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A narrative inquiry into the role of advocacy and activism amongst mothers with a child diagnosed with an Autism Spectrum Disorder

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ABSTRACT

This is a qualitative study into the role of advocacy and activism amongst mothers who have a child diagnosed with an Autism Spectrum Disorder (ASD). Previous research specifically examining this subject recognises it as a development to combat societal isolation (Ryan and Runswick-Cole, 2009; Woodgate et al., 2008). This study seeks to examine the concept further. Five mothers participated in a Free Association Narrative Interview (FANI) to gain an understanding of experiences related to advocacy and activism. The participants were obtained through a snowball sample, whereby personal links were utilised. It demonstrates the importance of advocacy and activism to the participants and their children. A thematic analysis identified three key emerging themes. Namely, developing supportive relationships, negotiating educational approaches and preparing for their children's future.

KEY WORDS:	**AUTISM SPECTRUM DISORDER**	**ADVOCACY**	**ACTIVISM**	**INTERVIEW**	**NARRATIVE**

Introduction

A predominant theme of the aetiology of ASD is that of parental blame. For instance, a historic representation of the autism aetiology blamed parents claiming they '...lacked expressive affect...' according to Kanner (1943, cited in Timimi et al., 2011:56). Our contemporary approach to the origins of autism is consumed by genetic theories, which have not yet been validated scientifically (Timimi et al., 2011). Despite the lack of genetic evidence, is it possible that a scientific explanation is being used to attenuate a more covert form of blame on the parents?

The rate of diagnosis of ASD continues to grow, despite the causality still remaining tenuous (Elsabbagh et al., 2012). It has been suggested the increase in diagnosis of ASD is effected more by cultural trends rather that biology (Timimi et al., 2011). This hypothesis corresponds to a Social Model of Disability, which explains disability in terms of a failure by society to adapt to the diverse needs of all individuals (Oliver, 1983). Timimi et al. (2011) stress that the cause of ASD is less important, than the evolution of a more tolerant society. Woodgate et al. (2008) found many parents who have a child with an ASD expend a significant amount of time and resources, so that they can attempt to destroy the isolation and intolerance barriers raised by society. Many parents are therefore motivated towards finding a solution to eradicate negatives attributions associated to the ASD and to safeguard their child from discrimination.

Statistics represent mothers performing the main caregiving role to their child with a disability (Dobson et al., 2001). Previous research has demonstrated that the experience of mothering a child with an ASD is associated with: social rejection (Green, 2007) and having to give up work to assume the responsibilities of a full-time carer (Gray, 2006). Additionally, mothers report frustration at having to continually explain their child's behaviour (Woodgate et al., 2008). The documented significance of this experience has resulted in mothers being the focus of this study. Using a selective sample criteria restricted to mothers was not intended to disregard the experiences of other carers to individuals with ASD. It was driven by the need to address a shortfall in the research knowledge and to examine in more detail the role of advocacy and activism amongst mothers.

Research suggests parents may find themselves repeatedly challenging their engagement in low expectations generated by society in relation to their children with a disability (McKeever and Miller, 2004). These expectations generated by society have previously caused mothers to feel embarrassed and have even led to mental health problems, such as depression (Estes et al., 2000). Interestingly, Green (2007) found the burden of caregiving to a child with a disability is associated with social rejection, and difficulties maneuvering around poorly coordinated statutory support systems. The difficulty associated with obtaining statutory services places an additional burden on mothers of children with a disability, when compared to other caregiving responsibilities. It has been demonstrated that the experience of being governed by socio-structural constraints has emboldened parents in challenging them in order to support societal change (Woodgate et al., 2008).

Research in relation to advocacy and activist behaviour by Todd and Jones (2003) demonstrated that mothers may challenge healthcare professionals and this may lead to tensions and hinder the development of good working relationships. Additionally, research by Woodgate et al. (2008) suggested that mothers develop a form of expertise surrounding their child's needs. There was a reported motivation towards activism, as experienced mothers were willing to educate other mothers about the best strategies to promote psychological growth for their child (Woodgate et al., 2008).

The sampling approaches of both Todd and Jones (2003) and Woodgate et al. (2008) represent flaws that may have produced questionable results. Todd and Jones (2003) recruited their sample

through a mother's response to a letter highlighting the study's aims, and therefore response rates could have been increased in mothers who had a particular issue they wanted to voice. Woodgate et al. (2008) recruited through an advocacy support group, and therefore advocate tendencies may be increased. Both these sampling techniques may have produced biased towards parents who are already involved in advocacy and activism. This study has used a snowball sampling technique to yield a more representative sample.

A continuum to show the graduation from advocacy to activism for mothers who have a child with ASD has been developed by Ryan and Runswick-Cole (2009). It is strengthened and validated by the experiences of the mothers. They are presented as participating in roles of advocacy, individual activism and collectivist activism as a result of societal isolation imposed on their child with an ASD. The findings from this study are however limited as they were an outcome of a broader study that was assessing the experiences of mothering a child with an ASD. The concept of advocacy and activism could have been investigated further and more emphasis could have been placed on providing an in-depth knowledge of the subject. Within this study advocacy and activism is the sole focus. This was an intentional objective of this study, since there is a clear research gap.

The socio-structural constraints discussed reinforce the existence of the Social Model of Disability. Furthermore, Sunderland et al. (2009) argue that political policy frameworks regarding justice and equality embody values that unintentionally emulate negative portrayals of disability. Therefore, even within a political arena negative concepts around disability continue to exist, reinforcing societal views that inevitably impact upon the lives of individuals with disabilities and those around them. Enforced social policies are also derived from limited survey data that does not delineate the experiences of individuals with a disability, instead they measure dependency levels (Purdam et al., 2008). This prevents the effective measurement of equality, and therefore hinders effective evidence-based policy improvement. Legislation therefore sustains and reflects the negative inaccurate interpretation of disability, and therefore it is questionable whether it safeguards or harms individuals with a disability?

Oliver (2013) also contends that current social policy maintains the existence of societal barriers. Funding for action to remove society's disabling practices has been reduced and society is returning to a Medical Model of Disability. Consequently, there is an increasing focus on individual assessment, which measure difficulties rather than ability and maintain societal barriers. Oliver (2013:1026) talks of the current trends taking society '...back more than 30 years to the time before the social model came into existence.'

It is also important to assess the effectiveness of an advocate's ability to remove societal barriers, and create more opportunities for an individual with a disability. The advocate's role can be one in which there is created power vacuum between the advocate and the person they represent (Kagan at al., 2011). The consequence of this may be that the opinions and views of the individual are not fully represented. Despite this, research has shown that there are many advantages and that the person with a disability gains many opportunities because of the advocacy (Thomas, 1999). Opportunities were created through the advocate's assistance to fight for the individual's rights. Advocacy therefore can preclude societal constraints for individuals, whilst activism could assist this on a wider scale. Recognition of this potential role is therefore important to consider, since it can have a positive difference of the lives of those individuals who have a disability. Additionally, since current policy is moving away from removing societal barriers (Oliver, 2013) advocate and activist roles may have a greater imperative.

A narrative design has previous been a beneficial approach that has explicated parental experiences surrounding their child with a disability (Goodley and Tregaskis, 2006). This methodology can identify and generate an in-depth knowledge about social, political and cultural realms (Goodley et al., 2004). Literature suggests advocacy and activism is a method to counteract societal isolation and intolerance for a child diagnosed with ASD (Ryan and Runswick-Cole, 2009; Woodgate et al., 2008). By utilising a narrative methodology a more in-depth knowledge about societal constraints is developed, which may serve to inform social policy about changes that need to be made.

This study set out to achieve the following objectives:

- To gain an insight into the types of experiences that have promoted the mother to perform actions linked to advocacy and activism.

- To explore the mother's relationship with healthcare professionals and whether these relationships have promoted their role as advocate to their child.

- To gain an understanding of whether a mother can develop expertise through a child's diagnosis of an ASD, and if so whether it facilitates the role of the advocate or activist.

- To explore strategies mothers may employ to encourage their child to reach their full potential and fight against societal barriers.

- To allow mothers to express the personal impact on them, of their child with a diagnosis of an ASD.

Method

This research used a FANI approach to investigate the role of advocacy and activism in mothers with a child diagnosed with an ASD.

Design

Quantitative research attempts to find numerical patterns that can be considered as a deductive outlook (Sanders, 2010). The qualitative paradigm however seeks to understand and interpret an individual's experiences (Willig, 2013). This crucial benefit led to the use of a qualitative method within this study. Mothering a child with an ASD is a significant life experience and is undoubtedly characterised by deeply personal and meaningful events. If quantitative methods were used, the subject would have been poorly represented, as it does not take into account the meaning behind emotions, behaviours and experiences.

A narrative inquiry has been employed to gain a greater understanding of the behaviours surrounding advocacy and activism. Gaining assess to narratives is a useful methodology, since it is associated with the ability to explicate elements relating to the social, political and cultural realms (Goodley et al., 2004). Thus not only did we discover the subjective experiences of those interviewed, we also revealed elements of societal conditions that have been inflicted on the individual as a result of mothering a child with an ASD.

Narrative research has evolved from an interpretation that a capitalist society 'alienates' individuals; thus creating the narrative construct of the self as a fixed identity (Parker, 2005). Narrative research therefore seeks to explore how the self is positioned in culture, and how it feels to have an identity

subjected to cultural constraints. This was particularly important since not only do the narratives have the ability to explicate personal meaning, but they can also provide meaning on a macro level. Furthermore, Bruner (2002) argues that we attend to narratives that have significant meaning to us. This adds validity to the study, since the narratives explicate a significant level of personal meaning to each interviewee.

Participants

This research required the recruitment of five mothers who have a child with an ASD. Participants were recruited through a snowball sampling technique, whereby personal contacts were the first point of enquiry. Personal contacts were developed through family members with a diagnosis of ASD. Post interview, participants were debriefed, and asked to distribute additional research invitations (Appendix 3) and information sheets (Appendix 4) to potential participants that met the criteria outlined above. These potential participants were required to contact the researcher directly for ethical reasons.

Naivety was utilised to confront any preconceptions about the participants (Willig, 2008) and therefore explicate elaborate narratives. Since participants were recruited through personal contacts, naivety was considered imperative.

All participants have been given pseudonyms to protect their identity. As the participant pool developed, it became clear that the participants recruited all belonged to nuclear families and were socially advantaged. The cultural origins of the participants may have led to differing experiences of advocacy and activism.

The Researcher

The researcher became actively interested in this subject when a close family member with an ASD was exposed to repeated episodes of societal intolerance, which resulted in an advocacy role being adopted by the mother. This resulted in the researcher wanting to learn more about this role. Passion about the eradication of such intolerances has therefore become a consistent theme throughout this research.

Data Collection

Each interview was digitally recorded capturing '...the deep meaning of experience in the participant's own words' (Marshall and Rossman, 2011:93). These interviews lasted from 25-55 minutes, and five interviews were carried out. Most interviews took place in the participant's home, which was both convenient to participants and provided necessary comforts.

The interview guide (Appendix 7) was bound by the principles of the FANI, where well-designed open-ended questions were used to encourage story telling (Holloways and Jefferson, 2000). The question topics were derived from an earlier literature review conducted for the proposal of this research. The order of questions was sometimes changed depending on each narrative told, but the same core questions were always asked. Additional questions were added in some interviews, so that narratives could be explored in more detail.

The interviews were later transcribed using the conventions outlined by Poland (2002), where these detailed conventions allow the reader to gain a full understanding of the interview experience. A summary of conventions is provided at beginning of each transcript (Appendix 11-15).

Data Analysis

A thematic analysis has been conducted to analyse the narrative data set. This was implemented based on the premise that an individual's life stories are internalised as they have a great level of meaning attached to them (McAdams, 2012). Therefore, when told to the psychological researcher the significance of these meanings can be interpreted and analysed for themes (McAdams, 2012). This thematic analysis therefore captured '...recurrent and distinctive features of participants' accounts...' relating to advocacy and activism (King and Horrocks, 2010:150). Additionally, the flexibility of this approach is deemed useful, since it can potentially explicate rich detailed themes that are representative of the data set (Braun and Clarke, 2006).

To ensure the themes produced are significant and relevant for those mothers interviewed, this study used the guidelines outlined by King and Horrocks (2010). These guidelines incorporate a number of valid sources for thematic analysis, including Braun and Clark (2006). The first step was to produce descriptive codes that were inclusive of the mother's advocate or activist role (see Appendix 8). These codes were clustered into categories of shared common meaning; interpretative codes were then used to identify the meaning of these. For example, behavioural complaints and a mother's ambition to facilitate an understanding within an educational context was given the interpretative code of a perceived lack of understanding by education professionals. The final stage involved defining the themes, where there was a focus on abstraction at a higher-level drawing on theoretical ideas. To provide a visual aid of this process, it is represented diagrammatically in Figure 1.

Figure 1- Thematic analysis process for the theme 'Negotiating Educational Approaches'.
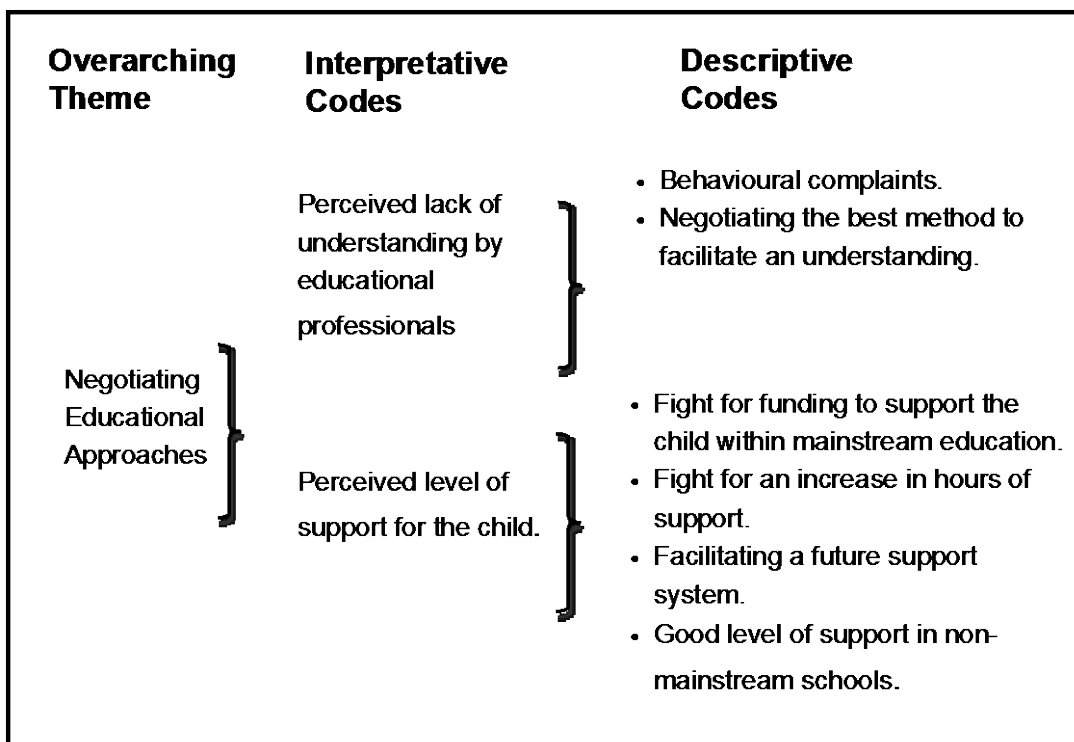
This process of analysis has been conducted for each theme (Appendix 9 and 10). This detailed analytical approach has produced themes that are enriched with quotes relating to advocacy and activism.

Ethics

This research adhered to all guidelines outlined by the British Psychological Society (2009). Further consideration of ethics has been achieved through the completion of an Ethics Check Form (Appendix 1) and an Application for Ethics Approval Form (Appendix 2). This standardised process is paramount for good ethical practice within a university setting. Participants were each given a research invitation (Appendix 3) and an information sheet (Appendix 4) at least twenty-four hours before interviews were carried out, so that participants could gain a thorough understanding of what the research entailed and what their rights were as a participant. These rights were verbally repeated at the beginning of each interview to ensure understanding, and a consent form was signed (Appendix 5).

One ethical concern was that narratives contain high amounts of information, which could lead to the identification of participants. However, after each interview was transcribed all identifying information was removed and pseudonyms replaced any names featured within the transcripts. This study also used process consent (Ramos, 1989) to avoid the misconception of consent being a singular event. This enabled participants to engage with the possibility of the withdrawal of their highly detailed narratives. Participants were also given the choice to negotiate what parts of the interviews were used. Although none of the participants chose to exclude extracts of their interview, it was important to retain choice. These processes were participant-centered helping to safeguard their identities, and protect against any potential harm.

Social ethics were additionally maintained throughout the course of this study. They offered participants a strong commitment to care and collaboration by the researcher (King and Horrocks, 2010). This was of great importance to the researcher because of a strong feeling toward the eradication of societal intolerance and discrimination. Rapport was therefore created with each participant through this collaborative aspect.

This participant-centered ethical approach reduced the risk of potential dilemmas to them. At the end of each interview, a debriefing form (Appendix 6) was provided to reiterate participant's rights and provide information regarding organisations that can provide appropriate support to them.

Analysis and Discussion

After transcribing the five interviews, a thematic analysis was carried out. McAdams (2012) maintains narrative accounts can be explored for patterns and themes, which may build on novel or present theories about life. Therefore, a thematic analysis is utilised in this study to find '...recurrent and distinctive features of participants' accounts...' (King and Horrocks, 2010:150). This analysis therefore reflects on narratives containing unique stories, but their shared meaning is subsequently formed into themes. They provide a rich insight into the role of advocacy and activism. The thematic analysis revealed three distinctive themes: negotiating educational approaches, the need for supportive relationships and future orientations. The following section comprises of a detailed analysis of the themes and raises specific discussion points.

Negotiating educational approaches

Most mothers framed their stories in a negotiation with education providers about the best way to facilitate their child's needs. Negotiation prevailed as the mothers felt they had an in-depth knowledge of their child, and could therefore advise on the best solution. However, to position the

more appropriate solution the mothers often had to negotiate the most effective method of expressing their ideas.

Some mothers represented the teachers as having a lack of understanding about their child's ASD-related manifestations. The following extracts demonstrated a frustration over a perceived view of teachers reflecting practises that demonstrated a lack of understanding.

> '…the teachers were often complaining about Paul's behaviour. Erm and I was forever trying to educate them. I would tell them about videos to watch or books to read…' (Rebecca, line 151-153)

> 'I worry about saying something to her that sort of criticised the way she has handled things because then she might be awkward.' (Joan, line 343-344)

Both Joan and Rebecca engage in a critical analysis of the methods used by teachers, but it is approached and negotiated in two different ways. Rebecca's narrative reflects a more direct route of action, in which she explains her child's needs by directing the teachers to material that could facilitate understanding. Rebecca essentially defines her role as that of educating the educators, which may reflect inexplicit motivation towards activism. Whereas, Joan negotiates her position to actively voice her opinion about behavioural strategies.

The perceived notion of teachers displaying a lack of understanding of ASD may be representational of intolerance within the education system. Murray (2000) argues that practice needs to disembody its perspective of viewing disability as a failure and adapt to strategies promoting equality. It is suggested that until this is embraced, notions of prejudice will continually dominate relationships between parents and professionals. Furthermore, Beckett (2009) argues current guidelines provided to schools fail to incorporate a sincere 'anti-disablist' approach. The Government therefore needs to reevaluate guidelines, and create a mandatory requirement for schools to incorporate this into their curriculum. If these developments are not embodied within the curriculum, collaboration between education professionals and parents will not be developed.

The mother's narratives reflected their attempts to negotiate an increased level of support for their child. Adele's narrative is used to provide an example of this:

> 'So we had to fight for that with the school and with the LEA to sort of get that funding for the school … The school was saying if we didn't get that then he wouldn't be able to continue with mainstream.' (Adele, line 34-38)

This perceived lack of support resulted in advocate movements, whereby she was determined to negotiate with the authorities and instigate support for her son. Adele further examines this role and recognises it as a form of activism.

> '…I don't think at the time that the school that Connor went to I don't think they had any support system in place for special needs kids … I think from that they just took it on board because I don't think that they had many special needs kids.' (Adele, line 66-67)

Therefore, from Adele's fight and negotiation with the school, the school recognised a need to change and therefore they implemented a more to supportive system, which benefitted other children with disabilities. Resourcing difficulties, the Local Education Authority structure, attitudes illustrated by staff and accommodating the parental choice have all been previously noted as difficulties towards

promoting greater inclusion (Evans and Lunt, 2002). To make inclusive education possible, it is therefore imperative for the Local Education Authority to reevaluate current strategies and procedures in order to create a more facilitated inclusive educational system.

Interestingly, one mother whose child went straight into a special educational needs school regarded her daughter's educational experience as positive.

> 'They were fully aware of the children's needs and had a good understanding of how to deal with her.' (Ann, line 90-91)

Therefore, within a non-mainstream environment it is clear that potential tensions disappear and negotiations are not required. The child is in a segregated environment, and therefore the behaviour is not problematic as the 'norms' are not broken. Could segregation therefore be attenuating to a societal intolerance? It is argued that inclusive education is the pioneer to equality and it is necessary to counteract the formation of intolerance within society (Bekerman, 2013). To make inclusion and collaboration possible, Brett (2002) proposes the need to integrate an Alliance Model alongside current models of disability. The aim of this model is to encourage the formation of an alliance with professionals and parents of children with disabilities. It is therefore necessary to engage with this model to further collaboration between parents and education providers.

The need for supportive relationships

Being supported by others enabled the development of advocacy. Some mothers who did not have supportive relationships believed them to be beneficial and aspired towards creating such relationships. All participating mothers in this study were from nuclear families, and some mothers therefore storied their relationships and general family life. The role of friendship was also storied within some of the narratives.

Those who do not have support from friends and family may be more reliant upon statutory services. The reality is that local services are subject to excessive financial constraints and are constantly being cut back (Oliver, 2013). It is interesting that one of the key issues for most of the mothers was accessing appropriate support within education in order for their children to access mainstream education. In order to achieve this, the mothers again have to rely on their skills of advocacy and in some cases activism.

Rebecca's story consists of how her and her husband would devise strategies together, and in doing so would support each other through the hardships of parenting a child an ASD.

> 'Fortunately me and my husband would sit and think things through and develop our own strategy as to what we are going to do.' (Rebecca, line 109-111)

This process of support led to a positive outcome that was perceived as consistent with the child's needs. Social support has previously noted as a tool that can alleviate parental stress (Sharpley et al., 1997). Woodgate et al. (2008) also found some parents can together evolve a vigilant type of parenting to ensure their success. Collaboration and cooperation therefore appears to lead to the implementation of successful strategies that can enhance the child's life experiences.

The difficulties associated with managing behaviours caused confrontation to be storied in some narratives. Joan stories her experience as negative as she reflects on a lack of cooperation between her and her partner.

'But he has been brought up a certain way (p) that he thinks it's okay to shout. But that doesn't help Tom. Like I say he undoes a lot of what I do.' (Joan, line 482-484)

The perceived lack of harmonious strategies between the parents resulted in strategies emplaced being less effective. However, Joan's story documents the fundamental need to have supportive partnerships to aid the child's needs. Bromley et al. (2004) highlighted the importance for mothers who care for a child with an ASD to have a supportive family. The significance of support is therefore an imperative.

Ann's story is rooted in her family's support for her daughter. Outside agents suggested the most appropriate solution for the care of Holly was in a residential care home. Ann immediately rejected this proposal, and stories her rationale as having positive family attributes.

'And she had limited communication, but she has a strong loving family … We are not prepared to give up on her.' (Ann, line 177-183)

Ann's narrative is representational of a family commitment and assistance to facilitating the child's needs. Unfortunately this level of commitment is not always a given with families. For example, Rebecca storied extended family relations as damaged because of intolerance to her child with an ASD. She maintains that she '…can't get the family back together again because it's historical' (Rebecca, line 334).

It is clear that family experiences can differ and this seems to be related to tolerance levels. Previous research has noted that some family stories attribute courage and human spirit as a means to help overcome the challenges of coping with a child diagnosed with an ASD (Schall, 2000). However, courage and human spirit are not always representational within families where there is an individual with an ASD. Ekas et al. (2010) have shown that a low level of optimism displayed by mothers has been associated with less family support and negative maternal outcomes. They suggested a Parent-To-Parent intervention in which the parents of newly diagnosed children are matched with more experienced parents, who share their experiences. Although this does not totally alleviate the difficulties faced by families, it can provide a source of optimism, and promote positive change.

Some of the narratives represented previous friendships as damaged, due to intolerance from others toward the child's ASD-related manifestations. The following excepts demonstrate a loss of friendships and family members:

'I also cut my relationships with everyone. You become isolated because nobody understands.' (Sarah, line 418-419)

'You actually end up losing family and friends because they don't want to be with you. They don't know how to react to this child.' (Rebecca, line 85-87)

These extracts emphasise the possibility of relationship breakdown as a consequence of a lack of understanding generated by societal intolerance. According to previous research, many parents face a loss of previous friendships and this is associated with intolerance towards their child's ASD (Meyers et al., 2009). Advocacy has been identified as a test of personal values (Kagan et al., 2011). Therefore, the breakdown of relationships is a consequence of this test, as the previous friendships no longer represent the mother's adaptive personal values. Timimi et al. (2011) suggests the increasing prevalence of autism is an outcome of cultural practices that are intolerant of ASD-related

manifestations. It is therefore necessary to find a macro solution that can counteract such intolerances within society and enable the development of more positive relationships.

Future orientations

The narratives featured within this study were entrenched in an attempt to find solutions that could enhance the probability of a positive future for their child, and break down barriers of societal intolerance.

One mother attributes this future building nature, as one centered on building social skills. Adele reminisces on work experience she organised to strengthen her son's skills.

> '…he was being sent to work with different people and he coped with that (p) you know quite well, so it was confidence building…' (Adele, line 120-121)

These skills are invaluable and they will help create a successful future for her child, as they are a prerequisite for success within the workplace. Ann represents future orientations by expressing her and her family's commitment of not being '…prepared to give up on her.' (Ann, line 183). Ann's statement reflects perseverance, which accommodates her child's future. Positive future orientations have been found in previous research. Altiere and Kluge (2009) found parents of children with an ASD reciprocate a nature of promptly mobilising resources to help their child. These resources can help stimulate a positive future.

A drive to gain knowledge from other sources was also featured in the analysis and was representational of seeking to build a positive future. The following excepts demonstrate this:

> 'And then I went to erm (p) a special needs conference and they had these harnesses, and it really worked (thankful tone). And I've used them for the past three years possibly (p) maybe even more. And yeah they are a lifesaver.' (Ann, line 238-240)

> '…just explanations from the different specialists that Connor seen through out the time that (p) they just explained what it was (p) and you know what was going on for him.' (Adele, line 96-98)

By engaging in a knowledge-based conference, a solution is found to the everyday struggle of travelling in the car. The fact that Ann calls the harnesses a 'lifesaver' reflects clear indication of growth from finding a solution. The explanations Adele received provided an understanding of her son's needs and helped her to engage with an empathetic approach. Previous research has represented knowledge as power (Kuhaneck et al., 2010). The knowledge gained permitted the mothers to advocate a development management approach, which can help build a positive future for the child.

Retaining positivity also allowed mothers to engage positive future orientations. Rebecca explicitly engages with the notions of hope: 'Yeah so when you get a diagnosis all that you have is hope.' (Rebecca, line 464). This perhaps provides a solution to dealing with the hardships of mothering a child with an ASD. Rebecca also speculates on a solution to overcome the hardships, she claims:

> 'I think parents need to be more positive. But there's nothing actually there telling you that they will always be like this, it will get better.' (Rebecca, line 63-65)

She emphasises the importance of remaining positive and having a positive outlook on the future, as she claims it will not always be constrained by hardships. This opinion could potentially fuel future orientations of activist movement, as she has an understanding of others, which may evolve into a yearning to change this. Adele also articulates on the importance of positivity. She facilitates this role by '…trying to be positive about everything that he achieves' (Adele, line 108-109). Thus it is a positive approach, which is implemented to assist the child's needs. King et al. (2006) found parents emphasise the importance of engaging in hope and seeing the possibilities for the future. However, many other mothers suffer from mental health issues as a consequence of the hardships associated with mothering a child with an ASD (Estes et al., 2000) and therefore interventions need to be implemented to increase positivity and hope. The failure of statutory services to provide meaningful support to the mothers has been associated with advocacy and activism (Green, 2007; Woodgate at al. 2008). It is interesting to know that none of the mothers appear to be aware of the multi-agency strategies that may help their child's future through a coordinated support approach by all relevant agencies (Department of Education, 2012).

Joan represents an activist tendency by engaging with social media to try to increase awareness of ASD-manifestations: 'I try to raise awareness amongst the public. Now and again I re-post awareness campaign pictures on Facebook…' (Joan, line 379-381). By engaging in this strategy, she actively engages in the attempt to change societal perceptions, and create a positive future for those diagnosed with an ASD. Individual activism has been previously found amongst mothers who have a child with an ASD (Ryan and Runswick-Cole, 2009). Therefore, it is not a unique phenomenon, but more an outcome of strong attitudes about their current situation and a motivation to change future perceptions.

Conclusion

To conclude, the mother's narratives are enriched with societal intolerances. These societal intolerances led the mothers to adopt the role of the advocate, and in a small number of narrative quotes, there was a determination towards small-scale activism. Specifically, the results of this study imply that mothers of children with an ASD negotiated educational approaches, sought comfort in supportive relationships and applied specific strategies to encourage a positive future for their child.

This study highlights that the Social Model of Disability continues to prevail. In order to reduce intolerance, policies and guidelines need to be revised. Rodger (2011) argues the current parent-partnership rhetoric within the UK policy, that supposedly assists a parent's everyday life is unhelpful and in reality disempowers them. This disabling attribute is formed through the hardships prevalent in gaining access to appropriate facilities and services. The mother's narratives all represent these hardships.

The incorporation of the Disability Discrimination Act 1995 into the Equality Act 2010 was designed to make the law relating to disability discrimination clearer. However, the mother's narratives demonstrated flaws within this strategy, and therefore improvements are imperative to increase its effectiveness. The Autism Strategy (2010) aims to increase awareness, develop local services and promote independent living. Integration is at the epicenter of the Government strategy. Although this is a positive step, it has been criticised, since there is no requirement for local authorities to measure or publish outcomes (Walsh and Hall, 2012). Therefore, in practice it can be ignored, and intolerance may continue. Alternative techniques and interventions therefore need to be considered by the Government to prevent further intolerance and discrimination.

Epistemological Reflexivity

Willig (2008) suggests that engaging in epistemological reflexivity encourages the researcher to reflect on the methodology, and the implications of chosen epistemological assumptions.

This project's narrative approach has permitted an exploration of societal constructs related to disability. It has also examined how mothers of children with ASD develop strategies to counter the adverse effects of these constructs. During the research process, I have become more aware of this. The project therefore has enhanced my knowledge on the subject.

Whilst conducting the interviews, I used the word 'activism' to question the participant's involvement. Response rates whilst using this word were limited. I became more aware of this, and decided to change the wording of the question, which fortunately led to more response. Activism may therefore be a word used more within academia. If this word was changed earlier, the study could have elicited more responses, and therefore the concept could have been explored further.

One aim of the study was to explore relationships with healthcare professionals. However, when I asked participants about them there was an almost instant switch towards narrating stories related to educational approaches. Hence, the theme 'Negotiating Educational Approaches' was developed. It would be interesting therefore to investigate relationships with healthcare professionals further.

A limited sample pool was unintentionally developed. As the interviews commenced it became clear that the participant pool was limited to mothers who were part of a nuclear family and all were socially advantaged. The study may have produced different results if a more diverse sample was recruited; therefore more research is required to further establish the role of advocacy and activism.

Overall, the narrative methods and stance chosen allowed detailed responses to be found. These findings also confirmed previous research, and highlight the role of advocacy and activism as a development to combat societal isolation (Ryan and Runswick-Cole, 2009; Woodgate et al., 2008). However, more research is essential to further establish this role.

Personal Reflexivity

Willig (2008:10) suggests personal reflexivity engages the researcher to reflect on '…values, experiences, beliefs, political commitments, wider aims in life and social identities that have shaped the research.' Therefore, reflexivity is essential as the project is embedded in the researcher's subjective position, and this may have impacted on the research findings.

This research commenced through a vested interest in ASD, which was prompted by a family member's diagnosis. I became particularly interested when I saw this family member experiencing isolation, intolerance and discrimination. As my research progressed, I realised that this was not a unique occurrence. I am saddened and disappointed that as a society we have not evolved to move away from discriminatory practices. My strong views and desire for societal change may have increased empathy, and this may have been communicated during the interviews. I feel that this may have elicited more detailed narratives.

This research has taught me a huge amount about our social worlds. I have learnt not to take it at face value, and to some extent challenge it when required. Learning more about the experiences of disability has given me the confidence to do this. This will assist my personal development and future work-related practises.

I found it heart-warming to hear the mother's stories about their advocate and activist role. I am now determined to pursue a career that promotes positive attitudes towards disability. I feel these results could provoke debate amongst both professionals and the mothers of children with ASD. It demonstrates that advocacy and activism can be empowering for the mothers and create a more positive experience and life for the children.

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