Northumbria Research Link

Do parents and carers experiencing violent and challenging behaviour from their children fit with a safeguarding model of support? Messages from a Facebook study

Abstract

This paper focuses on the experiences of parents/ carers of children with special education needs and disabilities who present violent and challenging behaviour. More specifically, the purpose is to explore how parents/ carers report how their support needs are met by social care services. This is a little researched community who express a continued desire to care for their children, often during much adversity and in receipt of little recognition or support from external agencies.

The study sought to explore how parents of SEND children displaying VCB experienced their world. Through an online, focus group. The research is an empirical study, which considers the challenging side of parenting children with additional needs. This is a phenomenon, which has largely gone unnoticed in research. Phenomenology is concerned with the exploration of experiences from the first person perspective, in order to uncover and unearth previously unnoticed issues. The study applied a participatory approach, with researchers and participants collaborating in designing and producing the research. Data from the study were thematically analysed.

Introduction

This article reports on themes emerging from an ongoing social media study of parents who experience violent and challenging behaviour (VCB) from their children with special educational needs and disabilities (SEND). The study seeks to explore how parents of SEND children displaying such behaviours experience their world, and this article specifically focuses on findings relating to how parents experience support through current United Kingdom social care systems. The term SEND is recognised and defined in Government documents and policy (Department for Education, 2015). Violent and challenging behaviour is a less-defined and more contentious term selected as a practical label by the study's participants. The experiences of these parents and their management of children's behaviour have been under reported (Ludlow et al., 2012, Coogan, 2014, O'Nions et al., 2018) and how they access and experience social care (adult and children's) has largely gone unrecognised though there has been more reflection on children's services, specifically in Ireland (Coogan, 2016). This is a little considered social issue with unknown prevalence and misunderstood consequences, particularly when many parents and carers are looking after children with hidden disabilities, such as autism, often with no formal diagnosis. There is, however, literature available which highlights the experiences of families that include a child with disabilities which indicate how a child's disability helps shape family life (Davey et al., 2015) and show how people with disabilities experience barriers to services (Shakespeare and Officer, 2014).

Whilst the prevalence of parents experiencing violent and challenging behaviour is unknown, the political and economic climate of austerity has created an increased demand for social work interventions amidst reduced public spending, requiring that more be done with less (Heslop and Meredith, 2019). A United Nations inquiry has found that people with disabilities have been disproportionately affected by UK austerity policies (Horridge et al., 2019; United Nations Committee on the Rights of Persons with Disabilities, 2016). Perceptions of declining access to services and support as autistic people reach adulthood is a reported worry for many families (Blacher et al., 2010). Preece and Jordan (2007), in their English study of social work with disabled children, suggest there is generally a too positive attitude about the ability for generic services to support families with an autistic child. Data from this study suggest that child to adult violence is underreported and misunderstood, allowing the support needs of SEND children and their parents/carers to go unrecognised. This study suggests safeguarding adults' processes are not available to parents/carers experiencing violence from their children.

Background to the study

In 2017, a UK-wide, BBC radio programme broadcast a discussion around children with SEND presenting violence towards their parents. The programme attracted contributions from a high volume of parents and carers sharing their own experiences, which significantly challenged existing assumptions that this was a comparatively rare phenomenon affecting only a minority of families. The issues highlighted during the radio programme prompted a series of discussions, which led to a national support group being created through a closed Facebook account. Social media platforms present convenient, easily accessible opportunities to connect with others experiencing similar issues. The Facebook support group proved popular and quickly attracted many more people, which suggests there is a community with similar experiences and adversities seeking support. Toma and Hancock (2013) suggest that self-affirmation theory can help explain rationales for people selecting Facebook sites to meet their needs and provide a haven when experiencing adversity. From its inception, the Facebook group established an important founding principle of not blaming the child; problems were contextualised as arising from a lack of adequate or appropriate support, rather than simply related to the child's difficult behaviour. The current research project emerged from this Facebook support group, with members invited to participate in a separate, closed online focus group.

Family violence and social care services

The recognition of violence within families and arriving at an agreed definition of what constitutes violent abuse has been problematic (Finkelhor et al., 1988), with Hörl (2007) concluding that:

> "Violence as a phenomenon is constructed by social groups according to selective perceptions that grow out of their special position in society. Therefore, some acts are not perceived as violent" (p.38).

Violence within families is most commonly associated with domestic violence and traditionally viewed as something that men perpetrate on women within intimate partner relationships; however, abusive behaviour can occur in any relationship. Statistics demonstrate that domestic violence is common, accounting for ten per cent of total crime and an average of two women each week killed by a partner or ex-partner in England and Wales (Women's Aid, 2017). In England there is no legal definition of child to parent violence and abuse, but depending upon the child's age, it may fall under the official definition of domestic violence, which is:

"any incident or pattern of incidents of controlling, coercive, threatening behaviour, violence or abuse between those aged 16 or over who are, or have been, intimate partners or family members" (Home Office, 2013).

Responding to adolescent violence in the family, the Home Office (2015) produced an *Information guide: Adolescent to parent violence and abuse (APVA).* Acknowledging that domestic violence relates to those over sixteen, this guide states "that APVA can equally involve children under 16, and the advice in this document reflects this" (p 3) and stipulates that ultimately APVA may be a safeguarding issue in relation to the child and fall under the jurisdiction of children's services.

The causes of child and adolescent to adult violence and challenging behaviour are multifaceted and little understood. The first large scale UK study of adolescent to parent violence, conducted by the University of Oxford between 2010-2013 (Miles and Condy, 2015), identified that the issue is subject to very little discussion within UK youth justice, domestic violence, policing and criminology systems. Child to parental violence is often portrayed as an intentional act: for instance, a Spanish study on child to parent violence reports that this includes acts committed by a child to intentionally cause physical, psychological, or financial pain to a parent (Calvete et al., 2013), or as an act of masculine violence from adolescent males (Baker, 2012). With children and young people with SEND, and particularly autism, such behaviour is commonly conceptualised as a *meltdown,* whereby the child loses control in association with their condition (Montaque et al., 2018).

The Facebook support group comprises of parents who perceive their child's violent behaviour towards them not as intentional, but as arising from their SEND status. The Home Office guidance therefore does not appear to fit the group's experiences and perceived support needs. To date, there has been minimal research in this area, with little evidence-based data available, and no specialist statutory training for frontline professionals who work with families. Social work assessments are concerned with risk identification, judgements and decision-making that are professionally and publicly accountable and statutory social workers have become increasingly concerned with responding to safeguard children and adults. Although social work is multifaceted (IFSW, 2014), childcare procedures (Munro, 2011) and an increased focus on adult safeguarding and risk (Lonbay and Brandon, 2017) mean that safeguarding has achieved paramountcy over all other responsibilities and tasks (Heslop and Meredith, 2019). There is, however, no unified safeguarding model of safeguarding support, because different systems and legal powers exist for adults and children. In the next section, we explore how English local authorities respond to their safeguarding duties.

Children's social care

The focus of contemporary social work childcare assessments is on safeguarding and the child's welfare is paramount. In England and Wales, the Children Act (1989) assigns to local authorities the duty to safeguard the welfare of children in need, look into child welfare concerns and make reasonable checks (with for instance family, health, education and police), and child protection enquiries (known as Section 47; s.47 CA89) to ensure children are safe and cared for appropriately. Parents are assumed to care appropriately for children unless assessed otherwise. Since 1989, safeguarding and child welfare has extended to include all organisations working with children (Children and Families Act, 2014) and local safeguarding arrangements reframed through placing a duty on local partnerships involving local authorities, any clinical commissioning groups operating in the area and the police to support children's needs in their area (Children and Social Work Act, 2017). Procedures in England have been updated through *The Working Together to Safeguard Children* (Department for Education, 2018) guidance, which details the appropriate actions professionals should take where there are safeguarding concerns. This guidance includes the *Framework for*

Assessment that focuses on parenting capacity, child's developmental needs and family and environmental factors. The other UK countries have adopted similar legislative/policy approaches, such as *Getting it Right for Every Child* (Scottish Government, 2015). The aim of any assessment is to reach a judgement; in relation to childcare social work, assessment is about identifying the nature and level of needs and/or risks that the child may be facing within their family. Childcare assessments are not easy or straightforward but they essentially focus services on the child's welfare with the implication that parental capacity could be viewed as lacking should the child be deemed in need or when there are welfare concerns. This focus on children's welfare leaves a gap where violence towards the parent is not identified or assessed. As adults it can be assumed that any assessment of parents' or carers' support needs would best fall under adult social care.

Adult social care

Section 42 of the Care Act 2014 places local authorities under a duty to make enquiries in order to decide what action should be taken in response to safeguarding concerns for certain - but not all - adults. Safeguarding adult policies, procedures and working arrangements must address domestic abuse that falls within the governmental definition presented earlier in this article. The safeguarding duty exists where adults with care and support needs are, because of those needs, unable to protect themselves from either the risk of, or the experience of abuse or neglect (Department of Health and Social Care, 2018: 14.2). Parents and carers of SEND children who present violence are unlikely to meet the remit for protection under safeguarding adults' processes unless they have care and support needs, for example, physical disabilities or mental health difficulties, in *addition* to their parenting role.

The Care Act 2014 places local authorities under a statutory duty to undertake assessments and provide information and services to promote the welfare of adults with care and support needs *and their carers*. Wellbeing is a broad concept, encompassing many issues pertinent to parents experiencing violence, such as personal dignity, physical and mental health and emotional wellbeing, protection from abuse and neglect, and domestic, family and personal considerations (Department of Health and Social Care, 6.16, 2018). Chapter 2 of the Care and Support Statutory Guidance (Department of Health and Social Care, 2018) sets out the local authority's responsibility to prevent, reduce or delay needs, making it clear that this applies to carers, and providing an example of how,

> "Some early support can help stop a person's life tipping into crisis, for example... a few hours support to help a family carer who is caring for their son or daughter with a learning disability and behaviour that challenges at home." (2.7)

Are parents carers? For the general purposes of the Care Act, a carer is defined as an individual who, "provides or intends to provide care for another adult" (Department of Health and Social Care, 2018, 6.16). This would seem to exclude parents and carers of SEND children under the age of eighteen and reinforce the idea that any care and support needs are the remit of children's social care. However, Section 60 of the Care Act places local authorities under a duty to conduct a 'child's carer's assessment' when a carer of a child is likely to have needs for support after the child becomes eighteen. For these purposes, a carer "...in relation to a child, means an adult (including one who is a parent of the child) who provides or intends to provide care for the child" (The Care Act, 2014, s.60 (7)). A carer has a right to request a child's carer assessment, although in the authors' experience this right is not well known and therefore rarely exercised. There is no age that the child must reach before which the parent or carer can request this transitional assessment. Taking into consideration the precedent that when young people with SEND have an Education, Health and Care plan under the Children and Families Act 2014, services must begin to prepare for adulthood from school year nine. There is the potential for

elements of the Care Act, which is viewed as exclusively adult legislation, to apply to carers of those as young as thirteen or fourteen.

Methodology

Conducting the research

The study sought to explore the experiences of parents/carers of SEND children who display violent and challenging behaviour. While the research question was very general, it was deemed to fit the wide scope of the study exploring an overlooked phenomenon with little empirical evidence. The research team comprised of five members: a parent of a SEND child who is the administrator of the Facebook support group and four academics, three with professional practice experience in different health and social care disciplines. A fifth academic member with 'safeguarding adults' expertise was recruited for the purposes of this article.

The research is an empirical study that considers the challenging side of parenting children with additional needs, a phenomenon which has largely gone unnoticed in research. Phenomenology is concerned with the exploration of experiences from the first person perspective, in order to uncover and unearth previously unnoticed issues (Doyle, 2017). Aspers (2009) describes empirical phenomenology as proceeding from the assumption that a scientific explanation must be grounded in the meanings and structures of those studied and that the actors' perspective is central in the analysis. The study applied a participatory approach, with researchers and participants collaborating in designing and producing the research (Chevalier and Buckles, 2019, McIntyre, 2008). Participatory action research has successfully been applied with diverse topics and groups, such as safeguarding adults and the independent sector (Simic et al., 2012) as well as patients and carers (Anderson et al., 2019). The administrator of the Facebook support group invited members to join the study that took place in a separate, closed, Facebook forum, which would act as an online focus group. Spence et al (2016) recognise that social media provides opportunities to explore and understand crises through the examination of responses to events as they unfold. The Facebook forum brought together a group of individuals online to engage in guided live discussion paralleling more traditional focus group methodology. Porta (2014) argues that focus groups are a particularly useful methodology when seeking to identify themes and collective identities of participants. The methodological approach and research practice of using a social media focus group is the focus of another article.

The study sought to maintain an actor-centred perspective, using the administrator of the Support Group as the facilitator of the focus group, posing questions to participants and monitoring the online discussion during real time. The administrator's lived experience as a parent and her interactions and discussions with members of the original Support Group, informed her construction of a series of questions which she posted for all participants to discuss. Overall, the focus group discussed sixteen questions. This article focuses on data arising from one specific question, which concerned their experiences of help from professionals and asked:

> Have you asked for help about SEND VCB from professionals, and who did you ask? (i.e. school staff, social services, police, healthcare professionals). What sort of help were you offered if any, did it actually help at all, and how supported did you feel?

This question initiated the online discussion involving research participants (n = 115) with the Facebook administrator providing further prompting and probing questions. Digital, online media services and social media are becoming an increasingly more commonplace mechanism to mediate

human activities. Utilising data from social media is a relatively new approach, which presents potentially unique rewards and challenges for social science researchers. The rewards reflect the potential ease of accessing data, particularly self-reported data, with relatively low financial costs. The challenges reflect the relative lack of control exercised by researchers when compared to more conventional face-to-face or questionnaire methods. There are distinct ethical considerations when using online data. Firstly, the boundaries between data belonging solely to study participants and information belonging to others is unclear, and in our case concerned children, other adults and professionals. Secondly, the boundaries between public and private information can be vague (Kosinski et al., 2015). Ethical approval was provided by Northumbria University. All participants provided their consent and pseudonyms were used so that their identities and locations were never disclosed to academic members of the research team. The administrator knew participants' identities and locations so that anyone presenting as highly stressed would be signposted to support services, and any posts presenting safety concerns could be addressed.

Data analysis

The focus group presented the research team with rich and in-depth data. The data were coded through NVIVO software package, memos drafted and reflected on by the research team (Saldano, 2009). Data were thematically analysed (Braun and Clarke, 2006) to generate themes exploring personal participation experiences. Thematic analysis has successfully been applied in focus group research (Porta, 2014), specifically on student perceptions of nursing programmes (McDonald et al., 2018). Porta (2014) and Stewart and Shamdasani (2015) highlight and detail the role of coding in analysing data from focus groups. To further validate themes and quotations draft publications (this one included) are forwarded to study participants before submitting for publication.

Research Findings

The project recruited 115 parents/carers to participate in the study. Most of the participants (n=110) were women and few were men (n=5). The participants reported they looked after 127 SEND children (96 male, 30 female and one child without data) who sometimes displayed violent and challenging behaviour. The age range of the children was between 3 years to 18 years, and with all but a few children aged under sixteen, most did not fall under English definitions of domestic violence (Home Office, 2013). The majority of the children looked after by the participants were classified by their parents/carers as diagnosed, or waiting on a diagnosis, of an autism spectrum condition, while nearly fifty children were identified with a learning disability/disorder and over thirty with, or suspected, attention deficit and hyperactivity disorder. The participants reported that most of the children were diagnosed, or suspected, as having more than one condition. Children could be represented in more than one category and the characteristics were reported by their parents/carers and were not independently verified.

Study themes

Whilst this article focuses on data from online discussions generated in response to one of the sixteen questions, a number of relevant themes emerged from the complete data-set, including the emotional scarring of parents and children, physical scarring of people and places, poor understanding and support as well as isolation and loneliness. These themes will be focused on in another article; this paper is concerned with what the data have to say about how participants' experienced professional support. The themes emerging from the data highlight how parents/carers experience adversity and show resilience in their daily lives. Themes specifically classified in relation to their experience of professionals' support are; persistence in accessing services, feeling excluded from services that are uncomprehending of needs, parental sense of blame, and seen as a potential risk to child. Each theme is illustrated through the written words drafted during the online focus group discussions. These

quotes are verbatim reproductions of these online discussions, including the typing slips, abbreviations and grammatical errors we all make during online conversations and therefore provide an authentic representation.

Persistence in accessing services

Many parents have become experts in the art of complaining, pushing for help and accessing any available support and training. There is a sense of being passed on from one service or professional to another over many months and years. Persistence in trying to access support is a common theme from the data:

> *If I had known then that asking for help was going to lead me down an almost five year, unnavigable maze of 'service land' I'm not sure I would have asked (Caroline White).*

Many seem to have a low expectation of the effect professional help will make but feel desperate enough to have some hope that it will and there is evidence of having to fight for services when:

> *There has been no help or support from school, we've had to fight and/or pay for any adjustments to be made (Jade Mitchell).*

There is a sense of frustration in the data of being unable to easily access services.

Exclusion from services which are uncomprehending of needs

Parents report feeling that professionals and services do not fully engage with them or recognise their ability and value as parents, and often referred them onto another service:

> *Social services told us to call the police, CAMHS initially refused to see him because he had ASD and they don't deal with that. Finally saw them a year later a fortnight ago and have heard nothing since (Violet Thornton).*

With another comment stating:

> *Social services didn't really take on board what we were asking for and instead offered us inappropriate adhoc support services which didn't meet either our son's or our own needs (Joan Richardson).*

Parents and carers reported difficulties in accessing services and when they did manage to access a service it tended not to understand their needs.

> *Absolutely!! It's shocking! We don't meet disabilities team criteria so can't even access it through that route (Barbara Robinson).*

A sense of frustration was evidenced through the forum discussions, particularly when:

> *Social care, on the other hand, useless and accusatory towards parents to start with and after continued pleas from us for help (children with disabilities team) nothing much forthcoming, until we reached breaking point (Charlotte Hughes).*

Blaming of parents

This sense of not fitting service requirements and feeling excluded from services led to many of the parents feeling blamed:

> *I think there was consensus that I needed help but I also felt under suspicion and blamed as my daughter did not present any of the behaviours I was describing during the school day (Caroline White).*

Parents reported experiencing their needs being minimised after it was identified they did not fit service entry criteria, with one commenting:

> *The manager and some of the staff told me it was all in my head. Despite him not ever joining in with the other children, totally avoiding contact, switching completely off, just staring at the other kids and holding his ears when it was noisy (Jean Carter).*

Professionals often attributed problems to a lack of appropriate parenting skills, therefore generic parenting classes were a commonly suggested solution, *"CAMHS said it was parenting and sent me on a parenting course. No other help ordered" (Tabitha Osbourne).* Another explained: *"They all said parenting classes were needed as it was all directed at me therefore I was the issue" (Louise Chapman).*

Seen as risk

The perception - and fear - of being seen as a source of risk to children concerned many of the parents. One described a rather confusing situation of receiving contrary advice from two different social workers:

> *One SW told me I should use a much more crosser angrier voice (that just escalated things) another SW said our son's VCB was being caused by tension at home and recommended our son be removed from the family home (so absolutely terrifying and sole destroying) to think we could lose parental rights to our son because we asked for help to manage his VCB (Amelia Davies).*

Another reported a similarly confusing experience when:

> *[I] asked for an assessment of R's [child] needs from social work as we were told this was the route to getting SDS [self-directed support], which would have paid for the 1:1 autism support worker I was paying for personally before my husband left us and we could not afford it anymore. This resulted in [named authority] social work accusing me of fabricating and inducing autism in R to "cover up for the results of your poor parenting"(Hannah Watson).*

The possible consequences of a child's VCB behaviour at school was brought to home with one parent when: *"after an incident at school the new head referred us to a safeguarding social services (who saw nothing to worry about)" (Elsie Morris)*. Another parent reported:

> *[We] were told definitely not Autism I could forget about that it was parenting and I was sent on a parenting course and referred to social services child protection team as they had resources CAMHS didn't have. Ended up under child protection even though the conclusion of the conference was that "the family were doing nothing wrong" (Harriet Parker).*

Discussion

The findings from this study of parental experiences yield stories that are sometimes harrowing and graphic, yet also represent admirable humanity and compassion in endeavouring to meet needs whilst battling poor understanding of their situation. Their stories relate to how they access, or are prevented from accessing, social care and social work support and highlight gaps in support services. In struggling to access services, the parents frequently experienced criticism and implicit and explicit questioning of their parenting. The gaps in services reported by study participants indicate that support needs routinely go unmet and, as a consequence of current assessment protocols, parents may be viewed as potential risks to their children, rather than as possible service recipients in their own right. The movement of social care policy away from universal public services and towards responsibilisation has focussed services on statutory rights and directed human and financial resources at protecting vulnerable children and adults from potential or actual abuse. Risks in social work are primarily responded to through safeguarding, and it is critical to recognise that this is not a neutral term. However well intentioned, when parents requesting support with their SEND child's violent behaviour receive a safeguarding response, they become stigmatised and subject to highly damaging assumptions that they must somehow present a risk to their child.

Services for autistic adults are fewer than those available for children (Graetz, 2010) and many autistic people may still be heavily dependent on familial support once they reach adulthood (Howlin et al., 2004). Many of the parents in this study expect to continue to care for their children into adulthood and long after parents can reasonably expect to care for their offspring. In previous research, parents of autistic children have reported that their biggest concerns related to uncertainty regarding their child's adult life (Little and Clark, 2006). Our study has highlighted the limited recognition of parental vulnerability, vulnerability that may well increase throughout the life-course as aging parents continue to care for adult children. The findings from this study raise a question of whether safeguarding responses emanating from either adult or children's services can support parents struggling to cope with their children's behaviour.

Limitations

A limitation of generalising this research is that the parents who participated represent a small proportion of the general community of parents of SEND children. While this sample is relatively small, it does allow an insight into the lived experiences of parents, enabling us to share this knowledge and information in order to better support parents of SEND children. The study emerged from the experiences of a self-reporting sample of participants who all share a common perspective, which they seek to promote. Consistent with principles of participatory action research, the participants directed their discussion and generated data with little input from the research team other than from the administrator. As a result, the study relies on the parents' definitions of disabilities, conditions, behaviours, challenges and diagnosis status of their children, and information and data were difficult to verify. The anonymous, online methodology restricts what we know about the participants and their children, and as information and data were solely from adults, children's views are not represented. Nevertheless, the themes emerging from this study are interesting in that they help illuminate family life of an unnoticed community of parents and indicate some implications for practice.

Conclusion and implications for practice

This research indicates a number of implications for social work practice. Firstly, there appears to be a gap in social services available to parents/carers who experience child to adult violence. Children's services seem an inappropriate avenue for support when their focus is on safeguarding children and not parental support or adult vulnerability. Adult services do not recognise this community of potentially vulnerable parents as triggering the safeguarding adults' process and therefore their needs go unmet and unnoticed. As parents age, their caring role may continue whilst concurrently they may become less able to manage the risks presented by their adult children. Secondly, social work is concerned with relationships and assessments, this study indicates that social work practitioners referred to in this study do not appear to consistently assess the needs of parents/carers looking after SEND children who present VCB in their own right. Finally, there are training needs for practitioners and this study suggests specialist training is developed to assess the needs and vulnerabilities of parents/carers looking after children who present VCB. The data suggest there are gaps in both adult and children's social care through which parents/carers in this study fall. More research is needed to investigate these findings and explore the skills and experiences of practitioners as well as children.

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