

A Practitioner Research Project exploring

What is the impact on a family of looking after a child with autism and/or learning disabilities who demonstrates violent or extreme behaviour?

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Abstract

National policy frameworks, such as Changing Lives, and Getting it Right for Every Child, have called for early intervention in Children and Families Social Work, and accentuate the need for transparent provision of services, and effective communication between practitioners and families. In this qualitative practitioner-research project, six carers of children with autism and learning disabilities were interviewed.

The study examined the experiences of carers of children with autism and learning disabilities, who exhibit violent or extreme behaviour. The findings confirmed the existing literature that carers experience a very high level of stress and exhaustion. They were often very concerned for their own mental and physical well-being, their ability to continue to meet the needs of their children, and the impact on the family as a whole. They worried about the potential for placement breakdown, and recommended an approach that better valued their own insight and expertise in caring for their own children, and more consistency and transparency in the provision of services. They felt that services were still too focussed on crisis management, rather than early intervention, and that professionals needed to be better able to communicate with them about the provision of services.

Introduction

Background to the project

This practitioner research project is part of an ESRC funded Knowledge Exchange Programme between Social Work, School of Social and Political Sciences, University of Edinburgh, City of Edinburgh Council and East Lothian Council. The aim of the project was to encourage culture change and practice development in Children and Families Social Work following a number of reviews of social work practice mostly recently that of the Munro Review of child protection in England.

The aim was to work with the City of Edinburgh and East Lothian Councils to build and support a culture of learning within children's social work services in order to maximise effective intervention with children and their families. It has been doing this through working on a Knowledge Exchange Project led by the School of Social Work and Centre for Research on Families and Relationships (University of Edinburgh). The project has had three main strands:

- Working with social work managers to support them to act as change agents to foster a learning culture, bring about changes in practice and in organisational culture
- Facilitating critical reflection groups with practitioners to build confidence in understanding and articulating effective practice in children and families social work
- Supporting small scale practitioner research projects around particular themes and practices that are consistent with what is known to be effective practice.

Policy context

Local and national policies highlight a number of areas that are pertinent when providing services for this client group. City of Edinburgh Council's policy of 'Creating a learning culture within Social Work' recommends that "we need to find more effective interventions which result in more children being able to have their needs met and remain safely within their own families and communities. ... I think that we can only achieve that with a strong learning culture in place that promotes and builds on the most effective engagement and practice." (Jeffries, 2013)

The policy cites the recommendations from The Munro Review of Child Protection (2011) as a basis for the future of children's services. Professor Munro recommends the development of a learning culture to encourage effective intervention with children and families. Munro criticised the "insufficient attention being given to whether children and young people are benefiting from the services they receive.... outcomes for children and young people [should be] the prime measure of whether the system is working well.... a top-down approach has also limited the system's ability to hear feedback from children, families or front-line workers about problems in practice...the review has set out recommendations that more attention is paid to the experiences of children, young people and their families and the effectiveness of help offered to them..." (Munro, 2011:129). The Munro Report also stressed "the importance of providing help at the earliest possible opportunity in order to improve outcomes for children, young people and families." (2011: 129-130)

Calls for change predate *The Munro report* and in Scotland *Changing Lives* was published by the Scottish Executive in 2006 as a template for social work services in Scotland. It recommended that services should “get better at preventing a crisis, rather than waiting for it to happen” (*Changing Lives* summary report, 2006:3); people that use services and family carers would have more control over the services they are getting; and people would have more of a say and take more of a lead in planning services, for example by having more say in their own assessments. “People who use services have little influence, having to accept what’s offered not what’s needed” (*Changing Lives* summary, 2006:9).

GIRFEC (Getting it Right for Every Child) is the national framework to help co-ordinate children's services across Scotland. The Scottish Government web-site states that “*Getting it right for every child* means for children, young people and their families:

- They will feel confident about the help they are getting
- They understand what is happening and why
- They have been listened to carefully and their wishes have been heard and understood
- They are appropriately involved in discussions and decisions that affect them
- They can rely on appropriate help being available as soon as possible
- They will have experienced a more streamlined and co-ordinated response from practitioners.”

It is these policies and reviews that form the policy context not only for social work practice in children and families but also for the Knowledge Exchange project and practitioner research project. As a senior practitioner in the Children Affected by Disabilities Social Work Team, I work with many children with autism and learning disabilities, whose violent or extreme behaviour has a severe impact on family life. This study explored the experiences of the primary carers of children who receive support and services from within the Children Affected by Disabilities Social Work Team. These children often displayed violent or extreme behaviour, and the primary carers were known to be under considerable stress in managing their children’s behaviour. This client group requires a large amount of professional resources, and often requires individually tailored responses with input from a wide range of professionals. The study aimed to explore how the demands of having a child with extreme or violent behaviour can impact on the family's ability to interact with the wider world.

The research aims to illustrate the severe impact that caring for a child with autism and/or learning difficulties with extreme or violent behaviour can have on the main carer and the rest of the family. The next section will explore the process of research before turning to a discussion of the literature relating to the topic, and then analysis of the findings.

Research Process

Methods

In order to identify families with children who met the criteria for the research project, I discussed with managers in the Children Affected by Disability Social Work team, and Barnardo's Intensive Behavioural Support Service which families would best meet the requirements of the study. This also allowed preliminary screening of those families for whom taking part in the study could have a detrimental effect on the family's well-being, for example as a result of the amount of stress that the family was already under.

This was a small scale in-depth study with six families. This approach was chosen to gather rich data that would highlight the specific experiences of these families. The in-depth and specific nature of the study will provide valuable insights about how families experience the behaviour of their children and reveal their perceptions about how professionals interact with them. This will provide valuable insights into how we can improve our professional practice as well as plan and prioritise services and support for the children and families with the most complex needs.

Individual face to face semi-structured interviews offered the most appropriate method of understanding the experiences of the family. It afforded them an opportunity to speak freely, without pressure from professionals, partners or family members. I used the answers from the interview questions to prompt further questions, to direct the interview towards the issues that affect them the most. As I did more interviews, I used themes from previous interviews to inform questions about issues that may be pertinent, whilst remaining conscious of the potential to bias interviews by suggesting certain themes. I returned to a point made in the context of new information, this reflecting back allowed me to confirm, challenge, or seek elaboration of the participants' account. (May, 1993)

I transcribed tape recordings of the interviews, and then coded the data according to emerging themes. Comparisons to existing literature were then made to place the findings in the context of the current evidence base.

Challenges particular to conducting practitioner research included time constraints within a busy work schedule, the nature of the relationship I had with the families, and tensions in relation to interviewing and presenting the views of clients, who could potentially be critical of my colleagues or the service as a whole. Interviewing the clients of my colleagues, and presenting findings that could be critical of the service also presented potentially awkward questions about how critical practice is embedded within the social work team.

There were also potential professional conflicts of interest regarding my role as a researcher, whilst being a member of the social work team. I felt, however, that having sent written explanations to my interviewees, they understood the differences between the roles of practitioner-researcher and social worker, and were happy to speak openly about their experiences. I was aware that this may have impacted on how they perceived me (Mitchell, Lunt, and Shaw, 2009).

Ethics

The Ethics Committee of Edinburgh Council agreed the research proposal before I could access social work records, or contact the participants.

I assured the interviewee that the recordings would be destroyed as soon as I had written up the research project. The families would also remain entirely confidential - I use pseudonyms throughout the transcription and report, and have done my best to ensure that they could not be identified by any circumstantial information. Discussion with the allocated social worker also helped to assess any potential harm to clients associated with the interview, such as whether they were under a particularly high level of stress. I also made it clear to the interviewees that they could stop the interview at any time, without needing to give a reason, and that participation was entirely voluntary.

Literature review

There is a significant body of literature that relates to families caring for a child with autism and/or learning disabilities and the impact it has on a family. The following literature review focuses on research that referred specifically to studies that considered the impact of this role.

Existing literature on the impact of looking after a child with autism/learning disabilities confirmed my own experience as a practitioner that severe behavioural difficulties as a result of autism and learning disabilities increased parental stress and could have a seriously detrimental impact on family functioning.

I read four main themes in the literature – The characteristics of Children with Autism; Impact on Family; What support best helps the family?; and listening to individuals, parents and families. I will discuss each of these themes from the literature before moving on to discuss the findings from the interviews in relation to previous research.

Children with autism

Understanding the needs and characteristics of the child with autism and learning disabilities and how it impacted on those around them was central to the study. I will briefly outline the literature on Autism Spectrum Disorder (ASD), to contextualise the needs of the children that the interviewees are looking after. ASD is a socially constructed diagnosis and changes in diagnostic criteria vary across time and country. ASD is a lifelong condition that is about four times more prevalent in boys, and is not influenced by racial, ethnic, or socio-economic status, and medical literature does not suggest any cures or treatment.

One of the earliest descriptions of ASD was presented by Kanner (1943) who considered the indicators of autism to be “autistic aloneness”, “desire for sameness”, and “islets of ability”, with autistic aloneness as the most fundamental (Frith, 1989). DeLong (1999) identified autism as defined

by three clinical features: impairment of reciprocal social interaction, impairment in verbal and non-verbal communication, and a markedly restricted repertoire of activities and interests. ASD involves a spectrum of qualitative deficits in social interaction; language, communication and play; and deficits manifested as stereotypes, perseveration and a narrow range of interests and activities.

Impact on Family

The literature strongly suggests that caring for a child with disabilities has a significant impact on the family. McCubbin & Patterson (1983) found that caring for a child with disabilities drained family resources; impacted negatively on family relationships and family activities; caused social isolation; and provoked grief reactions and continual worry about the child's prognosis and future potential. Kearney and Griffin (2001) highlighted carers' worries and fears about their child's development, and feelings of hopelessness. Quantitative research has also suggested that the increased demands due to a child's personal, medical, and educational needs may place parents at increased risk for stress and depression when compared to parents of typically developing children (Olsson and Hwang, 2001).

Attitudes widely held in society add an additional layer of complexity to the task parents undertake in caring for a child with disabilities. Many parents reported that coping with negative attitudes of others towards their child, including professionals, created an additional burden (Kearney and Griffin 2001), and experienced social stigma amongst other parents before their child was diagnosed (Dittrich and Burgess, 2012).

Literature indicates that there are factors, specific to parenting a child with ASD, additional to those experienced by parents of children with additional support needs. Khanna et.al., (2011) found that caregivers of children with autism had lower quality of life scores than the general population, and that the carer's level of functional impairment, social support, use of coping strategies, and the extent of the caring burden and behavioural problems influenced the caregiver's quality of life. Cadman et.al (2012) found that specific to ASD were significant associations between caregiver burden and the child's unmet needs in domains such as social relationships and major mental health problems. Dittrich and Burgess (2012) found that the impact of looking after children with ASD included decreased parenting efficacy, increased parenting stress, and an increase in mental and physical health problems compared with parents of both typically developing children and children with other developmental disorders. They also identified financial strain, time pressures, high rates of divorce and lower overall family well-being. Compared with mothers of typically developing children, mothers of children with an ASD reported significantly higher fatigue, including poor sleep quality, a high need for social support and poor quality of physical activity. Fatigue was also significantly related to stress, anxiety, depression, and lower parenting efficacy and satisfaction. Hayes and Watson (2013) also found that families of children with ASD experience more parenting stress than families of typically developing children or those diagnosed with other disabilities, such as Down Syndrome, cerebral palsy, or intellectual disability.

The severity of the child's ASD influences the level of impact. Lyons et. Al., (2010) found that the severity of the child's autism was the strongest and most consistent predictor of stress. Gray et. al., (2006) found that child emotional and behavioural problems contributed significantly more to stress

in mothers, parent mental health problems, and perceived family dysfunction than child diagnosis per se. However, Bristol (1984) found that regardless of the severity of the presentation, a child with autism presents unique challenges and stressors for the family.

Understanding these issues in very young children and their parents has important implications for intervention and long-term outcomes, and considering diagnosis alone is too simplistic. Sivberg (2002) showed that families of children with ASD rate their stress level higher than typical families, which reflected deterioration of social support due to stress on the family system. Thus, families with a child with autism may gradually lose their friends because of their limited availability. He found that social support is clearly important for families with a child with autism, but that it can be difficult for carers to find the time to access this support.

The literature also highlights the impact of caring for a child with disabilities on relationships between family members. Dunn et al., (2001) found that failure to receive and seek social support corresponded with increased levels of spousal problems, whilst Benson and Kersh (2011) found that marital quality was a significant predictor of maternal adjustment. Regarding the impact on siblings, Skar (2010, from Moeyson and Roeyers, 2011) found that children respond to a visible disability with compassion, but to an invisible disability with prejudice, doubt, and incomprehension, which may impact on sibling relationships with a child with autism.

Raising a child with ASD can also impact on the social support a family receives. Bristol (1984) found that families with a child with autism were less likely to engage in social and recreational activities than families without a child with autism. He found, however, that a well-functioning family with a child with autism is usually close-knit, able to express emotions, supportive of one another, and involved in outside recreational activities, partly due to the child's lack of adherence to social norms.

Although the majority of literature focuses on the more negative aspects of caring for a child with disabilities some researchers have published literature on the positive dimensions. Parents felt the experience of raising a child with an intellectual disability made them stronger and more tolerant of others (Kearney and Griffin 2001). Martin (2007) found that by developing a humorous outlook on life and finding humour in personally difficult situations, individuals can gain a new perspective and distance themselves from stressful situations, allowing them to cope more effectively with both stress and adversity, and consequently, enhancing their psychological well-being and functioning. The considerable positive impact of having a child with intellectual disabilities can occur concurrently with any negative impact (Glidden and Johnson 1999; Hastings and Taunt 2002). Experiencing both positive and negative feelings at the same time has been described as a "tension" for parents, whose joy in their child is also a part of the pain they experience (Kearney and Griffin 2001).

What support best helps the family?

Increased awareness, early diagnosis and early intervention are key themes that run through-out the literature. Awareness of current screening, diagnostic, and treatment methods increases the chance of early intervention, which can lead to better outcomes (Blackwell & Niederhauser, 2003). Gray et. al. (2006) highlight the importance of addressing emotional and behavioural problems in very young children with autism and/or developmental delay, and the need for early support and intervention for mothers, fathers and families. Dittrich and Burgess (2012) found that a lack of awareness and understanding of autism in many schools had a major impact on the childhood experiences of many

individuals and their families. Good autism awareness amongst pre-school staff and other professionals meant that children were recognised to have autism at an early stage and help was secured swiftly. They found that respondents felt that early diagnosis is crucial for early interventions to take place, and to limit the potential harm to the individual and family, such as social stigma and bullying, that can arise from misunderstanding a person's needs. Shyu et al. (2010) found that the experience of the diagnosis itself contributes to the way in which parents make sense of their child's disability, and found that the way in which parents explained their child's deficits impacted their personal well-being, their child's functioning, and the treatment methods chosen by the family.

"Families of children with Autism Spectrum Disorder are faced with a disorder for which aetiology is unclear and optimal treatment is contested. These families are thus often left navigating a complex and ever-changing course, all the while knowing that delays in accessing services could lead to poorer treatment outcomes." (Karst and Hecke, 2012:4)

Family support tends to focus on managing the difficulties that arise within a family. Kanna et al (2011:152) recommend "a multi-pronged intervention approach ... aimed at improving family functioning, increasing support services, and assisting caregivers in developing healthy coping skills." Dittrich and Burgess (2012) highlight how stresses on the parents and the family negatively impact on the diagnosed child and can often diminish the positive effects of intervention. A number of authors suggest interventions that aim to support parents. For example, Giallo et. al. (2013) recommend interventions to specifically target parental fatigue and its impact on families affected by ASD both in the short and long term. Sofronoff and Farbotko (2002) emphasised the importance of targeting Parental self efficacy in parents of children with ASD whilst Keen et al. (2010) reported that a parent-focused intervention led to greater improvement in Parental Self-Efficacy relative to a self-directed intervention. Research has also begun to move away from the deficit model of disability, instead focusing on the importance of positive perceptions of parenting a child with learning disabilities and ASD (Trute et al. 2010).

These findings suggested that Parental self efficacy in parents of children with ASD is malleable and amenable to brief, targeted intervention. Sofronoff and Farbotko (2002) also found that parents reported fewer child behavioural problems after intervention, suggesting that increases in Parental self efficacy in parents of children with Autism Spectrum Disorder can have a direct impact on the diagnosed child. Jones and Prinz (2005) stress the importance of valuing the caregivers' belief in their own ability to effectively parent their child, as parenting self-efficacy predicts the level of parenting competence. "...parents with higher parenting self-efficacy tend subsequently to demonstrate more effective parenting even in the face of challenging child behaviour" (Jones and Prinz, 2005: 358).

Listening to individuals, parents and families

A strong message in the literature was that more professionals need to listen to people with autism, and their parents and carers as experts in the needs of their own children (Dittrich and Burgess, 2012).

“Actually parents are experts about their family; parents know how daily routines happen and understand how each family member fits into routines. We have learned that how things work in the family is vital to finding the right way to support a child.” (Cox, Dunn and Foster, 2013: 87)

Cox et. al. (2013) found that professionals can offer well-intentioned suggestions that may not fit into everyday family rhythms. When professionals make suggestions that are outside of the family’s daily schedules, children do not learn how to apply their skills within their everyday life. They therefore suggest reflective discussions and not giving expert advice, to demonstrate confidence in parents’ abilities to work through everyday challenges. This provided more opportunities for parents to develop their own deeper insights and problem solving abilities as their children grow. They recommended 'coaching', through listening, asking guiding questions, making reflective comments, providing feedback and incorporating strategies into a plan.

Getting It Right for Every Child (Scottish Executive, 2008) also recognised that in order to improve outcomes for vulnerable children, agencies need to intervene earlier, in a better and more integrated way in response to identified needs and risks, and not when a threshold is reached to trigger action.

It is noteworthy that most interventions for ASD are evaluated only in terms of child outcomes, ignoring parent and family factors that may have an influence on both the immediate and long-term effects of therapy and support, and the importance of parenting and family factors on the well-being of the child. Although this study is small-scale, it will add to the body of work that explores how families experience the supports and services offered by social work, and will contribute to providing better targeted supports for children with autism and their families.

Findings and analysis

Four out of the six interviewees expressed very high levels of stress and were generally critical of services, whilst two interviewees recognised the stress they were under, but were more able to manage that stress with support and had a more positive view services.

Ludlow, A., Skelly, C., & Rohleder, P. (2012) conducted a thematic analysis of interviews with carers of children with autism, they identified five core categories: Dealing with challenging behaviour; dealing with judgements from others; lack of support; impact upon the family; coping and the importance of appropriate support. I initially used these five themes to categorise the data. However, I was mindful about allowing preconceptions from the literature or from my own experiences to influence how I analysed the data. I therefore used more objective categories which would include both negative and positive values, and which minimised the scope for biases as I coded the data. For example, I wanted to include positive behaviour, positive support from professionals, and positive judgements from others.

I was conscious about keeping a focus on the child, and the participants talked at length about the behaviour of the child. The direct impact on the family around him/her, including the impact on siblings and the relationships within the household, was a significant theme emerging from the interviews. Another category was the extent to which the family became isolated, and lost their social and support networks. I then noted an emerging theme of what coping and strategies were used by the carer or family, which included descriptions of how they were unable to cope, and how they attempted to manage the situations that they found themselves in. Finally, the families were

all keen to answer the question about the impact of the support that the family receive, with recommendations for how services could be supporting families better.

The following five categories therefore emerged from the data:

- The child: behaviour, well-being and development;
- The impact on the family of looking after the child within the home;
- The impact of looking after the child on the family's social interaction;
- Coping and strategies;
- Support from professionals and services, and recommendations for more effective interventions.

Some of the categories overlapped. For example, on-line forums and support groups could have been categorised under social interaction, coping strategies, or forms of support. Categorisation therefore became an iterative process, requiring categories to be re-defined, and revised to reflect the emerging themes. As I analysed the data, therefore it became apparent that each element impacts on another, so that "child behaviour difficulties ... contribute to parental fatigue, which in turn may influence use of ineffective coping strategies and increased stress." (Seymour et. al. 2013)

I will therefore discuss the findings from the interviews by considering what the interviewees said about each of the above categories.

The child - behaviour, well-being and development

This study will only consider the impact on the family of looking after a child with autism who demonstrates extreme or violent behaviour, rather than analysing which environmental, medical or genetic factors might influence the child's behaviour. As I analysed the data regarding behaviour, well-being and development, subsidiary themes emerged of: positive descriptions, development, unpredictability and impulsivity, and danger/sense of danger.

Positive descriptions of behaviour, well-being and development

Five out of the six families talked about how there were periods when they could manage their children's behaviour, and that it was a combination of external environmental stressors in combination with the child's autism/learning disabilities that caused their child's violent or extreme behaviour, rather than the child themselves being to blame for their behaviour. All the interviewees talked about how the child's autism led the child to react to environmental factors in a particular way, and about the developmental issues that the family had to manage.

All interviewees showed that they were putting the needs of their children first, and showed determination to do the best for them, even when it meant a high level of distress for them and their families. As one carer said: *"...trying to fight off a child that you love to bits, and ... then he can be his normal self, and it can be very difficult when you're physically hurt, bitten, scratched, and he has no understanding of that"*. This reflects what Kearney and Griffin found, as they highlighted the "tension" between the positive and negative aspects of having a child with behavioural difficulties (2001).

There were examples of how having a child with autism had positive aspects: *"Your children are climbing on everything, touching things, licking things, putting their tongues in the key-hole, and it's all that stuff that I find quite endearing. You know, it's quirky and sweet, and I think they're the loveliest children in the world"*.

Development

The interviewees all talked about how their children's development had been impacted by autism and learning disabilities. They talked about how their children need support to do everyday things, which impacts on their ability to function within the family and community. All interviewees confirmed the findings of DeLong (1999) that three characteristics of autism are: impairment of reciprocal social interaction, impairment in verbal and non-verbal communication, and a markedly restricted repertoire of activities and interests.

Four out of the six families talked about their children's inability to function socially, and to manage socially or educationally within a mainstream school, reflecting Gray's (1994) findings about the significant impact of disruptive and violent behaviour, inappropriate eating and toileting and inappropriate sexual expression. Two families referred to behaviour stereotypically associated to autism, such as 'spinning', and both emphasised that this behaviour was a result of stress and anxiety. Implicit in talking about their children's inability to carry out everyday tasks was the need for increased carer support.

Unpredictability and impulsivity were regular themes, which made it difficult for carers to plan their lives, and to understand the needs of their children. Outbursts were universal characteristics for all the interviewees, that impacted on the stress and anxiety of all the families, and which interviewees talked about as significant characteristics. The interviewees were often aware of what could trigger outbursts, but there were daily situations which could unexpectedly or inevitably cause distress, and the interviewees often found that known triggers would not always be responsible for an outburst. This included causing damage to property, bizarre behaviour, sexualised language, and physical aggression towards family members.

One carer said: *"It's unpredictability that actually wears you down, it causes a lot of anxiety, because you don't know what the next day's going to bring, and that is exhausting in itself."* The children all displayed positive behaviour for much of the time, but the families remained wary of the severity of aggressive or extreme behaviour when it arose: *"... from zero, he's up to a hundred within a minute... putting holes in the walls, he keeps smashing the car... the smallest little thing, like I've not read the right thing on his ipod, he just flips..."*

All interviewees talked about the lack of a sense of danger, and their children causing danger to others, examples included trying to open the car door when driving, putting fingers in sockets, or putting things in the microwave or toaster, running away when out in the community, wielding knives, or self-harming.

Impact upon the family

The interviewees described the impact on the family in very similar ways as has been described in the literature. The main direct impacts of behaviour on the family were:

- stress, anxiety, and deterioration in mental health;
- the carer's lack of any time for themselves;
- family relationships;
- the impact on siblings;
- financial and employment implications.

These findings echo Dittrich and Burgess's findings of the impact of behavioural difficulties being associated with decreased parenting efficacy, increased parenting stress, and an increase in mental

and physical health problems, financial strain, time pressures, high rates of divorce and lower overall family well-being. (2012)

Stress, anxiety, and deterioration in mental health

This was the primary finding on the impact of looking after a child with extreme or violent behaviour. Five out of the six interviewees described the ways in which violent and extreme behaviour had direct impacts on their mental health and ability to cope. There was a constant theme of the stress and anxiety caused by the unpredictability and impulsivity, which led two interviewees to talk about *“walking on egg-shells”*, and feeling constant fear of the child’s violent and unpredictable behaviour. This reflected Gray’s findings that parents in families with children showing violent or aggressive behaviour experienced high levels of stress (2002).

The interviewees often talked about not being able to cope, and worrying about breaking down emotionally. One interviewee talked about being *“in a big black hole”*, and having considered jumping off the Forth Road Bridge, whilst others worried about *“hanging on a thread”*, *“reaching breaking point”* or *“having a breakdown”* and having to be admitted to hospital, and having no one else to look after the children. The anxiety of what would happen to their children on the occasion of emotional breakdown was also a significant theme.

Lack of sleep was a frequent theme in four of the six families. This had a clear impact on the mental and physical health of the interviewees, and raised concerns about how this impacted on their ability to look after their children safely: *“I usually get between two and four hours sleep a night, for two years now ... it can't last forever. You just can't ... you're putting families in danger, I wouldn't hire a baby-sitter who had only got two hours' sleep for two years.”*

The carers’ lack of time for themselves

The carers felt that they were no longer able to live their own lives, with no time for their own social life, or their own interests. A regular theme was, in the words of one interviewee, that *“Life's very much an existence. It's not life, it's an existence”*.

The demands of constant care and anxiety about the safety of the children also meant that carers were unable to attend appointments and do daily routine tasks at home. The carers often used respite time for either catching up on sleep, or for giving much needed attention to their other children, rather than doing something for their own enjoyment or development. The importance of respite care was not only seen as an emotional break, but also as the only time that the interviewees could do the laundry, go to the hairdresser, the dentist, or the doctor, or fill in paperwork without the demands of looking after children who require constant supervision. One family had been banned from clinics because she had not been able to attend any appointments, and others talked about the demands of having to attend social work and school review meetings. This reflected Blackwell & Niederhauser's (2003) findings about the stresses of negotiating networks of professionals and supports.

Relationships

Lack of time and energy required many interviewees to prioritise the child with autism to a degree that impacted severely on their relationships with their partners, and their other children, with interviewees talking, for example, about *“no longer [being] husband and wife, only joint carers”*, and another whose husband had left because he was unable to cope. Caring for a child with autism had a big impact on relationships for four of the families interviewees, mainly because of the stress, and

lack of time for other members of the families. This echoes the findings of Dittrich and Burgess who reported families who experienced high rates of divorce and lower overall family well-being (2012).

Impact on siblings

The two interviewees who had other children without disabilities talked about the negative impact of the child's behaviour on their siblings, including the fear of their violent behaviour, and the need of the parents to prioritise the needs of the child with autism. This impacted on the ability of siblings, for example, to be able to bring friends back to their house without embarrassment, and for them to spend time with their parents. The two siblings both found it very difficult to understand the reasons for the behaviours, and both felt angry and frustrated at their sibling as a result. This perhaps echoes Skar's findings (2010, from Moeyson and Roeyers, 2011) that children respond to a visible disability with compassion, but to an invisible disability with prejudice, doubt, and incomprehension.

Financial and employment implications

Stress and lack of sleep also led to carers finding it very difficult to sustain employment, which led to increased stress for all the family. Two families talked about the impact of caring on both their employment and financial situations. One talked about her husband having to have multiple times off work, which has also affected them financially, echoing the findings of Dowling and Dolan (2001). Another talked about having to move to a bigger house to give their son more space, and because their relationships with their neighbours had deteriorated to the point where they had to move, they had to take on another mortgage to pay for a bigger house.

Impact on wider social interaction

From the category of the impact of looking after a child with autism on the family's wider social interactions, there emerged themes of isolation, support groups, and the judgements of others.

Isolation

The extreme or violent behaviour particularly impacted on the families' ability to go out with the child, as they were often not confident about managing their behaviour outside the house, for example due to concerns about the child running away, or becoming distressed. There were also examples of children hiding things, damaging property, and becoming distressed, self-harming and violent unless they could do an activity. These behaviours increased frustration and anxiety, and disrupted many aspects of family life. As a result, the interviewees all reported a loss of social life, because of the lack of time to invest in friendships, the practical difficulties of taking a child out, and the lack of people who could act as child-minders, either because it was difficult to find someone who would have insight into the needs of the child, or because the child would not accept other care-givers.

Isolation therefore became a significant theme from the data, as carers found it difficult to integrate their children into socialising with family and friends, as other children and families were unwilling to be subject to the threat of violent or extreme behaviour. The interviewees found it difficult to trust family and friends to look after their children, partly as they were often unaware of how to manage their behaviour, and partly because the children found it difficult to accept the care of others. For example: *"...the behaviour was so altered by this one night away [with their grandmother], that it was like they had been abused. That shook me probably more than anything, more than the diagnosis, the breakdown of my marriage, or anything like that. I think that was probably the worst*

point of my life, the day when I realised I was on my own...I spend all my time with the children. It's very lonely, I don't get much time for me, or being an adult, because it doesn't feel like being an adult any more. I don't really talk to grown-ups, and grown-ups don't really talk to me..."

Support groups

Three of the interviewees found support groups and on-line forums very useful, to be able to communicate for mutual support and advice. These groups allowed the interviewees to talk to other parents who would understand what they were experiencing, which they found useful for advice and guidance, as well as emotional support and the ability to speak openly without judgement.

Other carers of children with autism or behavioural difficulties were particularly useful as support, as they had similar experiences, and they could share the daily stresses and triumphs that were particular to children with autism. There remained barriers, however, such as finding the time and knowing about support groups.

Judgements of others in society

The interviewees talked about the difficulties of integrating their children into mainstream society, due to the lack of understanding of their behaviour as a result of their autism, bullying, and stigma. This perception that others found the behaviour of their children unacceptable led many to become more isolated. This reflects the 'negative burden' created by negative attitudes (Kearney and Griffin 2001), and social stigma (Dittrich and Burgess, 2012).

Coping and strategies

When talking about what the interviewees did to manage the child's behaviour within the house, themes emerged of coping, strategies, seeking outside support, and maintaining routines.

Coping

The interviewees often talked about ways in which they were trying to survive from day to day. All felt that they were often unable to cope, and were under a very high amount of stress in their daily lives. They also showed a high level of anxiety about not being able to continue the current level of stress, and the long-term effect on their mental health, for which they tried their own strategies. They were often very worried about the future, but felt unable to look to the future when they found the present so difficult to manage. One interviewee said that she could empathise with families who had "*driven off the Forth Road Bridge*", and that she "*had felt very close to that*", whilst others talked about "*trying to hang on*", and "*coming to an end point*". This was the most striking feature of the interviews, as this reflected the emotional well-being of the interviewees.

Strategies

The interviewees found difficulties in how to physically cope with the violence that the child was showing, particularly as they grew bigger, and the parents' physical health deteriorated. The interviewees often felt that they were physically unable to manage their child, and lacked strategies for intervening when their child was physically aggressive.

They were more able however to maintain routines, which were deemed to be crucial in maintaining consistency for children with autism. However, this also needs to be contrasted with

unpredictability and impulsivity, which was prevalent in the data despite the acknowledged need for firm routines.

Seeking outside support

The interviewees talked extensively about the unique understanding and insight that they had into their children's needs. This led to a belief that professionals need to listen to parents, as they had themselves developed the strategies and coping mechanisms for them and the children within the context of the family. This reflects Dittrich and Griffin's (2012) emphasis on the importance of involving parents in planning, and respecting them as the experts in meeting the needs of their children. "Actually parents are experts about their family; parents know how daily routines happen and understand how each family member fits into routines. We have learned that how things work in the family is vital to finding the right way to support a child." (Cox, Dunn and Foster, 2011)

The interviews confirmed Grey's findings (1994) that parents cope by using service agencies, family support, and social withdrawal. One particular emerging theme was the difficulty that carers had in asking for help, particularly when the provision of services was hard to understand, or if they felt that professionals were inconsistent in their approach.

The interviewees found it frustrating and patronising when professionals ascribed the behaviour of their children to a lack of routine or structure, and implied a deficiency in parenting. This led to criticisms of professionals who were not experienced or well-trained in working with children with autism, and two interviewees questioned whether it was more effort and stress to work with support services, than to manage on their own.

Support

Under the category of support, themes emerged of early intervention; attitudes of professionals; (lack of) communication; ability of professionals; systems; telling your story; (lack of) consistency; and positive examples of support.

"... the result of the section 23 [social work assessment] was that I had been having too much respite, and I honestly feel it's the only time I've been depressed. A lot of people talk about depression, and they feel sad, but I wasn't feeling sad, it was genuinely hopeless, demoralised, it was really difficult to keep going. I try not to be very emotional, and keep it together, and I think that's my character as well, but I felt devastated, and ... it was like I had completely given up, I felt absolutely spare..."

Early Intervention

All the interviewees were concerned that social work services were more concerned with crisis management than planned care, and that the mental and physical well-being of carers was not being safeguarded, despite the dependence that children have on their primary carer, and the cost that a breakdown in the placement would cause. They felt as a result that the social work system was not taking into account the stresses of looking after a child with violent or extreme behaviour, and that they were being pushed to breaking point. This created an unnecessary risk of placement breakdown, and they felt that it impacted severely on the quality of care that they could provide. Some interviewees had read the statutory guidance for social workers, and felt that early intervention was essential, but not being implemented, and that this was counter-productive and a false economy in the long term. None of the interviewees talked negatively about their individual social workers or support workers, but they found that if there was a more consistent approach and

a social worker allocated for the long-term, then they would be able to anticipate and prevent crises from happening.

The Munro Report (2010:6) points out the growing body of evidence of the effectiveness of early intervention with children and families, and The Munro review (2011:130-1) recommended that the Government should require local authorities and statutory partners to make sufficient provision for early help and to set out their arrangements to develop and implement this locally for children, young people and families.

Role of professionals

There was a general view that professionals were empathic, but were driven more by process and top-down considerations than meeting the needs of the family. *"I don't feel supported. I feel that the people who come are decent, and have listened, and I feel that they have been empathetic, but the process... I think the whole process I've been through is, to be honest with you, it's awful."*

Despite the evidence in the literature (Prinz and Jones, 1995, Gill and Harris 1991; Gray and Holden, 1992; Dittrich and Burgess, 2012) that the most effective support is collaboration with parents, and promoting Parental Self-efficacy, the findings suggest that there remains a top-down approach, which fails to respect the knowledge and experience of carers who are working with challenging behaviour every day. A strong message in the literature was that more professionals need to listen to people with autism, and their parents and carers (Dittrich and Burgess, 2012), as experts in the needs of their own children. As one carer said: *"I know [my son] better than anyone else, and I've found it massively frustrating that people aren't listening"*.

These findings suggest that the recommendations from the Changing Lives agenda (2006) are not being implemented, and that despite their expertise and knowledge, parents do not feel included in the provision of services. This was often linked to the feeling that systems are prioritised over human relationships, which the interviewees found very frustrating, particularly during times of crisis: *"I phoned my social worker, poured my heart out, cried my eyes out, only to be told that I'm not your social worker any more, you need to phone the duty team."*

Communication

The interviewees felt that a lack of communication from professionals often aggravated the uncertainty and anxiety that they felt about being able to manage care of their children. This led to feelings of being left to manage difficult situations on their own, and being left out of decision-making processes. They also found that different professional agencies did not communicate well with each other, and that there were often disagreements between agencies about funding, which one interviewee described as *"distasteful"*.

Many interviewees commented on the lack of communication from resource panels, which made it difficult for carers to understand the reasons for decisions being made. This led to a lack of trust with services such as education, health and social work, as they felt therefore that professionals were making decisions without proper planning, or for reasons such as financial considerations or professional self-interest, that were not about the best interests of their children.

There was also a frustration at the role of the panels who allocate services, and the quality and transparency of planning for respite and other supports: *"...from the social work side I feel that I don't have any faith at all. I don't feel there's any foresight or planning or organisation, it's only crisis management, all the time.... It's not that the people you talk to don't listen, I think it's the whole*

systems that are there. It's almost like you feel that there's another layer, and maybe they just need to put their toes in the water a little bit sometimes, and understand what the issues really are. I almost feel that in lots of jobs people get so removed, so what the people are dealing with, they've lost sight."

Sources of information

The interviewees found that books, courses, and on-line forums were the most useful sources of information. There was a common perception that professionals had insufficient practical knowledge or training about autism, and were giving ill-informed advice rather than listening and supporting. The interviewees felt that experience of spending time with children with autism was more important than theoretical knowledge, and that they should be given more respect as the experts in the lives of their own children.

Systems

Although the interviewees were aware of the general lack of resources, there was also a common belief that resources were not well used, as professionals were not listening, or properly assessing what would help families: *"I feel bad about complaining, because there's been a lot of support, I've been very saturated, but it's been inappropriate..."*

This was often related to a general confusion and frustration at the role of resource panels, and a call for more transparency, and carer involvement in assessments. This may have been a result of carers being frustrated at perceived injustices in the allocation of care, if they felt that the care being provided is insufficient, and that the scoring system for resources was unjust. Two of the interviewees felt frustrated that they would be given more resources if they started using drugs and alcohol, divorced their partners and lived in a smaller house.

There was a common suspicion that decision-makers lacked understanding of the realities of caring for children with disabilities, and that the panels felt very remote and lacked transparency. They often did not receive a sufficient explanation for decisions that were made, and felt that there were too many layers of bureaucracy.

Consistency

The interviewees found the consistency of workers to be very important, as it allowed them to build relationships with workers, and to have a consistent message to give to their children, who often need a high level of routine and consistency as a result of their autism. One prominent theme was the regular anxiety about what care would be provided with every time a social worker completed an assessment, and the negative impact of having support withdrawn or changed. This had a particular impact when the family was in crisis, and had to engage with a new worker, who often had little background information on the family, or when services were provided that created extra anxiety due to the child going to an unknown environment.

There was also frustration about a lack of organisational structure, and a *"piecemeal"* approach, which focused on reacting to crises rather than long-term planning. This was particularly detrimental given the needs of their children to have structure and consistency of people and environment.

Positive professional support

Positive feedback from the interviewees on professional support confirmed the importance of listening to clients, respecting their views and working alongside them in partnership. The interviewees all had positive relationships with individual workers, finding them in general empathic and “decent”, although the most productive relationships were with Barnardo's Intensive Behaviour Support Services (BIBSS), which was particularly valued.

“Only very recently have we received input from Barnardo's Intensive Behaviour Support Services, and I have to say what a breath of fresh air... he has done several home visits, and he's seen a great deal, and he truly understands, and to have someone like that who can say firstly, ‘you know what, I believe you, I've seen what's happening here’, and secondly to say, ‘right, OK, I'm going to try and help’, and thirdly to act as a go-between, between myself and school... he was there, and he witnessed what was happening, and he had also been to school earlier, and he could say, this is how he presents, this is what I can suggest”.

This approach gave more confidence to carers, and valued them as experts in the lives of their own children. The positive reaction to BIBSS reflects the findings of Cox, Dunn and Foster in their paper on coaching: “Parents said that their coaches exhibited confidence in them as they found solutions. Parents said they came to understand why certain strategies worked (or didn't work), and how to examine future challenging situations. By re-examining their perceptions and beliefs, parents became more mindful of what strategies were successful and what activities were the best fit for their child. Parents felt empowered and confident in their abilities to solve challenges that arise. These findings emphasize the importance of families feeling support and confidence in them from their providers. ... Rather than professional knowledge at the forefront of intervention, perhaps professional knowledge provides the backdrop for supporting families to gain their own insights in their own time to prepare them for a lifetime of successful problem solving”. (Cox, Dunn and Foster, 2011)

Implications for Practice

Early intervention

A strong theme in the data was that carers reported an exceptionally high and chronic state of stress, they were very anxious about placement breakdown and were constantly preoccupied by surviving day-to-day or trying to prevent a crisis from happening. Families clearly expressed that they needed services to recognise this and be there for them on an ongoing basis and not wait until they were at crisis point. The interviewees felt that services should not be waiting until crisis point until services responded to a crisis, which the participants felt could often be foreseen, as services were aware of which children were affected by autism, and should therefore be better able to anticipate problems before they occurred.

They were very concerned about the harm that placement breakdown would cause for the child, and also the extra resources that accommodating a child would require, as opposed to providing preventative support. The interviewees therefore felt that there needed to be a more structured, consistent, and coordinated long-term approach, with an allocated worker with whom they could build a relationship, rather than a new worker “parachuting in” when a crisis hit. They felt that services were aware of the child's needs, but were unable to anticipate problems before they came, even when families were able to warn services. This draws attention to the importance of workers

building relationships with families to safeguard their emotional well-being, and underlines the need for trusted and regular respite being available.

Information about services

Carers were frustrated with the lack of information about services, and also the lack of concrete and realistic guidance about managing behaviour, such as appropriate ways of physically restraining a child. Many carers found out about services, and discounts for activities for example, through informal channels such as other parents, rather than through professionals. One recommendation from an interviewee was a handbook of autism services.

Better training and awareness amongst workers

The interviewees felt that there needed to be better training and awareness amongst workers, particularly in mainstream environments, when workers were not experienced at working with individuals with autism. The overwhelmingly positive reaction to BIBSS confirmed the value of a 'coaching' approach, which respected the views of the carers, and promoted partnership working. As expected from their close relationship with their children, the interviewees demonstrated excellent insight into the needs of their children, and recommended a more collaborative approach, which would better respect their views and experience. This fits with the recommendations of the Munro Report (May 2011) for a more 'bottom – up' approach. This included more consistent plans that did not cause regular anxiety that services would be withdrawn, and that anticipated better where increased support may be needed.

Better communication with and between professionals

The interviewees wanted more transparency and involvement in decision-making, as they found the scoring system and resource panel hard to understand, and lacked trust in the reasons that panels gave for their decisions. They felt that panel members did not recognise the stress that they were living under, and the importance that consistent respite and other services had in preventing placement breakdown.

They also found that health, education and social work needed to communicate better between themselves and with them as primary carers. This included being respected as the experts in the lives of their own children, and consulted about what support would be most effective in meeting the needs of the child and the carers in meeting the child's needs.

Conclusion

There were limitations to the research project, which need to be considered in its evaluation. This was a small-scale research project, with a selection of interviewees, who are unlikely to be representative of the client group as a whole. However, the experiences of the interviewees should be taken into account in developing service provision, to inform ways in which support can be better directed to meeting families' needs. The interviews confirmed the findings in the literature about the severe impact of caring for children with autism who demonstrate violent or extreme behaviour, and about social supports needing to value the experiences and views of carers, and to be well coordinated in meeting the needs of children and families. Research literature and national policies such as the Munro Report, Changing Lives and GIRFEC are clear about the need for early intervention, multi-agency cooperation, and involving parents and carers in assessment and support. The findings suggest however that services are reacting to crises, rather than anticipating problems through consistent multi-agency planning in partnership with families.

Four of the six interviewees were generally critical of the ability of services to support them and their children appropriately, but it is also important to contextualise the findings in relation to the stress that the interviewees were under, and the fact that they often felt negatively about insufficient support at a time when council budgets need to be cut. Two of the interviewees were largely positive about social work and services as a whole, and the interviewees in general included positive impressions of individual workers.

I was particularly struck by the overall insight and articulateness of the interviewees, and the frustration that they experienced in working with services. The findings suggest that the most effective method of working with families is to value carers as the experts in the lives of their own children, and to 'coach' them in developing their own capacity to managing the behaviour of their children in a way that respects the unique circumstances of the child and family, which support the findings support the research of Cox et al. (2011) that behaviour support programmes that build parenting capacity, and enable families to develop their own solutions to the unique circumstances of their own families. This approach also meets the need for early intervention, where a more consistent approach to managing their child's behaviour helps families to avert crises and to access services more quickly when a crisis happens unexpectedly.

There remains the need for professionals in all services to be well-informed about the needs of children with autism, and what services are available. Better training for all staff in providing services for children with autism would help the identification of needs, and better advice and guidance for parents in how to access the appropriate supports. This is necessary for staff not only who are work regularly with children with autism, but also for staff in other areas, including resource panels, mainstream schools, where lack of understanding of working with children with autism can create additional problems.

Giving parents more choice about what services they can access through self-directed support, such as respite, play schemes, support workers, or 'coaches', would help to respect their expertise in the needs of their own families, and where they feel support is most needed. This would also decrease their dependence on social work and multi-agency systems to coordinate support packages.

However, it remains necessary for professionals to be well trained, well informed, and able to support and guide families. This requires listening to and respecting the views of carers in developing the most effective methods of supporting each individual family, and maintaining effective, consistent, and long-term relationships with both families and other professionals.

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