poses a real conundrum; these caregivers often view CAPVA as representing communication or sensory needs that have been unmet in some way and that their children are not deliberately wanting to hurt them. Research by Sutherland et al. (2022) explains disabled children's violence in terms of 'reactivity,' that is, violence occurring when disabled children are ‘stressed, overwhelmed, frightened or afraid’ (Sutherland et al., 2022: 5). In the United Kingdom, Yvonne Newbold's work has been highly influential and she would argue that violent and challenging behaviour (the term she prefers) stems from a place of extreme anxiety which can be triggered by a range of factors, often related to their disabilities, and it is the job of the caregiver (and their helpers) to unpack the triggers and understand what the child is trying to communicate, mainly about unmet needs, and then attempt to change the environments triggering the distress to reduce the anxiety, thereby decreasing the violent behaviours (Newbold, 2022, 2023). Newbold also argues that when it comes to control, the disabled child's control is based on their fear and anxiety that leads to them having a need to control the environment around them, rather than any element of vindictiveness or power over another person (Newbold, 2022, 2023). It is common for caregivers, in response to the violence, to turn to online support groups to seek support in a safe, non-judgemental environment and to have opportunities to share their dilemmas and challenges with other caregivers (Holt, 2016).

Interventions and resources for CAPVA

There are a range of promising interventions for CAPVA (Baker & Bonnick, 2021; Bonnick, 2019, 2023; Golan et al., 2018; Moulds et al., 2023; O’Hara et al., 2017; Paterson et al., 2002; Toole-Anstey et al., 2023). Some of these are focused on helping caregivers, some on supporting children and youth, and a few programs are run for both caregivers and children or youth concurrently. Programs use restorative, cognitive behavioural, and skills-based constructs and processes to help identify the issues, support caregivers in their parenting roles, and assist in the practice of respectful and safe relationships at home. Reductions in violence and abuse and improved relationships for family members have been reported (Baker & Bonnick, 2021; Moulds et al., 2023; O’Hara et al., 2017; Paterson et al., 2002). Non-violent resistance training has been tried for parents with autistic young adults and positive outcomes have been reported, and this kind of training, which helps parents de-escalate conflicts and garner external support, may therefore be useful for the FASD population, though no specific intervention has been developed yet for the FASD population (Golan et al., 2018). The respect intervention in the United Kingdom has also been adapted for use with autistic adolescents where CAPVA is present (Respect, 2023).

In addition to formal programs for caregivers and children and youth, there are a plethora of online resources for helping professionals to access and for families to gain both informal and formal supports. Bonnick's (2023) Projects and programmes | Holes in the wall webpages offer a wide range of information, blogs, and tips for professionals and families. Newbold's online resources (2023) provide a full range of workshops, webinars, online support groups, pamphlets, blogs, and tips for caregivers experiencing CAPVA. There are well-established help and support services in the United Kingdom, for example Respect (2023), PEGS Parental Education Growth Support (2023), and CAPA First Response (2023). In Australia, there have been programs available via specific organisations but mostly there is a dearth of support for families where CAPVA is a concern (Moulds et al., 2023). NOFASD Australia, a support organisation for caregivers where FASD is present, has been proactive in providing online webinars on the topic of CAPVA and FASD (NOFASD, 2020).
CAPVA in New Zealand

The issue of CAPVA in New Zealand has rarely been explored as a form of family violence, and only recently have practitioners and caregivers highlighted some of the experiences and impacts (Gibbs, 2023; Murphy-Edwards & van Heugten, 2018; Williams et al., 2017). CAPVA prevalence is unknown in New Zealand; it is a hidden form of violence. New Zealand’s recent family violence strategy (New Zealand Government, 2021) has fleetingly acknowledged CAPVA in terms of a general reference as part of the broad definition of family violence, but as it is such a recent initiative no specific policy, action plan, funding, or resources have been allocated to addressing CAPVA. While disability is acknowledged as an issue in the strategy, it is only in relation to disabled people being more vulnerable to becoming victims of violence, and no mention is made specifically of FASD, or indeed other neuro-disabilities. In New Zealand, FASD is an unfunded disability compared to autism and ADHD, and caregivers and advocates continue to campaign for resources and services to help them with the daily challenges of parenting the high and complex needs of their children and young people who live with this lifelong disability (Gibbs & Sherwood, 2017). In Australia, FASD fares a little more positively in that the National Disability Insurance Scheme will fund disability support for people diagnosed with FASD, but stringent criteria apply (NOFASD, n.d.).

THE STUDY

In New Zealand, there has been limited research exploring the impacts of parenting a child with FASD and no research on CAPVA with vulnerable populations. As part of ongoing FASD research at my university, I obtained University of Otago Ethics approval to undertake a qualitative project exploring the impacts of parenting a person with FASD on caregiver health and well-being. Caregivers were recruited through FASD online networks and word-of-mouth invitations at caregiver support events and workshops. Fifty-six semi-structured interviews were conducted during 2021 and 2022. Participants were asked to talk about their experiences of parenting a child with FASD, including the impacts and challenges, but also some of the positives. The interview schedule asked about impacts on physical health, on emotional or mental health, on relationships, and on their social life and finances. They were asked if they had support or used strategies that helped with any of the challenges they faced.

The group of parents or caregivers that I interviewed were in the main women (85.7% women and 14.3% men). They self-identified as 66% New Zealand European, 25% Māori, 4% other indigenous, and 5% other European. This group were well-educated and very experienced in fostering before permanent caregiving; they were highly attuned to the needs of their children; they had often become caregivers in their 30s and 40s. Eleven of them were birth relatives of the children they cared for, for example, grandparents and aunts (20%); 45 (80%) were non-kin long-term permanent legal caregivers. While caregivers all had at least one child with FASD in their family, I did not record the demographics of these children.

All semi-structured interviews were undertaken by me at locations of the caregivers’ choosing and lasted between 60 and 90 min. Interviews were recorded and transcribed verbatim and were reviewed and edited by the participants. Transcripts were analysed using a combination of inductive and deductive processes and themes were identified systemically drawing on thematic analysis suggestions and the general inductive approach (Thomas, 2006). For deductive processes, transcripts were read and re-read with the key research questions in focus, with major themes collated; for inductive processes, the transcripts were read to develop and review new emerging themes. Also, all transcripts were checked for similarities and patterns, and illustrative quotes were retrieved for the five themes collated. To assist with credibility, a research assistant co-analysed the transcripts, and two expert caregiver advisors were asked to review the findings. These caregivers both had children with FASD and had experienced CAPVA. They read the draft and provided feedback. I also have lived experience as a caregiver of youth with neuro-disabilities, and I am an experienced social worker.
The five research themes emerge from a focus on CAPVA, as reported specifically by 32 out of the 56 caregivers interviewed. The other caregivers did not report CAPVA. The themes pertinent to these 32 caregivers are: *Experience and types of CAPVA; Impacts of CAPVA; Systemic abuse experienced alongside the CAPVA; Strategies and self-care; and Silver linings.*

**FINDINGS**

For each thematic area, I will provide a summary of the findings to be followed by a range of appropriate quotations from participants.

**Theme 1: Experience and types of CAPVA**

For 32 out of 56 participants, CAPVA was present (57%). A range of physical, verbal, property, emotional, and financial abuse was noted. Self-harm and violence to animals were also noted. The self-harm aspect was noted as a way of threatening parents to try and get them to meet a demand. For caregivers, CAPVA was experienced as two to three very serious incidents in some cases, but for others, it was experienced as more frequent, even daily, verbal abuse and aggression.

Physical abuse could include being hit, shoved, kicked, grabbed, strangled, punched, pinched, or being spat at:

She'd hit us, she'd kick at us and she'd scream in a high-pitched voice. (Caregiver 5).

I was assaulted quite a few times, and I was too embarrassed to tell anybody. (Caregiver 3)

Verbal abuse could include being screamed or shouted at, being insulted or belittled or having to cope with threats, oppositional language, or enduring long meltdowns:

[I] couldn't say she was out of order, she'd go mad screaming, shouting. (Caregiver 12).

Property damage was mentioned by 18 (35%) caregivers, including breakages of all manner of household items, holes in walls, doors broken, phones, and TVs smashed or clothes shredded:

He would damage stuff, kicking in doors. We had no door in the house that was complete, they were all cracked and got holes. (Caregiver 6)

But, yeah, broken things, windows, door handles, everything ... the cost was going on, and on, and on. (Caregiver 4)

Financial abuse occurred and included stealing household and other items, as well as misuse of parent's credit cards, theft of cash, technology, or personal items like jewellery:

Taking hundreds out every night. We were done with it. Absolutely done with it. Then we sent son packing because of his stealing. (Caregiver 19)
The most frequent kind of abuse that parents mentioned was emotional and psychological abuse. This could include being controlled, harassed, intimidated, belittled, or their child telling untrue stories to professionals/others about the family, having to endure constant demands and sometimes feeling afraid of the child:

I've cried every day for nine or 10 years. I remember, I used to cry on my way – when I was going to pick her up from school because I knew I was going to get assaulted.

(Caregiver 5)

It throws you off your centre, and I guess you become hypervigilant, and you are always trying to dampen down fires, so they don’t suddenly explode.

(Caregiver 3)

At the more serious end of the violence, weapons such as knives were waived at caregivers or used to cause serious self-harm and threats of self-harm. Self-harm was quite common amongst children and youth with FASD, and parents viewed self-harm as either a cry for help or attempts to punish and control the parent when they refused a demand from the child. Self-harm by their children often causes as much distress as being threatened or harmed:

She was at home and she got a butcher's block knife out and she was waving it around and threatening to kill us with it.

(Caregiver 5)

I said look, this child is escalating. She is threatening suicide, she's cutting, she is putting coins down in between plugs, burning, she's been lighting fires inside.

(Caregiver 25)

Violent to others

Caregivers also noted that their child was also violent to others; siblings or peers or workers:

So, sister ended up locking herself in her room in the evenings, for fear that he would come in and hurt her and I used to get frightened as well, right, so I would fear for my safety at times.

(Caregiver 53)

Violent to animals

Also noted by a few caregivers was some violence to pets at home:

But when he was having a meltdown, the power and strength he had … We had a dining room table, and I was so shocked, he would only have been about 12, and he completely overturned that table, completely! And, really nasty, we would have to get the dogs out of the way as well, he would kick [the family pet].

(Caregiver 6)

**Theme 2: impacts of CAPVA**

The impacts of CAPVA on parents and caregivers were wide ranging and impacted how they viewed their health and mental well-being; how they viewed their relationships; and how their finances were impacted.
Each of the 32 caregivers described impacts on their health and well-being. The most common terms used were ‘stress’ and ‘exhaustion,’ but caregivers talked about poor health, like having had heart issues, cancer, autoimmune illnesses, or significant mental health impairments. Several caregivers were taking antidepressants, medications for anxiety, or beta-blockers to deal with racing heartbeats induced by stress. They related their physical ill health directly to the stress they suffered from parenting their children with FASD and the abuse they suffered:

Huge, huge stress, huge levels of anxiety. I would be ringing up mental health crisis lines.

(Caregiver 53)

I'm so tired, I just – I don't want to do another afternoon and night of managing her being nasty to her brother and snappy to her grandmother and the prolonged bedtime routine. But as of – at the moment, it's not to the point where every day I find it hard to get out of bed; it's just more that I'm exhausted all the time.

(Caregiver 56)

Caregivers described years of isolation and not being able to talk with wider family members about the abuse or problems they were facing, not being able to have a break, strain in the relationships between partners, and having to give up employment and holidays. ‘I haven't been able to have a relationship, or anything like that, because all I can cope with is son's demands. I haven't been able to work. I just couldn't.’ (Caregiver 7)

On a positive note, caregivers were able to join online support groups for FASD when they were made aware of such groups, and this resulted in some new peer-to-peer support relationships developing. ‘I mean we belong to FASD peer support networks which is great and some of these people have become very good friends.’ (Caregiver 57)

Caregivers reported that the significant damage to property both at the household and away (e.g., cars stolen and crashed) was a huge challenge, from both an emotional cost perspective and with financial costs, for repairs and replacements. Sometimes caregivers would have to pay for repair and fines incurred by their child damaging others’ property or stealing items from friends and strangers:

I mean, I just paid thousands. I bought him a car. Then it got trashed. I got it fixed. It was $2000 something.

(Caregiver 17)

Theme 3: Systemic abuse goes alongside the CAPVA

While caregivers understood that much of the abuse and harm they faced was coming from children with unmet communication, education, and sensory needs they felt the professionals they spoke to did not share their views. Many of the caregivers interviewed expressed deep dismay and disappointment at caring professionals who made them feel that they were to blame for the abuse and that the problem of abuse was not ‘that serious.’ Caregivers felt judged and shamed, and in some cases by asking for help their situation got a whole lot worse, as sometimes they were made to do parenting courses and expected to change their ineffective parenting. ‘So, through this whole process, the whole focus has been on me and my parenting.’ (Caregiver 8)

Caregivers who asked for help were often denied services because their child did not have the correct funded disability (as FASD is not funded for support services in New Zealand). Several caregivers in the study were forced to give up their teen children to full-time state-based out-of-home care because they could not get the help they needed to keep their family safe, with the child remaining with them.
There were no specialist CAPVA services they could turn to for help — only the police who criminalised their children, and formalised social welfare services which led to more trauma for all the family, and grief and loss for the child and caregivers. Caregivers felt CPAVA was in the ‘too hard basket’ for caring professions to be willing to acknowledge and address as a significant issue impacting families with disabled children:

Our children need support and it won’t cost the government any more money long term because they’re spending it anyway on incorrect interventions.

(Caregiver 5)

**Theme 4: Strategies and self-care**

Parent interviewees were innovative and skilled at implementing a range of strategies aimed at de-escalation, distraction, and restoring relationships once an incident was over. Caregivers had safety plans, used humour during tense moments and tried to cope with their child’s dysregulation with calm soothing communication strategies. Sometimes, they were able to call on a partner or nearby friend to assist but often they just had to face the full force of an explosive child or young person and brace themselves for distress. They also had to develop great skills of survival and self-care due to minimal formal support being available for children with FASD:

Well, definitely look after yourself, physically, and mentally. Get yourself on mindfulness or yoga. I think that that is really essential.

(Caregiver 6)

Prevention is really important, so implementing strategies of distraction and keeping my son occupied and doing the things he likes doing all of these things can be strategies of self-care because if he’s calm and happy then it means we have an easier life.

(Caregiver 57)

**Theme 5: Silver linings**

While the struggles with CAPVA were insurmountable, at times caregivers were able to note some positives about the impact of parenting a child with FASD and the lives they had been living. Caregivers talked often of ‘personal growth,’ developing ‘more empathy,’ and using their experiences to ‘help others’ facing similar challenges. In a rare one or two cases, caregivers said they would not wish for the same life over again, but most felt a deep love for their children and that they had made lifelong friends with others who had experienced abuse and violence:

I think what I have become is more compassionate for people in their situations. I am definitely more understanding.

(Caregiver 14)

**DISCUSSION**

This study shows that CAPVA is a significant and impactful experience for caregivers of children who have FASD. The frequent and intense levels of abuse at times impacted caregivers' mental well-being, their energy levels, their physical and social health, their relationships, their outlook on life — it was too significant to ignore. Yet, sadly, caregivers found that when they went help-seeking, from caring
professionals and even friends or family, they found they were not always believed, that CAPVA was viewed as too ‘hard a basket,’ or something taboo that should not be discussed, and that very few others, except other caregivers in the same situation, truly understood the extent of the trauma they were experiencing. Caregivers were always willing to ask for help, but rarely could they get any — this is a recurrent theme across the literature on CAPVA where parents experience violence from their children (Fitz-Gibbon et al., 2018; Holt & Birchall, 2022; Murphy-Edwards & van Heugten, 2018; O’Hara et al., 2017; Selwyn & Meakings, 2016), including from their disabled children (Newbold, 2022, 2023; Sutherland et al., 2022).

Murphy-Edwards and van Heugten (2018) note that the idea of children harming or exerting power over their parents is a socially unpalatable one. Not only do parents and caregivers feel shame and will often blame themselves but they also want to avoid further judgement, stigma, or invasive action occurring that could harm their children (Fitz-Gibbon et al., 2018; Holt & Birchall, 2022; Sutherland et al., 2022). Caregivers in my study were highly attuned to the needs of their children and felt that when these needs were not met, either at school or elsewhere, that their children and young people were likely to get distressed and aggressive at home. Caregivers tolerated the frequent abuse from their children because they understood the impact of having FASD on a child’s capacity to communicate and function. However, they often found their insights and knowledge about their child’s disability needs as it related to CAPVA were not shared by those they turned to for help.

Other studies on general abuse and violence towards caregivers have also concluded that caring professionals, because they don’t recognise CAPVA, fall into the blame parent discourse by assuming ‘poor parenting’ or ‘uncontrolled’ children (Baker & Bonnick, 2021; Selwyn & Meakings, 2016). This research on CAPVA has confirmed a level of systemic ignorance and denial that leaves parents unsupported, disbelieved, and sometimes presumed to be the trigger for their child’s violence or abuse. This is also noted by other researchers consistently over a range of studies (Bonnick, 2019; Fitz-Gibbon et al., 2018, 2022; Holt, 2016; Sutherland et al., 2022). Caregivers in my study felt that CAPVA needed to be highlighted during caring professionals’ training but also that FASD services and CAPVA services for neuro-disabled children and their families needed to be funded via a national strategy. The current New Zealand family violence strategy only fleetingly mentions CAPVA and the focus is not on supporting families where disabled children are violent to their parents. Hence, the strategy is limited in its capacity to highlight CAPVA, thereby developing policies for support. The findings from my research suggest that CAPVA is frequent and that families pay out significant amounts of money for damage, as well as suffering a range of physical and emotional health impacts. Hence, funding and support is vital. Sadly, CAPVA in New Zealand remains a taboo topic, felt daily in the homes of families with FASD, yet unrecognised in social policy, funding provision, and practice.

O’Hara et al. (2017) note that in dealing with CAPVA, systems of help are woefully inadequate and even contribute to the problems and stress for families, and in Aotearoa New Zealand, there is no doubt that little will change until both CAPVA and FASD are more formally recognised. But there is one avenue that can be explored further and increased — that is the way caregivers themselves develop resilience and strategies that both de-escalate the immediate threat of violence and help them cope with the day-to-day exhaustive nature of the abuse. The caregivers in my study made great efforts to learn about environmental changes they could make that would help reduce violence and abuse, and they focused on ‘less demands,’ more structure for and supervision of their child, and increased efforts at connecting to other parents for peer support and lived experience guidance. In New Zealand, we have FASD-CAN (2023), which encourages peer support for parenting children with FASD generally, but as yet there is no specific online support for dealing with CAPVA. In the future, it will be useful for the online support to provide opportunities for caregivers to speak specifically about the day-to-day realities of abuse and violence they are experiencing and share any tips or resources they have to deal with it. This might include the use of self-care, peer support allies, de-escalation techniques, or contacting professionals. There are examples overseas: in the United Kingdom, there are emerging peer support networks using social media platforms and app-based messaging services to help parents help one another (Baker & Bonnick, 2021; Holt, 2016; Newbold, 2022, 2023). Holt’s (2016) research on message
boards also confirms the benefits of peer-based online support groups, but as yet we do not have the groups, nor the recognition, nor the research established in New Zealand.

Also useful for caregivers in my study were finding caring professionals who would make an effort to work in partnership with caregivers, believe the parent, or see for themselves the extent of CAPVA and identify supports for the family. Bonnick (2019) advocates for a partnership model focused on identifying strengths and supports to support families once CAPVA is fully acknowledged and assessed — in New Zealand this kind of service is based on individual practitioners’ willingness to do this partnership work with families, rather than on national or regional services that are available. As a result, more coordinated education and training for social workers, police, lawyers, family therapists, and those who support families where violence is occurring is needed, instead of the current ‘ad hoc’ status quo (Toole-Anstey et al., 2023). Once the caring practitioner or therapist population can access specific education and training on both FASD and CAPVA, caregivers might start to feel there is some hope for recognition and support outside of their own efforts.

Limitations

This study is limited in that it provides only a small snapshot of a self-selected group of caregiver participants who discussed the impact of violence as they parented their children with FASD. The study did not explore linked issues like disability support or school exclusion or co-occurring adverse issues or conditions that might impact abuse experience or frequency. This study did not explore the specific dynamics of the ethnicity, age, or gender of the child/children with FASD who were abusing their caregivers. Most of the caregivers were women (85.7%), and as such it is predominantly female caregivers who discussed the abuse from their disabled children. Future research would seek to hear the voices more of male caregivers and include professionals working alongside families in this area.

Implications for the work of caring practitioners and therapists

CAPVA is very complex, especially with regard to families supporting children with FASD, and we have a long way to go before policy, practice, and protocols are put in place to understand what’s happening and to provide help. But caring practitioners and therapists can find many helpful resources online (Bonnick, 2023; FASD-CAN, 2023; NOFASD, 2020), and they can direct caregivers to these, and a range of other parent online supports too (CAPA First Response, 2023; Newbold, 2023; PEGS, 2023). It is possible for therapists to draw on generic programs that help young people with abuse issues (Moulds et al., 2023), but ideally, therapists need to be both knowledgeable in FASD and CAPVA even when using good generic programs. Practitioners and therapists need to be able to have the skills and empathy to ask caregivers what is going on at home and then believe them. Too often, caregivers deal with much shame and blame, and practitioners can be effective if they form trusting relationships with caregivers; assist with safety planning; offer genuine counselling and interventions; ensure good case management; and help parents support each other through peer-based opportunities (Fitz-Gibbon et al., 2018; Holt & Birchall, 2022; Selwyn & Meakings, 2016; Toole-Anstey et al., 2023).

Caregivers are often highly skilled and resilient, and they need professionals who will recognise the skills and strategies that parents are already using and provide additional CAPVA-informed strategies. This might include arranging for caregivers to have a break or to increase the ‘in home’ support. In New Zealand, this is likely to mean that they work alongside families in an advocacy role to argue for FASD to be accepted as a fundable disability so families can access specific disability support for their child.

Specialist programs drawing on models used overseas (Baker & Bonnick, 2021; Moulds et al., 2023; Toole-Anstey et al., 2023) might be helpful but given Aotearoa’s context of bicultural initiatives, it will be important that CAPVA resources and services are developed in local communities by local
Communities, using peer and lived experience expertise, resourced and supported by multi-agency teams and professionals who are committed to reducing CAPVA for all families, but especially those where children have a disability and are additionally vulnerable.

**CONCLUSION**

Caregivers of children with FASD in New Zealand experience significant impacts when their children abuse or harm them. Practitioners can demonstrate empathy and support in many forms notably in demonstrating belief and by making efforts to secure more than superficial help for families. New Zealand is a long way off from developing policies and good practice in this area of family violence, and caregivers want to see funding for FASD-informed services alongside CAPVA-specific supports.

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**Presentation by Anita Gibbs:**

Caring in the chaos – how caregivers of people living with FASD survive and thrive.


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