A socio-ecological exploration of adolescent violence in the home and young people with disability: The perceptions of mothers and practitioners

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ANROWS acknowledges the Traditional Owners of the land across Australia on which we work and live. We pay our respects to Aboriginal and Torres Strait Islander Elders past, present and future, and we value Aboriginal and Torres Strait Islander histories, cultures and knowledge. We are committed to standing and working with Aboriginal and Torres Strait Islander peoples, honouring the truths set out in the Warawarni-qu Guma Statement.

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Acknowledgement of lived experiences of violence

ANROWS acknowledges the lives and experiences of the women and children affected by domestic, family and sexual violence who are represented in this report. We recognise the individual stories of courage, hope and resilience that form the basis of ANROWS research.

ANROWS acknowledges that children and young people living in homes where domestic and family violence (DFV) is present are not simply “exposed” to DFV - they are experiencing it. There are no circumstances in which children and young people are exposed to DFV and are not also being impacted by this violence. Therefore, ANROWS will always default to using “experienced DFV” instead of “were exposed to DFV” or “witnessed DFV”. This language aligns with the National Plan to End Violence Against Women and Children (due for finalisation in 2022), which recognises that children experience DFV as victims in their own right, and also seeks to honour the voices of victims and survivors who have felt minimised, erased or unacknowledged as childhood survivors.

Please note that in this report, the authors have chosen to use the term “exposure to DFV”.

Caution: Some people may find parts of this content confronting or distressing. Recommended support services include 1800RESPECT (1800 737 732), Lifeline (13 11 14) and, for Aboriginal and Torres Strait Islander people, 13YARN (13 92 76).
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Acronyms

ADHD  Attention deficit hyperactivity disorder
ADV   Adolescent dating violence
AFV   Adolescent family violence
APD   Auditory processing disorder
APV/A Adolescent-to-parent violence/abuse
ASD   Autism spectrum disorder
AVITH Adolescent violence in the home
CD    Conduct disorder
CPA   Child-to-parent abuse
CRPD  Convention on the Rights of Persons with Disabilities
DFV   Domestic and family violence
ID    Intellectual disability
IPV   Intimate partner violence
NDIS  National Disability Insurance Scheme
ODD   Oppositional defiant disorder
PAD   Parental attachment disorder
PDA   Pathological demand avoidance
PDD   Pervasive developmental disorder
PTSD  Post-traumatic stress disorder
SPD   Sensory processing disorder
Executive summary

Background to the project

An emerging body of research into adolescent violence in the home (AVITH) has signalled concerns about the disproportionate rates of young people with disability receiving family violence services and/or legal responses to violence at home (Campbell et al., 2020). Despite these concerns, there is a distinct lack of research that extends beyond documenting disability as a risk factor for the use of violence. To date, research about AVITH has typically collapsed disability into a binary classification (e.g. disabled or not disabled), and then discussed it in ways that imply disability is causally linked to violence. No attention has been paid to the behaviours and the social and interactional context in which those behaviours arise.

Similarly, in domestic and family violence (DFV) policy (under which AVITH sits), disability is framed as a particular feature of individuals and families that may pose a “risk” to engagement and effective service delivery. While there is broad recognition at the practice level about the need to develop a deeper understanding about young people with disability who engage in AVITH, there is a stark lack of evidence to guide practice.

This report presents findings from our exploratory qualitative research that aimed to generate new knowledge about the intersection between AVITH and young people with disability. Our intention for this report is to begin to lay the foundations for a sustained and nuanced dialogue about the issues for and experiences of young people with disability and AVITH. We acknowledge that the perspectives and experiences of young people with disability are a critical missing piece.

Methodology

This qualitative study was informed by our prior conceptual review of the literature: Towards a socio-ecological understanding of adolescent violence in the home by young people with disability (Sutherland et al., 2022). In both the review and in this study, we applied the description of disability as per the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD): “Disability results from the interaction between persons with impairments and the attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others” (United Nations General Assembly, 2007, n.p.). We approached this project, therefore, by conceptualising disability as arising from the multifaceted ways in which impairments or health conditions interact with systemic and structural barriers within our society.

Data were collected from in-depth semi-structured interviews with 13 mothers who had experienced AVITH, and 16 practitioners with direct experience working with young people with disability and AVITH. All participants were from metropolitan and regional areas of Victoria, Australia. The interviews were conducted from July 2021 to February 2022.

Mothers of young people with disability

Although our recruitment materials spoke broadly about family members’ experiences – parents, carers, siblings – we only received expressions of interest from mothers. Mothers shared their experiences of violence involving 11 young people with disability who were currently using violence at home. Two mothers of adult children were interviewed about their past experiences of violence (i.e. experiences of violence when their child was young).

Practitioners

We conducted 16 interviews with practitioners working in disability and advocacy organisations; specialist AVITH services; community health organisations; community care and case management; child, youth and family therapeutic services; family and parenting programs; and specialist community legal services for young people.

Key findings

From the interviews a range of factors, processes and contexts emerged that may be important to consider in guiding approaches in prevention and response. We used the socio-ecological model as an organising framework to situate those contextual factors and processes at each level of the social ecology: individual, relationship, community and societal.
Experiences of AVITH

The mothers interviewed for this project spoke about complex circumstances and experiences of violence. They perceived that violent behaviours were often “reactive”, arising in situations where their child felt stressed, overwhelmed, frightened or afraid. Mothers also talked about their experiences through the lens of DFV. Several mothers drew on their previous experiences of DFV to make sense of their child’s behaviours.

Mothers spoke about wide-ranging detrimental impacts of violence at home including direct effects on their own physical, social and emotional health, on their ability to manage safety in the family home, as well as flow-on effects such as participation in the paid workforce. They expressed deep concerns about the impact on the young person with disability and on siblings. Mothers often spoke about feeling alone and isolated and feeling as though their family had been abandoned by the systems designed to support them.

Individual factors

A background of violence and trauma

A history of violence and abuse emerged as a significant theme across the interviews. While some mothers reflected on their backgrounds of DFV, others noted the direct impact of exposure to violence on young people with disability. This included violence in the family home as well as that observed beyond the boundaries of family life. Practitioners similarly reflected on how trauma manifests through violence experienced in and out of the home, and its significant and complex impacts for young people, families and service providers.

Violence as an expression of power imbalances

The concepts of power and control were important to mothers’ experiences of violence at home, most often in the context of the young person with disability feeling out of control of their physical, emotional and social lives. Mothers participating in this study talked about the use of violence by young people with disability to “control self” rather than to “control others”.

Gender, disability and AVITH

Gender emerged as a salient issue for mothers’ experiences of violence and was contextualised within their gendered position in families. Mothers perceived they were targets for violence, not only because they were present at home, but because they represented safety, security and protection – “mum won’t leave” (P02). Some practitioners also observed this gendered dynamic whereby mothers were most often targets of violent behaviours at home because they were the ones actively managing needs for support.

Relationship factors

Siblings

Mothers and practitioners perceived profound impacts of AVITH on family life and relationships, with a particular focus on siblings. Mothers raised concerns about siblings being directly targeted and harmed by violent behaviours. They also described impacts on siblings’ physical, social and emotional health; problems in family and other social relationships; inability to work; resentment towards parents and a deep sense of sadness and loss.

Stigma and social isolation

Stigma was a significant theme that emerged across the interviews. Mothers and practitioners in this study noted how stigma, and a desire to keep the violence used by young people with disability hidden for fear of further stigmatisation, significantly impacted on close family and informal support relationships. For families from culturally and linguistically diverse backgrounds, issues of social isolation were perceived as being further exacerbated by their prior experiences of stigma and discrimination about disability.

The contested role of parenting

Mothers and practitioners expressed a range of views about the intersection of parenting, young people with disability and AVITH, but their perspectives often diverged. Mothers recalled having their parenting skills and capabilities blamed or labelled problematic. While many practitioners acknowledged that they had much to learn about working with young people with disability and their families, they also spoke about the potential for parenting practices to be disempowering for young people with disability.
Community factors

Early intervention and support
Mothers frequently described their experiences of AVITH through the frame of much needed but inadequate or ineffective support. Most mothers in this study recalled a long history of engagement with support services and had employed a range of strategies and techniques to manage behaviours that were challenging or concerning, including violence. For the most part, however, they reflected on a significant lack of available, appropriate and timely support. While some practitioners also spoke about early intervention, support and engagement with services, this was sometimes framed in relation to the underlying causes of behaviours displayed by young people with disability.

Transitions
Negotiating transitions for young people with disability emerged from the interviews with mothers and practitioners as a key theme in relation to violent behaviours at home. Transitions occurred in educational settings (including transitions out of school), establishing and maintaining relationships with peers and changes to engagement with services. Schools were a particular focus for participating mothers, with many describing complicated relationships between young people with disability and schooling. Mothers’ and practitioners’ reflections on school and transitions were significantly shaped by their experiences of COVID-19 lockdowns.

The role of the National Disability Insurance Scheme as part of a multisectoral response
Mothers reported barriers to accessing and navigating the National Disability Insurance Scheme (NDIS), particularly in relation to accessing supports for managing violent behaviours in the home. While many noted the administrative burden as a key barrier to access, practitioners frequently expressed frustration at the difficulties that families experience when seeking support in the context of AVITH. Both mothers and practitioners in this project viewed the NDIS as an important component of a multisectoral response to AVITH.

Societal factors

Social norms and expectations of families
Mothers frequently described being the subject of strong value judgements and feeling as though their families were open to scrutiny and criticism in a way that other families seeking support were not. Sometimes this scrutiny was expressed as coming from within the family unit or from extended family, and at other times it was from service providers. Practitioners also noted the way social expectations of families can impact on isolation, stigma and preparedness to seek help.

A failure of services and systems
Participants – mothers and practitioners – universally described a failure across the spectrum of human services to support young people with disability and families where AVITH occurs. A significant thread emerged about specialist DFV services. While mothers described variable understandings of disability, the primary lament was the extent to which “mainstream” DFV services were ill-equipped to fully support young people with disability and their families.

Implications for policy, practice and future research
A key finding was the extent to which service systems broadly, but the DFV response system specifically, appear to be ill-equipped to support the needs of young people with disability using violence and the needs of families to be safe from harm. The “siloking” of knowledge and expertise around disability and family violence is likely to be a contributing factor. The lack of DFV literacy in disability policy and services and the lack of disability literacy in DFV policy and services appears to be a significant impediment to effective responses to this very complex issue.

Limitations
Implications for future research, policy and practice that emerged from this study need to be considered within its limitations. The study included a small number of mothers,
representing a small number of families, and a small number of practitioners working across a range of sectors and settings. That we were unable to include the views of young people with disability means that the findings represent an adult-centric view of AVITH.

Next steps
An immediate and practical knowledge translation and exchange activity from this project is the development of resources to build literacy about young people with disability across the DFV response system. While this research shed light on the lack of disability literacy broadly, the desire for practical information to assist service providers to better understand, support and respond to young people with disability was a consistent message we heard from practitioners and other people we engaged with during the project.

Conclusion
This exploratory qualitative research offered insights into the intersection of AVITH and young people with disability from the perspective of mothers who have experienced violence at home, as well as practitioners who work directly with young people with disability and AVITH. Our aim was to generate new knowledge and to lay the foundations for a much-needed dialogue about the issues and experiences of young people with disability and AVITH. This research, although small in scale and exploratory in nature, adds to a growing body of evidence about the significant detrimental impacts for children, young people, women and families when research, policy and practice in disability and violence prevention and response remain “siloed”. This project adds to the voices calling for urgent action.
Introduction

This report presents the findings from our exploratory qualitative research that aimed to generate new knowledge about the intersection of adolescent violence in the home (AVITH) and young people with disability. The research responds to a need across multiple sectors and workforces to establish a deeper understanding of the contexts in which young people with disability engage in violent behaviours (Centre for Excellence in Child and Family Welfare, 2020). The need for evidence-informed policy and practice arises due to concerns about the disproportionately high rates of young people with disability receiving family violence services and/or legal responses to violent behaviours at home (Campbell et al., 2020; Campbell, 2021; McCausland & Baldry, 2017). While there is a distinct area of policy, practice and research that focuses on young people with disability and challenging behaviours, it appropriately sits outside of the domestic and family violence (DFV) context. The conundrum remains, however, that the two areas – disability and DFV – do intersect in practice and policy when young people with disability and their families encounter the DFV response system. The focus of this research sits at this intersection.

The research draws on the insights of mothers of young people with disability as well as the perspectives of practitioners working across a range of sectors and disciplinary fields. From in-depth qualitative interviews, a rich body of data emerged about the contextual factors and processes that may be associated with AVITH and young people with disability. We located these across the four levels of the socio-ecological model – individual, relationship, community and societal – to illustrate how the dynamics and interactions among personal and environmental factors can affect the lives of young people and families. Although findings represent participants’ perceptions, families who experience AVITH and practitioners who work directly with young people with disability have a particular intimate and personally relevant knowledge to share. We acknowledge from the outset that not including the perspectives and experiences of young people with disability is a critical piece missing from this project.

Central to this report is the way language shapes our understanding of AVITH, both in relation to the genesis of behaviours and what can be done to guide appropriate prevention and response. Words matter and thinking about terminology is important. How disability is understood, and the way language and concepts regarding disability are used in research, policy and practice, can have material consequences for young people with disability and for families. It can, for example, impact on how service systems respond and work together, as well as the development of interventions, supports and therapeutic approaches.

Our prior conceptual review, Towards a socio-ecological understanding of adolescent violence in the home by young people with disability, provided an overview of the dominant fields of thinking in the general AVITH literature (Sutherland et al., 2022). We found that established ways of framing the problem of AVITH borrow heavily from DFV, but that violent behaviours by young people with disability do not easily fit within these prevailing theoretical or explanatory models. We also noted debate in the literature about the most appropriate language to use to examine the issue of young people with disability who use behaviours that are violent at home, including disciplinary differences in preferred terminology. We draw on that material here and begin with an explanation of the central concepts and terms in this research report.

Concepts, terminology and language

Adolescent violence in the home (AVITH)

Harbin and Madden (1979) were the first to consider violence used by children against their parents as a unique form of family violence, describing it through the prism of the parent experience. Though more than four decades have passed since they first described “battered parent syndrome”, there remains a lack of a universally agreed upon definition, and no common language to represent and describe the issue of young people with violence in the home (Holt, 2016).

A range of terms have been used to describe the complex social issue of young people using patterns of violent, abusive and intimidating behaviours against parents, carers and/or siblings. These terms include “child-to-parent violence” (CPV), “adolescent-to-parent violence and/or abuse” (APV/A), “adolescent family violence” (AFV) and, more recently, “adolescent violence in the home” (AVITH).
As the study progressed, our research team returned numerous times to consider how to appropriately describe behaviours within the context of this project. On the one hand, there is a significant body of research concerning challenging behaviours and young people with disability. Much of this literature relates to children, young people and adults with intellectual or developmental disability. Displaying behaviours that challenge is not a diagnosis, and the field is dominated by behaviourist approaches that define the term mostly in relation to how other people understand its impacts. Emerson’s work is widely cited and refers to a range of persistent behaviours that puts the person with disability and/or other people at risk of harm, and detrimentally impacts on inclusion, participation and quality of life (Emerson et al., 2001). While there is no behaviour or set of behavioural characteristics that are classified as “challenging”, the term is used to denote behaviours that may be an adaptive response to other factors.

On the other hand, terms like AFV are derived directly from the DFV literature and encompass a narrower range of intentionally harmful, violent, abusive and coercive patterns of behaviour directed towards others in the family as a means to exert power and control (Holt, 2013). While there are commonalities between the terms “challenging” and “AFV” in relation to patterns of behaviour with harmful outcomes, the terms are not interchangeable. There are important practical, social and ethical reasons not to conflate the terms, including the risk of further stigmatising one of the most highly marginalised groups in the community.

For this report, therefore, we elected to use “AVITH”. We use this term to encapsulate the complexity and diversity of circumstances that give rise to young people’s behaviours that are violent and that pose risks to family safety (Campbell et al., 2020). We acknowledge that there remains much work to be done to reach agreement, both within and across sectors, about the most appropriate definition and language to use to examine and respond to this issue.

We also acknowledge that not all people understand or experience “home” or “family” in the same way. As one of our project participants noted: “We know that families come in all shapes and sizes and are different for everybody.” (P12)

In this research project we refer to “home” as encompassing a range of family-based care arrangements including relative, kinship and foster care, but we have not considered violence used by young people in institutional-type settings (e.g. residential care, emergency/crisis, supported accommodation), even though familial-type relationships may be present in these settings.

In recognition of the diversity of neurodevelopmental trajectories from childhood to adulthood, this report adopts the World Health Organization’s (WHO) term “young people” to include adolescents, typically defined as between the ages of 10 to 18 years of age, and youth (or young adults) covering the age range 15 to 25 years (WHO, 2011).

Finally, given the importance of language in shaping research, policy and service responses, we strongly argue for using distinct terms to examine the issue of violence used by young people in their familial relationships with parents, carers and siblings, as opposed to young people using violence in other settings and contexts including, for example, intimate partner violence (IPV) in early dating relationships (sometimes referred to as adolescent dating violence; ADV). The drivers and reinforcing factors for IPV, including that perpetrated by adolescent boys and young men, are reasonably well established (McNaughton Reyes et al., 2021). What we know about the contributing factors for violence used against parents, caregivers and siblings is far more limited. The lack of evidence is even more stark in relation to AVITH and young people with disability.

Language used to describe violence

We have carefully considered the terms used in this report to describe those who use violence and those who are impacted by violence. We have avoided using perpetrator-focused language and instead opted to focus on behaviours used by young people. While the term “perpetrator” is commonly used to denote responsibility for violence in the DFV sector, the different language used in relation to AVITH appropriately acknowledges the complex pathways to violence for young people, including a background of trauma and victimisation. The shift away from perpetrator-focused terminology in the context of AVITH also aligns with policy and practitioner
preferences in a recent survey undertaken by the Centre for Excellence in Child and Family Welfare (2020).

We note that the language used by the disability sector to describe violent, abusive and threatening behaviours by young people with disability does not always accord with the language used by the DFV sectors or with that used in the AVITH literature. As previously noted, the terms “challenging behaviour” or “behaviours of concern” are sometimes preferred to “violence” in research about young people with disability. These terms acknowledge that there are a range of behaviours that can be challenging or concerning and not all of these involve violence towards family members. For young people with disability, it is particularly pertinent to adopt a language that does not conflate behaviours that may include violence in the home with criminal acts that constitute DFV.

**Understanding disability**

We use the term “disability” as described in the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD). The preamble to the CRPD, while acknowledging disability as an evolving concept, notes that disability results from the interaction between persons with impairments and the attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others. (United Nations General Assembly, 2007, n.p.)

This description, derived from a biopsychosocial or interactional model of disability, integrates insights from the “medical” and “social” models and, thus, acknowledges that contemporary understandings of disability are more nuanced than what is frequently referred to as a medical versus social dichotomy. Throughout this report, we consider the concept of disability as arising from the multifaceted ways in which impairments or health conditions interact with systemic and structural barriers within our society, with a particular focus on young people and their families.

We use the term “disability” – in the singular – as per the CRPD conceptualisation of disability as arising from social and cultural processes and interactions, and not as an inherent characteristic of a person (United Nations General Assembly, 2007). In doing so we offer a counter-narrative to much of the prior research on AVITH that positions disability as an individual-level attribute that is different and devalued, while overlooking the role of social and interactional factors in shaping young people’s lived experiences of disability.

In this research report, we have chosen to adopt person-first language to refer to “young people with disability”. Person-first language is the style that is most often adopted by service providers and government and reflects the preferred terminology in Australian policy. We acknowledge that there is no universally agreed-upon language choice and that identity-first language (i.e. “disabled young people”) is preferred by some people with disability, organisations and communities (Best et al., 2022).

We note additional considerations around language and concepts used to describe and define disability in diverse cultural contexts. For some Aboriginal and Torres Strait Islander people, for example, westernised and individualised concepts of disability do not accord with traditional beliefs about the diversity of the human condition (Puszka et al., 2022). Cultural contexts may influence whether or not people are less or more likely to self-identify or to identify another person as having disability (Clifton, 2020; Heneker et al., 2017; Mortimer & McMahon, 2018).
AVITH and young people with disability: The current state of knowledge

Prior research including several reviews of the literature have increased our understanding of the factors that place families at risk of AVITH, and the “profile” of young people who use violence at home (see Arias-Rivera & García, 2020; Moulds & Day, 2017; O’Hara et al., 2017; Papamichail & Bates, 2019; Peck et al., 2021a; Simmons et al., 2018; Toole-Anstey et al., 2021). While some reviews of the literature have noted disability as a risk factor for AVITH (Arias-Rivera & García, 2020; Hong et al., 2012; Moulds & Day, 2017; Simmons et al., 2018), these reviews have not drawn on research with a specific focus on young people with disability. Rather, disability has been conceptualised as a risk factor for violence because children and young people with disability are commonly identified in AVITH study samples.

That disability is conceptualised as an individual risk attribute is not unusual in research on AVITH because it is mostly studied through a particular lens – often a criminological one that focuses on incidence and characteristics to identify patterns of risk. As such, study findings tend to treat disability in binary terms by its presence or absence. There is a paucity of research that has attempted to examine the broader social context – that is, the behaviours and the social and interactional context of those behaviours – and none that has specifically focused on young people with disability who use violent behaviours at home.

Prior to commencing this project, we conducted a review of the international literature with the aim of identifying and synthesising evidence from studies of young people with disability and AVITH. Given the dearth of evidence available, we undertook a conceptual review with the aim of “knitting” together knowledge across topic areas and disciplines. The conceptual review covered three broad areas: 1) critical gaps in the evidence base pertinent to the experiences of young people with disability; 2) the dominant theoretical paradigms that inform policy and practice in AVITH; and 3) the contextual factors associated with AVITH and young people. This conceptual review – Towards a socio-ecological understanding of adolescent violence in the home by young people with disability – was instrumental in guiding this qualitative project (Sutherland et al., 2022).

Most relevant here is that our conceptual review revealed the lack of a theoretical approach for understanding how, and in what ways, AVITH and disability intersect. AVITH is a complex social issue, and unlike in adult-perpetrated DFV, there is only a short history of available theoretical frames through which to interpret the phenomenon (Holt, 2015). What is clear, however, is that the theories that underpin actions in prevention and response in DFV cannot simply be supplanted onto AVITH based on a set of similar characteristics. Although a framework informed by the intersecting fields of human rights, disability, public health and DFV may be relevant, currently there is no analytic lens from which to build an understanding of young people with disability and AVITH.
Project aim

This qualitative research aimed to generate new knowledge about the intersection of AVITH and disability. We drew on in-depth semi-structured interviews with family members of young people with disability and practitioners who work directly with young people with disability using violence at home. Our key objective was to use a socio-ecological lens to examine the contextual factors and processes that may be associated with AVITH and young people with disability at the individual, relationship, community and societal levels.
Methodology

Theoretical framework

Intersectionality
Our approach to this project was informed by the principles of intersectional theory and practice, reflecting our commitment to building evidence that appropriately acknowledges and addresses intersecting and interlinking forms of marginalisation. Although its theoretical roots date back to the early 1970s (Collins et al., 2021; Crenshaw, 1991; hooks, 1984, 1992, 1994), over the past several decades intersectionality has emerged as an important paradigm in both disability studies and scholarship on violence. However, little attention has been paid to how multiple social positionalities intersect to impact on experiences of AVITH. Our approach to intersectionality began, therefore, by challenging the assumption that all young people with disability share the same views, experiences and priorities irrespective of gender, age, cultural background, sexual orientation and other categories of difference. In the context of building evidence on AVITH, an intersectional approach reminds us to prioritise diversity over commonality.

Socio-ecological approach
Since it was first introduced by sociologists in the 1970s, the socio-ecological model has provided a framework to articulate how individual behaviour is influenced by a network of embedded interactions across the social ecology (Bronfenbrenner, 1979). Two decades later, Heise (1998) advocated for a socio-ecological approach to advance action on gender-based violence. She noted that this approach was broad in scope and allowed for a focus on the interplay of factors that lead to and enable violence against women to occur. Socio-ecological models or frameworks are now widely used in DFV research, policy and practice, and in many other disciplinary fields, to illustrate the multiple and interrelated levels of influence that protect people from or put people at risk of experiencing or using violence.

Although researchers working in AVITH have argued that socio-ecological approaches offer a template for understanding how and why young people use violence at home (Cottrell & Monk, 2004), to date there has not been a strong focus on theoretical models or their application in practice. In this research report, we adopt a nested four-level socio-ecological framework (as per Figure 1) as a heuristic tool to conceptualise AVITH by young people with disability and situate factors that emerged from the interviews at each level of the social ecology – individual, relationship, community and societal. The benefits of applying this multiple-level schema to our exploratory project is that it can act as a working template, providing flexibility for additional research and theory development to build from.

Figure 1: The nested socio-ecological model

Source: Centers for Disease Control and Prevention, 2002 (as cited in Dahlberg & Krug, 2002).
Challenges, limitations and adaptations

The original proposal for this research was to undertake in-depth qualitative interviews with young people with disability using violent behaviours at home, and family members who have experienced violence (recruited as two separate cohorts, not as dyads). We then planned to engage with sector stakeholders to consider how to understand the evidence emerging from the interviews in the context of how they viewed their practice. This approach to the research was designed to attend to the problematic lack of young people’s voice in the framing of AVITH. However, we experienced several challenges to involving young people in the project.

Many of the organisations we approached agreed that it was important to hear the perspectives of young people. As one practitioner noted:

I find it challenging to speak, certainly with any authority, about young people and the motivation behind their behaviours and whether or not it’s family violence or a reaction to family violence or reaction to their disability, or their mental health presentation, or substance use. I’m sure you’ll interview young people if you can, but how they speak about their disability, or their mental health diagnosis can be very different to how their parents categorise them or their carers. (P05)

We actively sought to recruit young people with disability, and many organisations disseminated information about the research project to families and young people with disability engaged in their services. However, we ultimately only received expressions of interest to participate in the project from family members, all of whom were mothers. As the research progressed, our team spoke with a range of stakeholders about other ways to engage young people with disability in the project. During the interviews we also asked participants about what we could do differently to engage with, and hear the perspectives of, young people. Practitioners noted that the complex support needs and significant trauma often experienced by young people with disability using AVITH meant that engagement in a one-off interaction with researchers, for example in an interview, was unlikely.

Practitioners’ recommendations for the research team were to consider using ethnographic approaches, which would require being embedded within therapeutic services, to work with service providers and to build trust and engagement with practitioners, young people and families over a long period of time. Practitioners described this long-term process of engagement as one of the features that characterises best practice in their work. They also noted it as one of the key barriers to quality and effectiveness in service delivery – that is, specialist services and supports designed to attend to the needs of young people with complex needs are often not funded sufficiently, or for sufficient periods of time, to build the level of trust needed to affect change.

These conversations revealed the previously undocumented perspectives of practitioners in multiple sectors grappling with the issue of young people with disability receiving DFV service responses to AVITH. In response, we refocused the project to capture practitioners’ perspectives. A limitation of the project remains, therefore, that the findings reflect a parent- (mother) and practitioner-centric view of AVITH, and not the views of the young people themselves. We have been mindful in conducting the interviews, interpreting the data and reporting the results to focus on the experiences of the participants (mothers and practitioners). Their views, perspectives and experiences are not intended to speak for young people with disability, nor assign meaning to young people’s behaviours. Despite this acknowledged limitation, to the best of our knowledge this is the first research that specifically examines the intersection of AVITH and disability from the perspective of mothers as family members who experience violence at home and practitioners who work with young people with disability.

Data collection processes

From July 2021 to February 2022, we conducted in-depth semi-structured interviews with mothers who had experienced AVITH and practitioners with expertise in AVITH and DFV, legal, community health and/or disability specialist services. All participants were from metropolitan and regional areas of Victoria, Australia.
In-depth interviews with family members/carers

Recruitment, consent and participation

Family members and carers of young people with disability were approached to participate in the research via the project team’s network of collaborators and community partners. This included disability advocacy organisations, national and state-based peak bodies for child and family and carer services, and peak bodies in DFV prevention and response. Discussions with these agencies early in the project shaped our recruitment strategies and determined how we engaged with families and carers.

A brief advertisement/flyer inviting participation was developed so that organisations could distribute details about the research project either directly to clients of their services or via other communications channels, such as organisational or community newsletters (e.g. Tandem eNews). These recruitment materials were carefully worded to focus on the behaviours that families might experience in AVITH (e.g. the young person damaging personal items, breaking things around the home, shouting, yelling or screaming, hitting or punching) and their impact (i.e. making other people in the family feel frightened or afraid). We heard a strong message, particularly from the disability advocacy sector, about the importance of language when communicating about the project.

To support informed consent for family members and carers who expressed an interest in participating, we provided a plain language statement and consent form, with Easy English alternatives. These project materials described the project’s purpose and aim, how the research was to be conducted, the types of questions we were interested in exploring and the project’s wider contribution to the field of AVITH. Participants were provided with an opportunity to speak to the academic researcher conducting the interviews and ask any further questions about the project and their involvement prior to taking part.

COVID-19 restrictions in Victoria significantly impacted recruitment. This was partly due to increased workload for services and practitioners supporting young people and families at the time, as well as the need to flexibly meet the needs and preferences of family members and carers as they experienced the challenges of working from home and remote learning.

Interviews and participants

Due to COVID-19 restrictions, all interviews were conducted by an academic researcher over the telephone or via Zoom. Interviews lasted between 55 minutes and two hours, with an average of 70 minutes. Interviews were digitally recorded with participants’ permission and transcribed for coding and analysis. Consent to participate was collected electronically and verbally and stored securely on the University of Melbourne’s cloud storage. A small gift voucher ($40) was offered to participants in appreciation of their time.

The interview guide was informed by our prior conceptual review of the literature (Sutherland et al., 2022). The interview questions explored the following topics: experiences of AVITH; participants’ perceptions of the underlying drivers of and contributing factors for AVITH; help-seeking practices; access to and utilisation of services; social and informal supports; and family safety and wellbeing. At the commencement of each interview demographic information was collected about the interviewee and the young person with disability (see Appendix A).

A total of 13 in-depth interviews were conducted with mothers who had experienced AVITH. Although we did not specify family or caring role in our selection criteria, all 13 participants were mothers. They were aged between 38 and 68 years of age. Three mothers were from culturally and linguistically diverse backgrounds; nine were from metropolitan areas, with the remaining four living in regional areas of Victoria. Seven mothers were single parents, while six were partnered in a two-parent household. Most of the mothers interviewed were also raising siblings of the young person with disability, with other dependent children living in the house. Two mothers were in full-time employment; seven were in part-time or casual working arrangements; and four were not in the paid workforce due to unpaid caring responsibilities. Seven of the 13 mothers described having an impairment and/or health condition; some talked about
their experiences of post-traumatic stress disorder (PTSD), anxiety and depression.

Young person with disability
Mothers shared their experiences of violence involving 11 young people with disability who were currently using violence at home. They were aged between eight and 21 years. Two mothers were interviewed about their past experiences of violence (i.e. experiences of violence when their child was young). Their children were currently aged 42 and 29 years. Ten of the 13 mothers reported that the young person using violence was male, two reported that the young person was female, and one mother reported that the young person who had used violence at home was a trans woman. One mother reported that their child identified as Aboriginal. Eight of the 11 young people with disability who were currently using violence were receiving a National Disability Insurance Scheme (NDIS) support package.

During the interviews, the mothers talked about the complexity of their young person’s impairments, disability and support needs. Co-occurring neurodevelopmental, intellectual and/or psychosocial disability was frequently reported, including combinations of specific conditions/diagnoses of autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), oppositional defiant disorder (ODD), conduct disorder (CD), parental attachment disorder (PAD), sensory processing disorder (SPD), auditory processing disorder (APD), pathological demand avoidance (PDA), pervasive developmental disorder (PDD), PTSD, anxiety and depression.

Practitioner interviews
Recruitment, consent and participation
Practitioners were recruited through our early engagement with the project team’s network of collaborators and community partners, and later as we expanded our contact with organisations and services that were interested in contributing to the project.

We developed a brief advertisement/flyer that could be distributed to relevant organisations inviting participation from practitioners working across the multiple services and sectors that support young people and families experiencing AVITH. This included disability support and advocacy services; DFV services; child, youth and family services; specialist AVITH program providers; and legal services and supports. We used snowball sampling whereby participants were asked to identify other people within their organisation or networks who we could approach to participate. ANROWS additionally supported recruitment by including a call for participants in their newsletter, Notepad.

All practitioners were provided with a plain language statement and consent form and had the opportunity to speak to the interviewer and ask any further questions about the research project and their involvement. The ongoing impact of COVID-19 restrictions on all health and social services in Victoria was significant. While practitioners expressed interest in participating, some were ultimately unable to do so due to work demands.

Interviews and participating practitioners
All interviews were conducted by an academic researcher either over the telephone or via Zoom. Interviews were between 40 and 90 minutes long, with an average of 50 minutes. Interviews were digitally recorded with permission. Consent to participate was collected verbally and electronically and stored securely on the University of Melbourne’s cloud storage. The interview question guide was designed to complement interviews with family members and carers. We had already completed some interviews with mothers prior to commencing recruitment of practitioners, so we were able to build early learnings into the interview guide. Questions included experiences of how AVITH presents for young people with disability in their services, perceptions of the underlying drivers and contributing factors for the use of violence at home, and perspectives on the services and supports available to young people with disability and their families. At the commencement of each interview, demographic information was collected about each practitioner to place in context their work and experiences (see Appendix B).

We conducted 16 interviews with practitioners working in disability and advocacy organisations; specialist AVITH services; community health organisations; community care and case management; child, youth and family therapeutic
services; family and parenting programs; and specialist community legal services for young people. The practitioners who participated in the study included disability advocacy managers, DFV therapeutic specialists, DFV policy advisors, social workers, senior case workers, DFV lawyers, practitioners specialising in complex and multiple disability and specialist DFV advisors. Nine of the 16 practitioners worked in organisations based in regional Victoria; the remaining were from metropolitan areas of Melbourne. All but one practitioner was female.

Analysis of data
Transcripts generated from the interviews with mothers were coded and analysed separately from transcripts generated from practitioner interviews. Coding of the two sets of transcribed interviews, supplemented by detailed interviewer notes, commenced as soon as there was sufficient data from each group to begin code generation. We used both deductive and inductive qualitative data analysis methods (Braun & Clark, 2006). Our initial review of a subset of transcripts from interviews with mothers was used in a deductive process drawing on key concepts documented in our prior conceptual review of the literature. This early deductive analysis was undertaken separately by two researchers, and then discussed to build in the inductive themes emerging from the data. We then repeated this process with a subset of interviews with practitioners and cross-referenced with themes emerging from the interviews with mothers. From here the two coding frames were developed and the remaining interviews were coded using NVivo research software.

Ethical considerations
This research project was approved by the University of Melbourne Human Research Ethics Committee (Ethics ID: 21759.1). In line with ethical requirements, all those involved in the project were provided with detailed information in a plain language format and had an opportunity to ask questions about the project and their involvement. All participants were over 18 years of age and were able to provide independent voluntary consent.

We were mindful that we were asking participants to share sensitive, potentially distressing and highly personal information about their family circumstances, their own experiences of violence and their professional practice. We approached data collection with a deep sense of awareness that participants, as well as project team members, may experience emotional reactions to the research process.

Of note, our data collection coincided with Victoria’s fifth and then sixth COVID-19 lockdowns that involved restrictions on movement and social interactions, school closures and work-from-home directives. These rules were in place in Victoria from July 2021 to October 2021. This added an extra layer of complexity to our ethical considerations for participant and researcher safety and wellbeing.

In response to these complex ethical considerations, we developed a safety protocol to guide the researchers interactions with interviewees, with particular attention paid to minimising participant distress and responding to emotional distress if it occurred. The protocol drew on existing ethical and safety guidelines for engaging victims and survivors of DFV in research, and on the prior work undertaken by members of this research team (e.g. Vaughan et al., 2016). The key tenets of the safety protocol were guided by a trauma-informed approach that included:

- openly and clearly expressing respect for the autonomy and decision-making of participants, ensuring they were aware that they had choice and control regarding their involvement in the research process
- forewarning participants about the sensitivity of any specific questions, reinforcing that they could elect not to respond to particular questions
- mindfully proceeding with questions and discussions out of respect for the participants’ pace and direction, as well as communication and accessibility needs
- phrasing questions about participants’ decisions or actions in a non-judgemental manner
- avoiding excessive questions or seeking information that would evidently cause distress
- offering a pause or bringing the interview to an end, with the participant’s permission, if the impact of the questions became too negative or distressing.
Although some participants did respond emotionally during the interviews, no situations of significant distress or discomfort arose. No participant withdrew from the study. Rather, most participants expressed an appreciation for being able to share their family story. Some of the mothers interviewed specifically described being dismissed and silenced in the past and welcomed the opportunity to talk about their experiences, describing it as “therapeutic” and a place to consolidate their thought processes and sense-making practices.

I’ve told this story so many times. I want to tell it. I’ve been telling it because I’ve been asking for help for a long time ... because there’s more me’s, there’s more [siblings], and there’s more [son with disability] and we’re all suffering terribly. (M05)

All participants were provided with written information about relevant national, state and local information, advice and support services. Due to the complex nature of AVITH, this included information about mental health (Lifeline, beyondblue); DFV (1800RESPECT, Safe Steps); carer support (Carers Victoria); sibling support (Siblings Australia); and holistic family services (drummond street services).

In this research report, care has been taken to protect the anonymity of participants and their contributions to the project. We have not used participant names but have employed numeric identifiers, prefaced by either “M” to denote a mother or “P” to denote a practitioner. We have withheld specific details about participants in situations where that information may be potentially identifiable. Some direct quotations have been minimally edited prior to inclusion in this report to aid readability. We have taken care to ensure the intended meaning has not been altered.

Reflexivity statement

Reflexivity is a process of critical analysis of the positionality and power that researchers occupy in the research process and in the production of knowledge (Rankl et al., 2021). It is recognised as a core component of qualitative research. This project brought together a team of seven researchers (five project investigators, one postdoctoral fellow and a research assistant) from different disciplines and career stages to explore this vastly understudied area. It was important for us to critically reflect on how our personal and professional backgrounds, interests, assumptions and life experiences shaped our approach to the research and, ultimately, the knowledge produced. We were particularly mindful about our positions of power, including when making decisions about whose voice was amplified in the data we presented. In this reflexivity statement we share our disciplinary composition and the ways in which we practiced reflexivity.

The research team concentrates on several areas of expertise: women’s health, gender, disability, social and health inequality, prevention of violence against women, family and young people and migration and displacement. At different stages of the project, we engaged in reflexive and critical discussions of our understandings, assumptions and biases as a team and attempted to balance our positions. This was not always seamless; our reflexive practices were not always “comfortable”. It did, however, provide opportunities for assumptions and interpretations to be challenged. In writing this report, for example, we engaged in critical discussions about the interpretation and reporting of research findings and the limitations of our methodological approach. We engaged in discussions about ways to disseminate knowledge about this very complex and largely hidden issue that were respectful and empathetic and did not contribute to the further stigmatisation and discrimination of young people with disability.
Discussion of key findings

In this section of the report, we present and discuss key findings from the interviews with mothers and practitioners. The style of this section is intended to present a critical discussion drawing on theory and research on AVITH interwoven with key findings from the interviews.

Initially we provide an overview of experiences of AVITH, including the types and targets of violence, how behaviours are interpreted and understood by family members, and the impacts of AVITH on families. For this overview we drew mostly, although not entirely, on the interviews with mothers.

Next, we used the four-level socio-ecological model (as described earlier) as an organising framework to situate the themes that emerged from the interviews. In this section, we bring the perspectives of mothers – as family members who experience AVITH – together with practitioners who work with young people with disability in the context of AVITH. However, this approach is not intended to conflate their perspectives. Rather, we acknowledge their different world views and have used their distinctive perspectives to develop a more nuanced understanding of this issue. We have used illustrative quotes from each group and note that while the perspectives of mothers and practitioners frequently aligned, we have used counter examples to demonstrate where views diverged.

We begin by focusing on factors or processes at the individual level, including:

- a background of violence and trauma
- violence as an expression of power imbalances
- the intersection of gender, disability and AVITH.

We then focus on interpersonal factors in the immediate family unit and its support systems. These relationship factors include:

- the impact of violence on siblings
- stigma and social isolation
- the contested role of parenting.

Next, we describe the settings that make up community-level factors, including:

- support and early intervention
- the perceived impact of transitions on behaviours at home
- the role of the NDIS as part of a multisectoral response to AVITH.

In the final section we focus on factors at the societal level, describing the norms, structures and practices that impact young people with disability and their families, including:

- social norms and expectations of family
- a failure of service systems.

Overview: Experiences of AVITH

The mothers interviewed for this project shared stories that were characterised by strength and resilience. They were motivated by a strong desire to see change happen and to ensure other families experiencing violence at home did not encounter the same services and systems that they felt had so abjectly failed them. Practitioners were similarly motivated by wanting change to happen but for different reasons; they were mostly driven by the stark lack of evidence to guide and inform their professional practice. As previously noted, no young people with disability were interviewed: this is an important perspective missing from this project.

Types and targets of the violence

The mothers interviewed for this project spoke about complex circumstances and experiences of violence. They described experiencing overlapping and repeated forms of violence including verbal and emotional abuse (shouting, screaming, yelling, swearing and humiliation); property damage (to other family members’ belongings and the family home); and physical violence (hitting, kicking, punching, throwing objects). Although less common, a few mothers described violence by young people that involved threats or use of weapons such as knives and bats. Most mothers noted that
violence had been part of their family’s lives for a very long time. In this context, mothers spoke about constantly needing to be “on guard” for violence to occur or escalate. “It’s like walking on glass, broken glass – you never know when the explosions are going to go off.” (M11)

Most mothers saw themselves as the primary target of their child’s violent behaviours, often because they were more likely to be present at home than other members of the family. This was frequently contextualised by mothers within the dynamics of the child–caregiver relationship, particularly in relation to safety, security, trust and companionship.

Making sense of violent behaviours

Participating mothers spoke about their experiences of violence in the context of their child’s disability. They perceived that the violence was used in the context of their child feeling stressed, overwhelmed, frightened or afraid, and, for some, not having any other means of communication such as verbal language, signing or other communication tools, familiar to or easily understood by other people. Understanding behaviours at home through a DFV frame also emerged as a significant thread, and one we continue to explore in latter sections of the report. Several mothers drew on their previous experiences of DFV to make sense of behaviours. Acknowledging behaviours as a form of DFV was often accompanied by descriptions of what they understood were central in DFV. This included, for example, when they felt threatened, intimidated or frightened by the behaviours, as well as when they felt they had to adjust their own behaviours, routines and family life due to threats or violence. As one mum noted:

I’ve been in intimate partner violence before, and it’s exactly the same feeling. I mean, it’s just another form of family violence, that you walk on eggshells, knowing that something can erupt at any time, and you will be at harm. (M01)

While some mothers made comparisons to prior experiences of violence, including IPV, they also expressed the vastly different power dynamics at play. Mothers particularly noted the complexity of responding to violence within a parent–child relationship. Many practitioners also described the way in which power dynamics (and intent) were often inverted in AVITH, highlighting the ways in which services are not readily aligned or adaptable to these particular circumstances:

This is not a traditional family violence dynamic, and it can be very hard for services to understand and to support the people, the victims as well as the perpetrator. That’s the other thing; the victim would want the perpetrator to be helped, not “Okay, lock that person up, they’ve hurt me.” (P01)

Perceived impact on families

Mothers spoke about their perceptions of wide-ranging detrimental impacts of violence at home, including direct effects on their own physical, social and emotional health. They were more likely, however, to express deep concerns about the impact of violence on the young person with disability, and on other children at home. This included how DFV response systems (e.g. police, courts, services) might contribute to trauma experienced by their child with disability. Mothers also talked about concerns for siblings having less access – physically and emotionally – to the concept of “family”: “My older daughter coped by going to the library to study, by working a lot, by getting out of the house.” (M10)

Several mothers spoke about having to make difficult decisions about managing safety at home, including the possibility of having to remove the young person with disability or their siblings from the family home, either for a period of time or permanently. Practitioners similarly spoke about the far-reaching effects of AVITH on whole-of-family safety and wellbeing.

It’s very, very traumatic. I’ve had families who’ve had to lock themselves in rooms and wait until the young person’s behaviours of concern – once they’ve calmed down a bit. So that can take minutes to hours where they’re locked in their room, just waiting for the young person just to calm down and be in a place where they’re approachable. So, the trauma, and grief, and sadness, and depression seem to be very common in these families. (P07)

Mothers talked about how supporting a child with disability had significantly altered their capacity to work, in terms of when, how or even if they could work. While there is a large
body of evidence about participation in, and patterns of, work among primary carers of children with disability (Brown & Clark, 2017), mothers in this project described that barriers to workplace participation were significantly amplified by experiences of violence at home. This was especially noted by those mothers heading up single-parent households or those taking the major responsibility for unpaid care work at home.

However, of greatest impact as described by the mothers was feeling alone – isolated and abandoned – behind the closed doors of the family home.

I think a lot of the stuff that happens for families like mine happens behind closed doors. There’s probably a lot more behaviour and stuff that goes on that people don’t ever find out about because it’s embarrassing to say, “Look, I’m pretty much controlled by my 16-year-old so he can feel safe, and in the meantime, he yells abuse at me and punches holes in the wall.” I mean, you’re not going to go around telling people stuff like that – it’s a very lonely and isolated place to be in. (M03)

Individual factors

A background of violence and trauma

Current and past histories of violence and abuse emerged as a significant theme across the interviews with mothers and practitioners. This included prior and current experiences for mothers who frequently identified as victims and survivors of DFV. This finding is consistent with the general body of literature in AVITH that adversity in childhood, including exposure to violence and abuse in the home, is a significant predictor of AVITH (Contreras & Cano, 2014; Kennedy et al., 2010; Margolin & Baucom, 2014). Within this context, prior research has also signalled the importance of intergenerational transmission of violence (Peck et al., 2021b). This literature typically frames violence used by young people as a learned behaviour – that is, early exposure to violence, often in the context of exposure to IPV, predicts its later use.

In this project, however, mothers didn’t perceive that violence used by young people was “learned” or “copied”. They were much more likely to draw connections between experiences of violence and trauma, and its complex and multigenerational impacts. As one mum noted: “I’ve had trauma in my background, which I’ve always been very aware of. I had a very critical, narcissistic, controlling father.” (M10)

While some mothers reflected on their backgrounds of DFV and the extent to which that trauma may have impacted on their parenting practices and/or responses to violence, others noted the direct impact of violence on their child with disability. This included violence observed beyond the boundaries of family life. Practitioners similarly reflected on how trauma manifests through violence experienced in and out of the home, and its significant and complex impacts for young people, families and service providers.

Violence as an expression of power imbalances

AVITH is a complex form of family violence that doesn’t always neatly resemble violence perpetrated by adults in familial relationships. In Australia, however, commonly used definitions of AVITH draw on similar concepts to describe how and why violence happens (Cottrell, 2001). This includes the use of violence to exert power and control over others. For mothers participating in this study, the use of violence by young people with disability to feel “in control” emerged as a strong theme. However, mothers were more likely to describe that the purpose or intention of the violence was not to exert power over others but as an expression of an imbalance of power.

He [my son] describes it as being in the boot, not in the driver’s seat, and – because he’s heard the Hulk say that in a movie, so he’s saying, “I was in the boot.” (M13)

The concepts of power and control were described by mothers as important to their experiences of violence at home, but most often in the context of the young person with disability having little agency, power or control over their lives. The need to exert control in situations when young people were feeling out of control was often described by mothers as a point of escalation towards violent behaviour: “And the problem is that she [daughter] has so little control over so many things in her head, that she exerts control through her behaviour.” (M01)
The issue of intent, however, was not always clear cut, and was often a secondary consideration in the face of more pressing needs. Many mothers spoke about the complexities of balancing the care, safety and needs of the young person with disability using violence and care and safety for themselves, siblings and other family members. The following scenario recounted by one mother illustrates this complexity:

The police officer arrived to serve the intervention order. And he just looked around the living room and said, “Well, what happened here?” And I said, “Oh, I told her that you were serving an intervention order.” And he said, “What did you do that for?” And I thought I was supposed to. Being a parent, you try and prepare your kids for anything they have to deal with. (M05)

Gender, disability and AVITH

Gender emerged as a salient issue for mothers’ experiences of violence and was conceptualised within the context of their gendered position in families. Although AVITH is sometimes described as being less “gendered” than DFV perpetrated in adult contexts (Daly & Wade, 2016), this most often relates to the sex categories of those who are more likely to use violence (adolescent males) and those who are more likely to experience it (mothers, female siblings). Mothers in this study perceived they were targets for violence, not only because they were present at home, but because they represented safety, security and protection – “mum won’t leave” (P02). Some practitioners also observed this gendered dynamic whereby it was mothers who were most often targets of violent behaviours at home because they were the ones active in managing needs for support: “In my experience most of the people who stick around is mum, sometimes a sibling behind mum and sometimes dad stays but often he doesn’t.” (P02)

Similar to participants in prior research in the general body of literature on AVITH (Fitz-Gibbon et al., 2018), mothers who participated in this study perceived that it was their responsibility to place themselves at the centre of their child’s violent behaviours, often as a mechanism to shield or protect siblings and other family members. Indeed, this was a striking theme across mothers’ narratives: the conflict between the deep love they expressed for their child versus the need to keep themselves and other family members safe.

As one mother noted:

He was pulling knives and scissors on me. [His siblings] and I had to lock ourselves in my bedroom and barricade the door because of [son]. And he was on the other side of the door, kicking the door, and tried to open it. Normally I think I have to be around him, because I have to make sure that he’s safe, and this time I had to make sure I was safe. And I felt so bad making that call. (M04)

Relationship factors

Siblings

Mothers and practitioners perceived profound impacts of AVITH on family life and relationships, with a particular focus on siblings. Mothers raised concerns about siblings being directly targeted and harmed by violent behaviours as well as ongoing impacts on their physical, social and emotional health; problems with family and other social relationships; disruptions or inability to work; resentment towards parents; and a deep sense of sadness and loss. As one mother noted:

The impact on my younger son, who doesn’t remember a time before these behaviours, has been really significant initially by way of digestive problems, then anxiety, school refusal, and now has significant anxiety issues, where he cannot work, go into shops, talk to people he doesn’t know or even walk where there are going to be other people. (M05)

Mothers noted the challenges of keeping family relationships intact, especially during periods of significant violence. They noted the extent to which violence can change the structure and function of families.

You get to a point where you design your life around it – it’s sort of like when a river is going through the least – the path of least resistance, it’s a little bit like that. (M03)

One of the most significant impacts that mothers described, however, was violence used by siblings in response to ongoing exposure to violent behaviours at home. While mothers sometimes described situations where siblings used violence in retaliation, they also described behaviours used by younger
siblings as “learned”. Violence carried out by adolescents against their brothers or sister is underexplored in the context of AVITH. There is a larger literature, however, that explores the impact of chronic challenging behaviours on siblings of children, young people and adults with intellectual disability and other neurodevelopmental conditions such as ASD (Angell et al., 2012; Orsmond & Fulford, 2018; Yacoub et al., 2018). To our knowledge, this literature has not focused on early identification and intervention to ensure that cycles of violence in families are disrupted.

Stigma and social isolation

Stigma was a significant theme that emerged across the interviews; its impacts were located across multiple levels of the social ecology. We observed here a significant intersection between stigma and discrimination associated with AVITH and disability. Prior research suggests that stigma and discrimination about AVITH can impact on disclosure and help-seeking (Fitz-Gibbon et al., 2018). The challenging behaviours literature similarly describes parents’ fears of stigma as a barrier to participation and inclusion (Griffith & Hastings, 2014). Mothers and practitioners in this study noted how stigma, and a desire to keep the violence hidden for fear of further stigmatisation, also impacted on close family and informal support relationships. This included for the young person with disability, siblings and parents.

Several mothers described how negative attitudes and harmful misconceptions about disability from close family resulted in them feeling deeply mistrustful about reaching out for help when violence occurred. For families from culturally and linguistically diverse backgrounds, issues of social isolation were further exacerbated by prior experiences of stigma and discrimination about disability. Practitioners also recognised the particular difficulties around isolation and exclusion experienced by some migrant and refugee families.

For some people, disabilities are quite stigmatised so that person is hidden away, or the community might not know that there is a disabled child or young person in the family and so that community doesn’t necessarily help or actually hinders the situation around violence. (P01)

The contested role of parenting

The influence of parenting practices remains a contested area in relation to its links to AVITH, not least because this implied link contributes to the narrative that poor parenting practices are to blame when young people are violent at home. While mothers and practitioners expressed a range of views about the intersection of parenting, young people with disability and AVITH, their perspectives often diverged.

Mothers described a range of ways that their parenting “styles” or “practices” were entwined with their experiences of AVITH. Some mothers described self-education about disability and about child–parent relationships as the key material action they had taken after having their parenting skills and capabilities blamed or labelled “problematic”.

Many noted the wide-ranging advice they had received about supporting or managing behaviours at home, including for violence. They explained that while some of the recommended approaches were disability- and trauma-informed, others were punitive and ableist. There was a degree of frustration expressed by some mothers about the disconnect between information and support provided by DFV services, their understanding of disability and their experiences of being a parent of a young person with disability. As one mother noted:

I don’t know how that might sound to domestic violence counsellors, because they’d say, “It is the right decision to remove yourself from that kind of behaviour when it affects you so much.” But, I mean, how can you do that when you’re trying to get your daughter – keep her well; how can you do that? (M10)

Many practitioners who participated in this project were cognisant that they had much to learn about working with young people with disability and their families. They considered parents and “parenting” to be a key part of a systemic response to violence used by young people with disability. Several practitioners, however, acknowledged the potential for parenting practices to be disempowering for young people with disability, particularly among older children and adolescents who may need a level of support that would not be provided to a child without disability of a similar age.
Often the young person might be 17, but the parent or the carers might say, “Yes, they’re really eight” … which I think then has really big impact in the way that they view the young person. So, part of my work is… really trying to clarify, “Okay, what do you want to do here, what’s possible, what is non-negotiable this young person needs support for, what are some things that actually you might actually let the young person experiment or try to do on their own.” (P03)

Community factors

Early intervention and support

Mothers frequently described their experiences of AVITH through the frame of much-needed but inadequate or ineffective support. Most mothers in this study recalled a long history of engagement with services and had employed a range of strategies and techniques to manage behaviours that were challenging or concerning including violence (e.g. positive behavioural support). For the most part, however, they reflected on a significant lack of available, appropriate and timely support – for the young person with disability, for siblings and for themselves. The limited number of specialised services available for families with young people with disability with complex needs for support and/or the lack of options if a particular therapeutic approach was ineffective for managing or changing behaviours was identified by mothers as significant impediment to supporting family safety.

Despite recognition in the general AVITH literature that early intervention is critical for effective responses, mothers in this project raised concerns that often revolved around difficulties being heard, particularly in relation to early behaviours of concern.

A year in the life of a family that’s imploding, and a boy that’s starting to learn inappropriate responses to his challenges, is huge. It’s almost like a lifetime. (M08)

While practitioners also spoke about early intervention and support, engagement with services was sometimes framed in relation to differentiating between different cohorts of young people with disability. One cohort was described by practitioners as being characterised by a lack of early intervention and engagement with disability and other specialised support services. In this case, practitioners perceived the violence as arising largely from ongoing unmet needs – underlying physical or mental health problems that had not been adequately addressed.

They described a second possible cohort of young people characterised by extensive histories of engagement with intervention, treatment and support services, but for whom violence behaviours persist. Some practitioners suggested that in this circumstance violent behaviours may mirror those which are found within common definitions of AVITH – that is, violent behaviours that are intentional and used to gain power and control (Cottrell, 2001).

Transitions

Negotiating transitions for young people with disability emerged from the interviews with mothers and practitioners as a significant theme in relation to their perceptions of violent behaviours at home. They noted that violence seemed to escalate in frequency and/or intensity during times of transition for the child with disability, including in educational settings and transitions out of school, establishing and maintaining relationships with peers, and change or disruption to services and supports. While mothers were more inclined to discuss transitions in relation to emotional and social impacts, practitioners also raised the importance of considering physical and developmental transitions. One practitioner spoke in detail about puberty and young people with disability:

There may be a whole range of hormonal changes, a whole range of sexual thoughts, sexual feelings that are happening that are completely unaddressed, and are also often treated like deviance … So, you get this sort of permanent childhood that starts capping off at around 11 and 12 where the person’s cognitive level is perceived to be, and I think that probably does exacerbate the frustration of the young people who are unable to speak for that. (P02)

Schools were a particular focus for participating mothers, with many recounting their family’s long and complicated journeys through the education system. Their recollections about both “mainstream” and “specialist” schools highlighted significant stigma, discrimination and exclusion. Mothers
expressed particular concern for how experiences at school – being treated poorly by others, bullied, discriminated or made fun of – may have influenced behaviours at home. Reflections on transitions were significantly shaped by the disruptions caused by COVID-19-related lockdowns. As one mother noted:

She doesn’t have any contact with friends her own age anymore, since life has become, basically, trauma for both of us, under lockdown. It’s been very difficult for her friends to maintain contact. Because she also transitioned to high school in this period, but she’s never been in a class. So, she’s lost a lot of the friends from primary school. None of them are at her new school. But as I said, she hasn’t engaged with that new school anyway. (M01)

The role of the NDIS as part of a multisectoral response

Eight of the 11 young people currently using violence at home were receiving an NDIS support package, with a further two mothers noting that they were in the process of applying after prior applications had been unsuccessful. All of these mothers reported barriers to accessing and navigating the NDIS to support their child towards non-violent behaviours in the home. While many noted the significant administrative burden as a key barrier, practitioners frequently expressed frustration at the difficulties that families experience when seeking support in the context of AVITH. As one practitioner noted:

We know that there’s a real gap there [in the NDIS] around understanding disability and disability services and family violence. There’s a lot of learning to be done and I think there’s a lot of talking that needs to happen around trying to understand what the best approaches are. (P03)

While mothers and practitioners in this project clearly conceived of the NDIS as an important component of a multisectoral response to AVITH, there was much uncertainty and frustration about the extent to which AVITH was visible in relation to eligibility for the scheme. One mother shared her frustrations:

[son’s] case is so incredibly convoluted, with so many multiple problems that they [the National Disability Insurance Agency] just keep seeing the trauma and not the other stuff, and they consider trauma to be a temporary problem. But I, well I disagree, especially when it comes to children, because it’s shaping the rest of his life. (M11)

Societal factors

Social norms and expectations of families

While almost all mothers described feeling a deep sense of guilt and shame, many expressed this as a function of society’s expectations of how families “should” be, and the increased scrutiny that comes from deviation from expected norms and practices. Mothers perceived that they had been subjected to strong value judgements regarding how children should be raised and behave, and that they and their families were open to scrutiny and criticism in a way that other families seeking support were not. Sometimes this was expressed as coming from within the family unit or from extended family, and at other times it was from service providers. The outcome, however, was that mothers often felt compelled to handle challenging circumstances and violent behaviours in “private”.

Practitioners also noted the way cultural and social expectations of families can impact all components of their lives. They could see the way families were left behind by the systems designed to support them. One practitioner described the following scenario:

When her mum was asking for more respite, the case manager from the department said, “Well, when are you going to stop working?” So, it’s very much this idea that you need to just stop your own life and don’t ask us for anything; you need to do all this yourself. (P01)

A failure of services and systems

Participants – mothers and practitioners – universally described not just a high level of unmet need but a failure across the gamut of human services to support young people with disability and families where AVITH occurs. This failure spanned education, health, disability, social services, welfare, DFV and justice systems. There was little evidence of collaboration and partnership with services and professionals.
One mother described their family as pincushions underneath a spotlight of services. I don’t mind if all of it is coordinated and it actually makes sense, but all of these things operate in silos and none of them talk very well to each other. (M03)

While there were examples of good practice, most mothers spoke negatively about their interactions with individuals, organisations, services and systems. Most mothers were readily able to draw on examples where a failure of services and systems contributed to trauma for young people and families. The extent to which mothers and practitioners acknowledged that gaps across the specialist DFV and disability services sectors resulted in substantial added complexity and stress for families, particularly in moments of crisis. As one mother noted:

We were asking on a number of occasions, begging for help, for somebody to come and take him, or to find us somewhere for him to live, and Protective Services’ response was, well, it would have to be a prison cell, because we’ve got nowhere for him to go. They told us that the only way he could get help would be to have him admitted to hospital and then you refuse to pick him up, or that if he entered the criminal justice system. (M08)

A significant thread also emerged from the interviews about specialist DFV services. While mothers described variable understandings of disability, the primary lament was the extent to which the “mainstream” DFV prevention and response system was ill-equipped to provide appropriate support to young people with disability, or to families experiencing AVITH. Practitioners similarly described challenges about the “rigidity” of DFV service provision. As one practitioner noted:

Particularly with family violence counselling services, if the person who chooses to use violence is still in the home, often services will not take on a parent. So that makes it difficult. (P12)

This finding speaks to a well-known but significant shortcoming of services – they tend to have limited strategies, skills and funding models to support people living with, and who will continue to live with, someone using violence (Vaughan et al., 2016). Many practitioners noted the need for an intersectional and multidisciplinary approach where all those involved come together, allowing for an approach that can work across both spaces of disability and DFV services. Many DFV practitioners expressed a strong desire to see change happen.

I think if we, as [family violence] practitioners were educated more around disability – any education is going to improve our practice, and it’s going to benefit the young people and benefit – the outcomes are going to be better … We get educated on trauma and attachment, and strength-based approach and all sorts of theories, but nothing about how to work with someone with ASD or a disability. (P09)
Implications of the study

This exploratory qualitative research aimed to generate new knowledge about the intersection of AVITH and young people with disability by drawing on the insights and experiences of mothers, as well as the perspectives of practitioners working with young people with disability. From in-depth semi-structured interviews emerged a range of factors, processes and contexts that may be important to consider in guiding tailored approaches in prevention and response. We used the socio-ecological model as an organising framework to situate those contextual factors at each level of the social ecology – individual, relationship, community and societal. To our knowledge this is the first study to qualitatively explore the intersection of disability, young people and AVITH by considering the broader social context – that is, the behaviours and the social and interactional contexts in which those behaviours occur.

Limitations

Prior to considering the implications of study findings, it is important to acknowledge that we interviewed a small number of mothers, representing a small number of families. The small sample size means that the study findings may not be representative of diverse family experiences including, for example, experiences of Aboriginal and Torres Strait Islander families or migrant and refugee families. Missing from the family member and carer perspective is fathers, siblings and carers, particularly those providing out-of-home care for young people with disability. We also interviewed a small number of practitioners working across a range of sectors and settings. All participants were living and/or working in Victoria, and although this included metropolitan, urban and regional areas, their experiences may not be representative of people living in other Australian states or territories. Future research that expands to include diverse samples of families and family members, service providers and young people with disability is necessary to consider the extent to which the themes identified here are generalisable.

That we were unable to recruit more family members, carers and practitioners into the study speaks to the complexity and the importance of the work. It reflects the priorities of families and those providing services to families who are already under significant pressure in their day-to-day personal and professional lives. We were undertaking the study at a particularly difficult time in Victoria where young people, families and services (and the researchers) were facing the additional challenges of COVID-19 lockdowns including remote working, school closures and the loss of face-to-face service delivery. Some participants who did express an interest in taking part were ultimately unable to find the time to participate.

Finally, the study is limited because it represents adult-centric views of AVITH and not those of the young people with disability themselves. We acknowledge that until recently, disability has only been understood through the prism of mostly adults with disability – parents and health professionals – and that it is well past the time for this to change.

Implications for policy and practice

Keeping these limitations in mind, a key practical contribution of the current research was the extent to which service systems broadly, but the DFV response system specifically, was fundamentally ill-equipped to fully support the needs of young people with disability using violence and the needs of families to be safe from harm. We are cognisant that the DFV response system, and the services that sit within it, is vast and complex, comprising both mainstream services (i.e. police, other legal and health services) as well as specialised services for those experiencing and using violence. Findings from this study showed the greatest area of need was in circumstances where services and supports were predicated on the victim and survivor no longer cohabiting with the person using violence or planning to leave. This finding aligns with what we already know about shortcomings of some DFV policy and service delivery from research with other groups in the community that are highly marginalised such as migrant and refugee women experiencing violence (Vaughan et al., 2016). This is the first time it has been highlighted as significant barrier to services and supports among families experiencing AVITH from a young person with disability.

Our findings suggest that DFV response services trying to support mothers and families experiencing violent behaviours from a young person with disability need to understand the violence contextually – in this case, in the family home – and
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within diverse families. Although some of the behaviours and consequences of those behaviours may be the same as in other DFV contexts, the power relationships and contexts arising when a young person has disability are very different. We heard a strong message from mothers that balancing the needs of all family members – including the care and safety of the young person with disability using violence and care and safety for themselves, siblings and other family members – was not well understood or accommodated across the spectrum of DFV services. While both mothers and practitioners spoke about the profound impacts of AVITH on siblings, their experiences and needs for support were often neglected.

While some practitioners involved in our study were cognisant of this complexity, in the absence of tools, knowledge, collaboration and partnerships with disability services, family violence services find themselves falling back on notions of power and control to frame their understanding and responses to violence. They are additionally limited by tools they do have to support safety (e.g. the Duluth model, intervention orders, safety planning). In many ways, this “falling back” is also framed by prejudice and deficit-based understandings of disability. Mothers who had encountered the DFV response system and practitioners working within the DFV sector both described variable understandings of disability. Within this context, it is difficult to ignore the impact of “siloed” knowledges around disability and DFV as a contributing factor. The lack of a shared understanding, however, is not limited to only one sector or system.

This research, although exploratory and limited to one jurisdiction in Australia, also speaks to a lack of capacity in services that support young people with disability and their families where there are persistent challenging behaviours and experiences of violence that are a risk to family safety. Similar to the concerns raised in this study, prior research has also documented parents’ and practitioners’ concerns about challenging behaviour-specific service provision, including ineffective strategies being suggested, a lack of expertise, an “experts know best” philosophy that disempowers young people and families, and exclusionary practices (Dreyfus & Dowse, 2020; Mahmic et al., 2021; McConkey et al., 2013 Wodehouse & McGill, 2009). With growing concerns about the disproportionate rates of young people with disability in DFV services and receiving legal responses to violence, it is reasonable to suggest that young people with disability and families may not get to the point of crisis, or encounter the DFV response system (e.g. police, courts, specialised services), if earlier and targeted supports were readily available and accessible. Mothers in this study, although representing only a small group, certainly framed their experiences of violence at home around much-needed but absent support.

The lack of DFV literacy in disability policy and services and the lack of disability literacy in DFV policy and services appear to be a significant impediment to effective responses to this very complex issue. The impact of the lack of a common language, “siloed” knowledges and little collaboration between and across sectors is that young people with disability using violence and their families fall through the service gaps. Unfortunately, this finding is not new.

In the literature that traverses the specialist DFV and disability service sectors, it is a common finding that significant problems arise for people with disability – mostly women, children and young people – from a lack of cross-sectoral and cross-disciplinary collaboration. Within the stable of ANROWS-funded projects that have considered these interconnecting issues (Campbell et al., 2020; Dyson et al., 2017; Maher et al., 2018; Robinson et al., 2020), each has noted the significant disconnect between policy and practice in DFV and disability. The risks posed by sectors that do not have the resources or will to share their knowledge, skills and expertise have been noted in relation to women with disability accessing DFV services (Dyson et al., 2017) and justice responses to violence (Maher et al., 2018); legal responses to AVITH (Campbell et al., 2020); and mothers and children with disability accessing DFV prevention and early intervention services (Robinson et al., 2020). We now also raise this same problem in relation to young people with disability and AVITH and call for meaningful and urgent action to remedy the “siloing” of the DFV and disability sectors, workforces and knowledge.

**Implications for future research**

This project, although only small in scale and exploratory in nature, laid bare the significant challenges of untangling the
complexities of young people with disability and AVITH. As discussed in the section above on the limitations of the study, this project highlights the need for an investment in research that is sufficient, in terms of time and budget to prioritise the views, perspectives and experiences of young people with disability. There is also the need to consider the needs of a diversity of family experiences, and a whole-of-family perspective and then where the service blocks are in relation to appropriate, timely and effective supports. Focusing on these issues and priorities would also advance the field in terms of prevention – that is, what is needed to prevent or minimise violent behaviours in the first place.

Another area ripe for future research investment is a better understanding of the different policy settings under which considerations for young people with disability and AVITH fall. While the intersection of DFV and disability policy is crucial, there are many other policy actors in play – not least the rapidly transforming influence of the NDIS, a complex policy intervention that has the potential to drive better supports for young people with disability and families in the context of AVITH. This is certainly not the first research to document the significant complexity and difficulties that families face accessing NDIS-funded support (Carey et al., 2021). Our findings are novel, however, in relation to the interface between the NDIS and DFV and the extent to which eligibility for support extends to young people and families where AVITH occurs. Our project provides an ideal platform for future research to refine and elaborate on the role of the NDIS.

Finally, we note the need for research to explore the representation of young people with disability in Australia’s out-of-home care system. There are multiple reasons why young people with disability are in out-of-home care arrangements, including their experiences of violence, neglect and abuse in the home. Yet there are also concerns that families may turn to out-of-home services in response to young people who are violent when other service and support mechanisms fail to respond to risks to family safety (Children and Young People with Disability Australia, 2014). To date, however, information about disability within routinely collected child protection or out-of-home care data is woefully inadequate. In some states, data on disability for children and young people in state-based care is not even collected.

Next steps
An immediate practical knowledge translation and exchange activity from this project is the development of resources to build literacy about young people with disability and behaviours that are violent across the DFV response system. While this research sheds light on the lack of disability literacy broadly, the desire for practical information to assist service providers to better understand, support and respond to young people with disability and their families was a consistent message we heard from practitioners who participated in the study and from other people that we engaged with during the project. There was a particular interest in developing a deeper understanding of neurodevelopmental conditions such as ASD and other conditions relating to behaviours. Such a resource could be tailored for different parts of the system, including multi-agency services such as The Orange Door in Victoria, or for first responders such as the police. While we can draw on the themes that emerged from this project for these resources, having the input of young people with disability is paramount in development and dissemination.
Conclusion

This report presents findings from our exploratory qualitative research that aimed to generate new knowledge about the intersection of AVITH and young people with disability from the perspectives of mothers who have experienced violence at home, and practitioners who work directly with young people with disability and AVITH. From these interviews emerged a range of factors, processes and contexts that may be important to consider in guiding future research, policy and practice.

To the best of our knowledge, this research, although small in scale and exploratory in nature, is the first that specifically examines the intersection of AVITH and disability from the perspective of mothers as family members who experience violence at home and practitioners who work with young people with disability. It adds to a growing body of evidence about the significant detrimental impacts for children, young people, women and families when research, policy and practice in disability and violence prevention and response remain “siloded”. This project adds to the voices calling for urgent action.
References


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APPENDIX A:

Interview guide – Family members/carers

1. Demographic information

2. About the family
   • family life arrangements, caregiving responsibilities
   • relationships with other family members

3. Behaviours that young people with disability use at home
   • e.g. shouting, yelling, screaming; throwing objects; damage to property
   • circumstances, target of the behaviour, frequency
   • views on the intention to harm

4. Impacts of violent behaviour
   • on relationships with self, parents, siblings
   • access to support to help cope with difficult situation at home
   • feeling un/safe at home
   • physical and mental health, employment and/or education
   • future prospects

5. Types of services and supports that families receive, and the impacts/outcomes
   • formal/informal support
   • role of the NDIS
   • specialist support
   • crisis support

   • behaviours at home
   • usual activities
   • availability of and access to supports and services
APPENDIX B:

Interview guide – Practitioners

1. Demographic information

2. Role and responsibilities within the organisation
   • clients
   • role within organisation

3. Types of services and supports that the organisation provides
   • types of services and supports on offer
   • methods of engagement to connect with clients
   • key barriers and facilitators to engagement

4. Behaviours that young people with disability use at home
   • types of violent behaviours and the target of behaviours
   • why behaviours occur
   • access to support

5. Types of services and supports that families receive, and the impact/outcomes
   • formal/informal support
   • role of the NDIS
   • impacts on education and employment prospects of young people with disability and their family members
   • cross-sectoral collaboration

6. Questions about the impact of the COVID-19 pandemic
   • behaviours at home
   • usual activities
   • availability of and access to supports and services
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to Reduce Violence against Women & their Children
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