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Exploring the Experiences of Families of Children Diagnosed with Autism Spectrum Disorder

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Abstract

The purpose of this piece of research is to explore the experiences of families of children diagnosed with Autism Spectrum Disorder. This research examines the effects of having an autistic child in the family and identifies the coping strategies that parents adopt on a daily basis, looking particularly at the social, emotional and financial impacts on family life. Assessing the supports and services in place to assist these families and children to live a better life is a key aspect of this research. The research draws on interview data with female carers of children with autism. It finds that carers experience social isolation and financial stress, which is exacerbated by socio-economic circumstances, evidencing an emergent two-tier level of access to resources and support services.

Keywords: Autism; support services; coping mechanisms.

Introduction

This research on which this article is based focuses on four main research questions. First, it explores a short history of the discovery and diagnosis of autism. Second, it reviews policy-making and service provision for children with autism and their families in the Irish context. Third, it examines, through qualitative primary research the different effects of having a child with autism on families. Fourth, it identifies the

supports and coping strategies that families adopt to deal with having a child with autism. This article focuses on a selection of these issues. In particular, it takes an in-depth look into the effects of having a child with autism and examines how the families cope with the extra stresses they have to deal with. This research provides a clear picture of what supports and services are currently available and of benefit to these families and highlights the areas which are in need of serious reform through first-hand accounts of research participants.

Autism

The medical definition of Autism proposes that this ‘represents a broadly defined disorder of behaviour and cognition with onset prior to age 3 affecting the core domains of language and social development and involving abnormal repetitive and restrictive behaviours’ (Geschwind, 2008: 391). Autism is a neuro-developmental disorder that affects the development of the brain in areas such as social interaction and communication and is identified by extreme problems in communicating and establishing relationships with people, in developing language and in using abstract thoughts. The three main areas of difficulty for an autistic person are known as the ‘Triad of Impairments’ and these include; Social Impairments, Social Interaction and Social Imaginations. These are areas which are not visible externally, therefore autism is referred to as a ‘hidden disability’. People with autism view and respond to the world differently from ‘other’ human beings or the so called ‘neurotypicals’. For example a child with autism sees detail but not the bigger picture, yet a neurotypical will tend to include all parts to conclude an overall picture (Northumberland County Council Communication, 2004: 118). Autism is a spectrum disorder meaning you can be severely autistic or a little autistic. This makes autism a very complex and interesting condition.

Awareness of this lifelong disorder has developed and it is much more prevalent in society today with the number of diagnosis on the rise all over the world. Approximately 1 in 100 children are diagnosed in Ireland today (Hill and Frith, 2003: 281). Autism is understood in relation to two main frameworks, the social model and medical model, and both hold their own views on how autism can be understood. The Medical Model follows the guidelines of the DSM-IV manual and believes that a gene variation is the cause of autism and that medication and therapy are the only treatment

(Molly et al, 2002). The Social Model alternatively looks at autism through a totally different lens to that of the medical model, where it believes that it is society which must change and the stigma of autism needs to be removed to allow autism to be seen as ‘normal’ in society . (Molly et al, 2002). While both views provide a competitive argument, we have to wonder, can autism really become a disability which is considered ‘normal’ in society? This shows that despite some coherent advancement in research and technology the complex issue of autism still proves puzzling and remains an area under much scrutiny.

Challenges faced by families with a child diagnosed with autism

Planning and preparing for parenthood is a huge and exciting time in a family’s life. However parents rarely think that their child could possibly have developmental disabilities. Many parents don’t always see the difference in their child at a young age as ‘autism often is not diagnosed until the child is over 3 years old and children have no visible signs of impairment’ (Ryan and Cole 2008: 43). However from the minute parents’ suspect that something is wrong with their child – that they are not developing like other children – families of ASD children immediately begin to confront hurdles that set them apart from other families.

Emotional impacts

Autism is a never ending emotional roller coaster experience which commences before the child is born and continues throughout its life. Research by Dillenburger et al highlights that mothers with a child with autism spectrum disorder frequently reported to be in ‘poor/fair’ mental health compared with the general population (2010: 13). Furthermore, one in three families of children diagnoses with ASD was headed by lone parents and divorce rates of 82% in these families were recorded (ibid). This highlights the impact and strain that having a child with ASD has on a family, as it can create anger and resentment between spouses as they feel frustrated that the parenting experience they have is not what they had envisioned. Existing research in Ryan and Cole (2008) emphasises the devastation a mother experiences when she is unable to comprehend what her child is looking for, her inability to teach, or to comfort or control her child’s day to day behaviour is heart breaking. According to Bloch and Weinsteins (2009), mothers for this reason regularly perceive themselves as a failure and this causes her sense of self and ambition to shrink.

Having a child with ASD is not just challenging emotionally for the parents but also for siblings and the extended family. Siblings can be unintentionally neglected but also they may suffer from embarrassment as their brother or sister functions and interacts in unusual ways.

Social impacts

A parent once described his experience of being a father with an autistic child as the 'journey through the grief of broken dreams' (Naseef, 2011: 1). The journey affects the family socially as they experience a huge change in their daily activities. Many mothers quit full time employment and take on the dedicated job of looking after their autistic child on a daily basis, diminishing the mother's personal aspirations and sense of identity (Cole and Ryan, 2008). She also loses social contact, she becomes deprived of adult conversation and companionship, and as one mother stated 'there is not much for me now; I live in a world of autism' (Cashin, 2004: 167). Socialising for some of these parents can often be off putting as they continually feel that there is a perceived judgement by others and the need to then explain why their child is acting in a particular and unusual way becomes tiresome and often embarrassing. The reduced contact with friends and social meetings results in the social contact being lost and broken off along with lack of enjoyment and time for one's self and this can result in the loss of self and alienation.

Financial

The financial impact on families of autistic children is enormous. Firstly some families are hit hugely with the immediate cut of half their income as one parent in many cases leaves the work place and becomes the stay at home parent and dedicates their time to their autistic child. The lack of household income puts increased pressure on the partner to work longer hours to be able to financially support the family (Ryan and Cole, 2008). For some families the high costs of child care and the loss of benefits creates huge pressure for the family. Despite social supports offered to families, on its own it is not enough to cover the shortfall that exists between the costs of bringing up a child with ASD and the benefit offered.

Coping Mechanisms

Raising a child with autism is an extremely complex and diverse task. It is particularly difficult for families to come to terms with the change in their life and it can be a very stressful and difficult time on the whole family. In order to adapt to these changes and overcome the challenges, stress and anxiety the family adopt coping mechanisms to manage the specific demands both internally and externally which are exceeding their limits.

Internal Supports

An internal balance is the most important when it comes to coping with a child with autism. Depression and poor mental health can be a reason for parents to break down and simply lose control of the situation at hand. As Mouzourou et al, state ‘ I am not saying that having a child with autism should become a problem for everyone in the family, but I also feel that it is not right to isolate the issue and forget about it’ (Mouzourou et al, 2010: 699). Taking control of the situation is very important way to enable parents cope. Studying what autism is and means is a method by which parents learn to cope (Kingston, 2007). Internal supports come from within, through one’s own thoughts. Positivity comes from the mind and adopting a new view of a situation. Some families have found that accepting their child’s disability and acquiring a perspective of positivity that their child, while they will always display symptoms of autism, can develop their functioning with their parents help. Adopting a new set of values has also been a positive coping mechanism for mothers (Altiere, 2006)

Formal External Social Supports

Most families begin by seeking formal support to aid in caring for their child with autism. These families enlist the supports of; medical doctors, therapists such as speech and language and occupational therapies, respite care, psychologists, social workers and special education teachers. Respite care is extremely important for certain families as it allows them to take time to themselves, to spend it with other child or simply to get a peaceful night sleep. The additional medical and educational advice allows parents to take confidence in these people to ensure that they are also looking out for the best interest of their child and that they seek to promote their qualities and abilities. This can be very reassuring for families explain Kingston (2007) in her book, *Mothering Special Needs*. Kingston (2007) highlights the

extensive support that social workers and other professionals offer to parents in the form of guidance, additional information, and simply as someone who understands the needs of parents and who can offer a positive word about their parenting and their child. However, there is a large amount of negativity emerging throughout the literature regarding the professionals and whether they are really helping parents or adding to their stress.

Counselling and family counselling is another effective coping strategy for couples and families however is usually the last resort for families, they never seem to think they need it until the situation erupts. It is very important when it comes to sibling relationships as the altered family dynamic, despite the fact that each member may be coping with the disability may have a big impact on siblings 'psychological development. Siblings play a big role in each other lives, and after parents are deceased adult siblings may be responsible for caring for the sibling with ASD, therefore it is important to ensure siblings are coping at an early stage.

Informal External Social Supports

After acquiring formal social supports to fulfil the physical and psychological needs of the child, the family typically seek social supports such as family members outside of the home, friends and support groups. Sharpley, Bitsika and Efremidis (1997) found that family members who provide assistance and have an understanding of the child's difficulties are the most valuable support. Research also indicates that the invaluable support of mother's mother was a reoccurring theme. The core bond between mothers and daughter was essential to the coping ability of many mothers (Kingston, 2007). Further literature by Altieri (2006) highlights the importance of finding friends who are accepting of their child's disability and helps them to carry out a normal life without judgement or embarrassment. This enables parents to feel comfortable and at ease. Community support groups and peer groups are another beneficial resource in helping parents cope with their complex lives. This support helps to target the loneliness and lack of understanding which parents incur on a daily basis. The support groups enable parents to gain independence and offer support to other parents who may need it and, in turn, gain the reassurance, support and positivity which they need to keep going. As Ryan and Cole (2005: 45) suggest,

‘membership of “self-help” groups can also lead to a new sense of self for the member’.

Methodology

This research is based on analysing the experiences of families living with a child with autism and adopts a qualitative approach. This approach is focused on exploring life experiences and situations in a changing world and it enables an in-depth insight into the lives of the families and an understanding of their perspectives, emotions and feelings. Interpretivism is the main theoretical framework which I used to analyse my research data. Interpretivism in social science tries to understand why people act or think in a particular way and it aims to reveal what common ideologies, beliefs, symbols, motives or conduct they live by in order to provide a reason for these actions. This research is based on seven one-to-one interviews (detailed below). As Silverman notes, ‘active interviewing is a form of interpretive practice involving respondent and interviewer as they articulate on-going interpretive structures, resources and orientations with practical reasoning’ (1997: 121).

Date Collection, Selection and analysis

To gather my sample of families, I drew on what can be described as ‘convenience sampling’ or ‘snowball sampling’ (Bryman, 2008). The convenience sample was very accessible to me as I work with special needs children and therefore have a close rapport with their parents. I also used a snowball sample this is a method where ‘the researcher makes initial contact with a small group of people who are relevant to the research topic and then uses these to establish contacts with others’ (Bryman, 2008: 184). This method was invaluable to my research as it encouraged me to interview people outside of the study area, therefore broadening the scope of my results. The research data was collected by conducting seven semi-structured interviews with carers of a child with autism, all of whom were female. Most were mothers and one participant was a sister of an autistic child, who was very experienced in the area of special needs. I hoped to better understand exactly what it was like to live with a child with autism and to understand the lengths families go to in order to help their child and also to discover what facilities are out there for these families and more importantly what additional services are needed to improve both the child and families’ quality of life.

Ethics

Intervention occurs on most occasions during social research, and intervention often results in the need for thought on ethical issues for the research. Creswell (2003) outlines a very important ethical issue in social research, which involves the respect and treatment of the respondents by ensuring that they are fully aware of the nature and purpose of the study. It is essential to ensure that the respondents' understanding of the topics is the same as the interviewer; this guarantees that they are fully aware of what they are agreeing to. Privacy and confidentiality is a feature of research which is so often needed. It is important that the information provided is treated in confidence and that their trust is not breached, ensuring anonymity at all times. An informed consent form was obtained in all interviews stating the facts of the interview. In carrying out my study I guaranteed participants total anonymity by using pseudonyms and utilising my information in a way that ensures that the respondent can't be identified or that anyone could use their information against their personal interests. This anonymity was ensured at all stages including the final stage of data disposal and storage following transcription.

Findings and Analysis

In order to analyse this information the researcher divided the key themes into five headings: (1) initial suspicions, (2) following the diagnosis, (3) challenges and coping mechanisms, (4) socio-economic circumstances and (5) the experience of raising an autistic child.

Diagnosis Process

Initial Suspicions

The initial suspicions for most families were quite similar with common features emerging such as lack of speech, unresponsiveness, uncharacteristic and long tantrums and poor social skills. All respondents explained that it was their child's lack of speech which was their first concern. They all noticed that their child was not advancing or meeting milestones like most normally developing children should be. Also many participants stressed that their child's lack of interaction, desire to play and lack of response was another major reason for concern.

Diagnosis Process

The length of time varied for the diagnosis process for all participants, for some it took until they were 18 years of age before they were diagnosed and others were diagnosed as young as three and a half. However it was clear that the diagnosis process didn't start for some children until later in their life. Parents had different views as to why this was the case but they did have one particular common answer, in which they believed that the lack of awareness about autism and expertise in this area caused for long drawn out processes in search for an answer.

All participants in my research specified that, it was in fact, they themselves who had to lobby for their child to be assessed as they knew there was something wrong. However, for three of my participants it was the school who encouraged them to get their child assessed as they also spotted the child's unusual behaviour in the playground and in the class room and knew that they seemed to be different to other children. As narrated by a this participant:

When it really kicked in was when he was in first class in primary school and I was called into the school and they basically told me that they couldn't teach him. He has no attention span and he was constantly bored and he had no interest. The teacher at this point advised me to take him to a special needs school and get him an assessment' (Respondent number six, 20th February 2012).

While schools spotted the differences in the children, the poor link between the education system and the HSE does not allow the school to follow up on their observations because they have no support from the HSE, in which they have to rebound the problem into the parent's hands to solely sort, explains two of the participants. One participant in particular had quite a different experience to the other participants, as she explained:

We applied through the assessment of need which speeds up the process because there was a two year waiting list, but you can apply through your European rights. You have the right to be assessed within six months of applying but the authorities didn't like people going this route at the time. I had my son diagnosed when he was three and a half' (Respondent number two, 28th February, 2013)

This respondent's expression is directly linked to the Disability Act, 2005. The Assessment of Needs Act, 2005 makes up the second half of the Disability Act, 2005 and aims to decide what health and education needs arise from a child's disability and what services are required to meet these needs. This Act is relevant to all children under the age of five. It is quite alarming that no other parent has availed of this Act considering it is their right.

Effects of late diagnosis

Overall, all participants portrayed a sense of rage at the excessively long waiting lists and firmly believe that if these were avoided and there was early intervention then their child would be a different child today. A particular complaint which four out of the seven participants highlighted was that their child's life and family life would have been much smoother as most parents were disciplining their child as if they were simply a disruptive child. One participant explains:

I was told to do things such as the naughty chair, you should never really do this with an autistic child and I was doing it persistently. Naturally, he was really undisciplined being autistic, so we had murder in the home and caused a lot of upset within our family' (Respondent number one, 21st January, 2013).

Furthermore, one participant stresses that early intervention would have caused for a much less stressful and imbalanced life for the child also that if the intervention was there at the early stages in her child's life he wouldn't be so far behind in his reading, writing and speech. This resulted in a very slow progression in his education when he finally did get diagnosed and received the supports necessary.

Following the Diagnosis

The area of service provision was one of the main areas of concern for the researcher and the participants. They felt that there was a significant lack of services and resources available to their children and to them as parents that was causing for the poor outcome for them as families.

Additional Services Requested by Parents for their Autistic Child

Parents are continually lobbying for more services and intervention for their children. They are fighting to create a better quality of life for their children as they believe that much more can be done to assist their progression. While early intervention was their main wish, all of their children have gone beyond this stage, therefore instead they can simply hope for; consistent therapies and weekly sensory integration, supports the whole way through to third level education, the desire to get trained and qualified teachers in autism and to ensure that services are in place for their children when they reach adult services. These parents are confident that these additional aids for their children are what will make the vital difference in both their child's life and their own family life.

Challenges and Coping Mechanisms

The challenges of having an autistic child are extremely difficult for families to both address and overcome. All participants expressed that they met challenges socially emotionally and financially but that they have adopted coping mechanisms to help them deal with the roads blocks they have come across.

Emotional

Emotionally the diagnosis of a child with autism can be a very difficult and stressful time for families. Parents explain that the diagnosis has puts a huge strain on their relationship but also on the extended family as the extra demands create a lack of one to one and family time. The diagnosis diminishes parent's confidence in themselves as they struggle to understand their child, but also as the stigma around autism has created an extreme boundary for parents to overcome. People simply don't understand what it means to be autistic and the lack of prospects for their child is a view which participants can't seem to get beyond.

The majority of respondents addressed the period when their child was officially diagnosed with autism. They expressed their ambiguous feelings at this time, as in one way they are relieved to finally put a name on it and to begin to address the problem. They can in some way try to understand what it is their child wants. Participants explain that it was a relief to also realise that the disruptive and poor behaviour was not a productive of their parenting, as a participant stated:

I was so relieved because then I know that it was not my bad parenting. Sometimes I wonder was it because I didn't give him enough tummy time or he spent too much time in his chair' (Respondent number two, 28th January, 2013).

Another participant addresses the guilt she felt when her child was diagnosed, she was upset for her child that it was not spotted sooner, the stressful life that her child has possibly lived due to her inability to comprehend her and meet her needs.

In addition to this it was the stigma attached to autism which made the journey so difficult explains the participants. People really don't understand what autism is and what really goes on in the child's mind. Each child is unique in their autism and it is the many misconceptions which create a picture of autistic children 'sat in the corner, flapping their hand,' explains participant number four, 2013. In fact as a participant denotes it necessary for us to consider the 'want' versus the 'can't':

kids who have autism are misunderstood, they may appear lazy but in fact it is that they may not know how to deal with the task or situation at hand, they are overwhelmed' (Participant number one, 21 January, 2013).

Supporting this argument some parents express their heart ache and rage at the bullying their child has experienced in school. One participant explains her story, stating that her son was bullied in school. She sat outside the school for a week at the break time and watched 'other children throw stones at my son because he was vulnerable and knew they would get a reaction out of him' (Respondent number one, 21st January, 2013).

Social

Socially, participants report alarming changes in their lives. Participants found changes in their daily routine: many mothers gave up their job, the autistic child became the priority, and there were no more spontaneous or unplanned adventures. Their lives became simply a routine with an underlying goal to cope and to get by from one end of the day to the next. The seven participants had to give up their job once their child/sibling became bigger and they noticed a difference in them. One participant indicates:

I used to work in a clothes shop, I loved it but I had to give it up. I just had to do something and sort this out, and I'll do anything to help me son' (Respondent number six, 20th February, 2012).

Participants expressed that it was from here that they lost their own identity and felt that they no longer were independent people. As one participant states;

It has affected our life hugely, we don't live – we exist. Our life is our daughter's life, we have no choice but to live like this because there is no support (Participant number five, 4th February, 2013).

A daily routine did not exist for some of these participants. While some children's behaviours are quite mild, other children are extremely challenging. These participants stress that their ability to plan a spontaneous day out was gone. They no longer could plan last minute, their lives ran on a day to day process and it always depended on the autistic child's mood what they could take on in a day. One participant explains: 'I have no routine, my routine is coping' (Respondent number four, 29th January, 2013).

Adult company is a feature which participants highlighted to be lacking and which they miss in their lives. However, in many ways it is they themselves who lose the contact because they are simply too busy with the daily tasks of coping with their autistic child, but also, they reported that the embarrassment of bringing their autistic child out with them was too much. If their child didn't comply with social norms, the societal judgement was simply too much and this created an isolated world for the parents.

Financial

The financial implications of raising an autistic child are enormous. Dillenburger, (2012) indicates 'the total cost of raising a child with a disability is estimated to be approximately three times greater than the cost incurred by running a typically developing child' (2010: 14). This complies with the respondents financial complaints. All respondents are receiving the domiciliary care allowance however, when respondents were asked if the social benefits which they were receiving covered

their child's extensive range of needs, most were unanimous in their view that their child's expenses were way beyond their means.

Socio-economic circumstances and the experiences of raising an autistic child

As outlined by Virginia et al, 'lower-income parents are at a disadvantage in terms of both information and support. They are less likely than middle- and upper-income families to gain either information or support by attending workshops, conferences, and autism support groups' (Virginia, 2001: 49). They highlight that inequalities do exist and it does have an effect on the outcome of the child. During my interviews it became apparent that the families differed greatly in socio-economic circumstances. What was common to families was love and commitment given to their child. However in the case of lower-socio economic circumstances parents seemed to lack the knowledge and ability to reach out to the many alternative treatments and supports available. They were fearful on many fronts; they felt unable to fight and were accepting of their situations because they were unaware of the value of alternative treatments. I particularly noticed this when I asked participant seven had she done any extra reading on services and she exclaimed: 'No, we don't need to because the social worker has told us what to do' (Respondent number six, 22 February, 2013). Money was a controlling factor: participants' concerns they couldn't afford the services and supports were a big worry, even though many of these services can be availed of for free. However they still felt that to become involved would incur costs. The issue of time is another factor for many as they often lacked outside support and the sole responsibility fell on the mother who was often engaged with other time commitments such as work and school pick-ups.

Families from higher-socio economic circumstances on the other hand were far more able to access resources available to them; they did not fear the professional or the system. They had better access to computers to find information and the ability to speak out on their child's behalf created further opportunities for them. I also became aware that these higher-socio economic families seemed to be able to manage their time better and were more confident to ask for outside help, e.g. from family and friends. I also became aware that external family were more involved in their lives, which assisted them to cope but also making the experience more enjoyable. For these families where money was not such a big issue, parents did not hold back in involving

their child in support systems. One participant highlights: ‘thankfully we are able to provide [him] with these services, I don’t know what we would have done without them, they have been so successful for [him]’ (Respondent number two, 28th January, 2013).

Overall conclusion

The interview process proved to be an easy process because of the participants’ willingness to take part and their enthusiasm about my interest in autism. They were eager to share their experiences with me as they hoped that my research might benefit other children in the future.

In general all participants interviewed seemed to be merely coping with their situation and many participants expressed quite negative views during the interview. This negativity was conveyed by their lack of faith in the services provided by the state. The economic downturn has placed an increased strain on these already limited services, thereby lowering the chances of a positive outcome for those of a lower socio economic status. A two tier system has evidently emerged as those able to afford private services are sourcing these services elsewhere. This division can create a sense of isolation and loneliness for poorer parents. This issue must immediately be addressed and the provision of equal opportunity services is vital. Inclusion of all is a very important feature which must be addressed for autistic children and adults. Autism is not the ‘alien’ which most people think it is. Autistic people can be highly intelligent individuals and given the opportunity can succeed in anything they wish. The way the government is dealing with issues of special education appears to be highly dismissive and they do not seem to acknowledge that these autistic children are losing out on valuable learning time. Ireland is known for its high quality education system around the globe yet the state is failing to address the area of special needs integration into mainstream schools. While it must be agreed that the area of autism is a learning process for everyone, the development of these services needs to rapidly be addressed along with raising the awareness of exiting services available to these families e.g. Assessment of Need Act, 2205. There needs to be an immediate and renewal of policies to ensure that the needs of the child comes firsts.

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