The Experiences of Parenting a Child with Autism

Katie Kelly Foran

18313533

Supervisor: Dr. Conor Nolan

B.A. (Hons) in Psychology

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Name: Katie Kelly Foran

Student Number: 18313533

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Table of Contents

Abstract

This qualitative study explores the experiences of parenting a child diagnosed with autism spectrum disorder. This study consisted of eight parents sharing their experiences, including daily challenges, adjusting to the life of parenting a child with ASD, their support and coping strategies. The study also explores the parents' reactions to their child's diagnosis and their perception of their partner's reaction. A thematic analysis of the data identified five core themes: 'Shock, Denial, Disbelief': Initial response to diagnosis, The Learning Curve, The ASD Journey, and Minding Yourself as a Parent of a Child with ASD. The findings revealed many challenges faced by parents, including the lack of support which caused them tremendous stress. It was also found that parenting a child with ASD is a learning process in which parents learn about ASD, and discover things about their child, and themselves. This study concluded that there is a need for awareness interventions put in place, and family-centred supports, which support the child and their families. This is to ensure that the parents are being supported throughout the process of adjusting to life parenting a child with ASD and to support and guide them throughout the journey. The implications of this are discussed.

Introduction

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental disorder, which impacts individuals' behaviours, thoughts, and perceptions presenting in early childhood and continuing throughout adult life (Chaidi & Drigas, 2020). This can impact one's attitudes and interests (Ahmed et al., 2020). Individuals diagnosed with ASD typically struggle to socialize and interact with others (Blackman et al., 2020) and lack understanding of others' emotions (Hartley & Fisher, 2018). The cases of ASD can vary, some cases within the spectrum can be quite severe although others can be mild (Booth, 2016) which determines the level of support the child will need (Ahmed et al., 2020). Individuals diagnosed with ASD can also be verbal or non-verbal (Ahmed et al., 2020). The Autism and Developmental Disabilities Monitoring Network (2018) shows that in Ireland around 50% of individuals diagnosed with ASD also have an intellectual disability (Department of Health, 2018). According to the Department of Health (2018), 30% of individuals with ASD were diagnosed with childhood autism, which is when children aged under 3 years old show symptoms within the three core areas of autism symptomology such as difficulties in reciprocal social interaction, communication, and a lack of flexible thinking.

In a survey, practitioners reported that the process of receiving an ASD diagnosis for a child can be long due to initial assessment waiting lists (Ward et al., 2016). Siklos & Kerns (2007) found that many of the parents who participated in their study waited three years to receive a diagnosis for their child following their first appointment with a professional regarding their child's development. When a child is first diagnosed with ASD, their parents experience a variety of difficult feelings (Wachtel & Carter, 2008). However, there are insufficient findings in the literature as to how parents reacted when their child was first diagnosed, and their perception of their partners' reaction, this study aims to address that gap, as it may bring awareness to the emotions a parent experiences when receiving a diagnosis for their child, therefore professionals can provide them with the information and support they need (Murphy & Tierney, 2006). This qualitative study ‘The experiences of parenting a child with autism’ aims to explore parents’ experiences caring for children with ASD, including their stressors, coping strategies, and supports available to them, whilst gathering information as to how they reacted and adjusted to their child’s diagnosis, and their perception of their partners’ reaction. The following literature review will discuss the stress levels of parents of children with ASD, and the coping strategies they use. It will also explore the support available to parents.

Challenges faced by parents of children with ASD

Individuals diagnosed with ASD require lifelong care and commitment, which may cause severe stress for their parents (Reddy et al., 2019). The daily challenges faced by parents of children with ASD are endless (Bonis, 2016), and their behaviours may contribute to many difficulties for parents (Cappe et al., 2020). Hattier et al. (2011) found that challenging behaviours in children diagnosed with ASD had a higher percentage than those of typical development. Some challenging behaviours in children with ASD are aggression, self-injury, and tantrums (Matson et al., 2011). After a child’s diagnosis, both the parents and siblings within the household have to adapt to life living with a child with ASD, as many things within the household may trigger the child, therefore all individuals must be mindful and learn to adapt to a new way of living for the best interest of the child with ASD (McStay et al., 2015).

Cappe et al. (2020) found that parents caring for children diagnosed with ASD have significantly high-stress levels. Parents’ stress levels are related to their child’s degree of impairment, the severity of their cognitive, language, and social deficits, their behaviour problems, and autism severity (Ingersoll & Hambrick, 2011). Many studies have found that parents of children with ASD showed higher stress levels than parents of typically developing children, and children with any other disabilities (Bonis, 2016; Dunn et al., 2001; Rivard et al., 2014), such as Down syndrome, cerebral palsy, and intellectual disabilities (Padden & James, 2017; Matson et al., 2011). In the past recent years, there has been more awareness of ASD (Dillenburger et al., 2015), however, parents are still being judged in public settings about their child's behaviour which significantly increases parents' stress levels (Farrugia, 2009; Schwartz, 2001). Although, in a study conducted by Salleh et al. (2020), parents of children with ASD reported that they were judged for their child's behaviour as there still is a lack of knowledge and awareness of ASD. In public settings, parents face hostile staring, comments, and encounter avoidance (Gray, 2002). The literature shows that stress in parents of children with ASD not only comes from the child's behaviours but also from being judged by society because of the behaviours of their child (Salleh et al. 2020).

Parents of children with ASD also have many more challenges, which causes them a tremendous amount of stress (Rivard et al., 2014) such as having to deal with educational systems (Connolly & Gersch, 2016), and fighting for the system to be better concerning the needs of their children (Woodgate et al., 2008). They also have high-stress levels as their child has a lifelong neurodevelopmental condition in which they may be dependent on their parents throughout their whole life (Myers et al., 2009). Parents of children diagnosed with ASD worry about their child in the future regarding how they will cope with the real world as an independent adult (Watson et al., 2013). They also worry if their child will ever be able to have a job and earn a living, and if they will have the ability to form relationships with people to have friends and a family, although parents stress about this, they remain hopeful that their children will be able to do these things in the future (Watson et al., 2013). The literature shows that parents of children with ASD face challenges related to their child's behaviour and society's judgements on how a child should behave, however they also face challenges such as worrying about how dependant their child is on them and what the future holds for their child living with a neurodevelopmental disability (Myers et al., 2009).

Supports

As Autism has become more known and broadly researched, individuals are now being diagnosed at younger ages compared to previous years, therefore there is now a higher demand for support services (Cassidy et al., 2008). According to Stoner et al. (2005) when a child is first diagnosed with ASD the first thing the parents do is seek information and advice about ASD. In a survey conducted by Murphy and Tierney (2006) parents of children with autism reported that they need supports before their child’s diagnosis, during the process, and after their child’s diagnosis. The same survey also has brought to attention that the first people that the parents contacted for help after the diagnosis of their child, was their local professionals, such as their GP’s or their public health nurse, who could not provide to them sufficient information about ASD (Murphy & Tierney, 2006).

A study conducted by Salleh et al. (2020) found that healthcare professionals need to be more educated and aware of the challenges parents of children with autism face and how badly it affects them. If professionals become more educated and aware, it would help the delivery of supports that the parents need, which would make an enormous difference to the lives of both the parents and the children with ASD (Salleh et al., 2020). Similarly, a study conducted by Reddy et al. (2019) found that parents need more support services throughout their journeys caring for children with ASD as it has a massive impact on their lives. Doherty et al. (2000) also found that over one-third of the keyworkers participating in their study did not receive any training on autism and that the keyworkers wanted parents to be more involved and have the assurance that their child’s support will be ongoing. In a study conducted by Connolly & Gersch (2013) parents who availed of professional support for their child reported major benefits for both the child and parents.

The findings of a study conducted by Cassidy et al., (2008) suggested that there should be more family-centred interventions and support services available to parents from when their child is first diagnosed and throughout the child's life. There is sufficient research finding that there are not adequate supports for parents of children with ASD, as another study conducted by Dardas (2014) resulted in the parents needing much more support services and need more educational interventions about Autism. This study aims to receive in-depth information from parents of children with autism in regard to support received, if any, if it was easy or hard to avail of, and if it is helpful to them as parents. The literature and research show that there are studies conducted on parents of children with ASD focusing on how high their stress levels are due to lack of support (Deschamps et al., 2019). The following literature will discuss coping strategies for parents of children with ASD (Lai & Oei, 2014).

Coping strategies

It is important that while raising children with autism that parents have coping strategies, these coping strategies not only focus on their emotional health but also focus on their child's physical health (Gona et al., 2016). Lazarus and Folkman's (1984) transactional model of stress and coping explained, coping is a phenomenon that includes cognitive and behavioural reactions in which the individual then uses to try and manage their stressors (Echemendia et al., 2019). According to Lazarus and Folkman (1984), there are two types of coping responses such as emotion-focused and problem-focused. Professional support is a resource which all parents seek to help them gain knowledge about ASD and to cope with the challenges they face daily (Twoy et al., 2007), however for many parents it is a struggle for them to avail of these services due to long waiting lists (Mulligan et al., 2012).

Previous research on coping in parents of children with ASD has been limited, and there were very few studies conducted on what coping strategies are used (Hastings et al., 2005). However, according to a study conducted by Lai and Oei (2014), the coping strategies used by parents of children with ASD to help individuals reduce stress were problem-focused coping and social supports. When a parent of a child with ASD uses social supports as a way of coping, they seek encouragement from family and friends, and they would seek guidance and support from other families that have been through similar experiences, such as other parents of children with ASD (Twoy et al., 2007). Another study conducted by Robertson and Frydenberg (2011) resulted in families using social supports, and positive reappraisal to cope. Positive reappraisal is a cognitive coping strategy that is used by individuals who are dealing with stressful situations (Nowlan et al., 2015). Positive reappraisal aims to restructure an individual's views of a negative stressful situation into a more positive situation (Nowlan et al., 2015). Similarly, in a study conducted by Dardas (2014), it was found that positive reappraisal was the most frequent coping strategy used by parents of children with ASD to help them manage their stress levels.

This Study

The literature shows that many studies highlighted the stressors of parents of children with ASD. This study aims to explore the life experiences of parents caring for children with ASD using qualitative methods such as interviews, which will give an in-depth view of the parents' lives. Any common feelings, emotions, and challenges that may reoccur throughout the participants' interviews will be examined, and if they feel there are sufficient supports available to them. It is evident from the literature that there were insufficient findings on how parents react and adjust to their child's diagnosis and their perception of their partners' reaction, therefore this study aims to address that gap. The findings of this study will potentially help individuals understand more about the experiences faced by parents of children with ASD, and bring to light a direction for more research to be conducted to gain more awareness on this topic, more intervention development, and better practice.

Methodology

Study design

The research study was qualitative by design. The proposed study was suited to qualitative analysis as it allowed the researcher to obtain detailed perspectives from each participant. Using this approach, semi-structured interviews including open-ended questions were conducted to grasp an in-depth understanding of the parents' stress levels, coping strategies, the supports available to them as parents of children with autism, and an understanding of how the main caregivers and their partners reacted and adjusted to parenting life with a child with autism. This study was conducted using Braun and Clarke's (2006) six phases of thematic analysis to analyse the data, and explore any similarities/differences within the interview transcripts and choose common themes (Smith, 2015).

Ethical considerations

The proposed study was ethically approved by the National College of Ireland. Permission was granted from the administration of the 'Irish Society of Autism', and the administrators of Autism Support Groups within Ireland on Facebook, who assisted with recruitment for this study. Participants were provided with a study information sheet containing all the details of the study. An informed consent form was retrieved from all participants before the interviews took place (See Appendix III). All participants could ask questions at any time before, during, and after the interviews. Consideration was given to the fact that some participants may have become distressed throughout the interviews when sharing certain experiences. Therefore, this was documented on the information sheet (See Appendix II), and a list of supports in Ireland available for parents was provided on the debriefing sheet if they needed further assistance (See Appendix V). This information was also mentioned to all participants verbally at the start of every interview. The researcher had also considered that due to government guidelines all interviews had to take place online using an internet connection, which not all participants had access to, therefore some other contact details were gathered. Participants' personal information such as names, email addresses, phone numbers were not disclosed and were all removed after the interviews were transcribed.

Sample/participation

Participants for this study were recruited using a purposive sampling strategy, as it is commonly used in qualitative research (Palinkas et al., 2015). This study required a target audience, which was parents of children diagnosed with ASD who would like to voluntarily participate in the study, therefore it was advertised to recruit that exact target audience (Elfil & Negida, 2017).

The recruitment poster outlined the nature of the study and the requirements which the participants must have met to take part in the study was posted on ASD parent support groups on Facebook and a recruitment blog on the Irish Society for Autism website (See Appendix IV). The research sample consisted of parents of children diagnosed with ASD in Ireland, both male and female. A requirement to participate in this study was that all parents must have been 18 years or over. The child diagnosed with ASD must have been under the age of 18 and diagnosed for at least 6 months before the recruitment of the study.

As many researchers cannot quite determine exactly how many participants should be recruited for qualitative research, many books and articles found that anywhere between five to fifty participants should be adequate (Dworkin, 2012). Following Braun and Clarke's (2019) suggestion that a researcher's sample size should be determined, depending on the data within the research project, this proposed study consisted of eight participants.
All participants in this study met the participant requirements. This study consisted of 7 females and 1 male participant. The participants' ages ranged from 30 to 54 (M = 39.5). Four out of eight participants were cohabiting, three were married and one was

single. Seven of the participants were identified as their child’s main caregiver, the remaining one participant described their partner as their child’s main caregiver. The age of the children at the time of diagnosis ranged from 2 to 8, and at the time of this study, the children’s age ranged from 4 to 15. Five out of eight children were male. Three of the children attended a mainstream primary school, two of which had an ASD unit. One of the children attended a special education primary school. One of the children attended an autism pre-school, and three of the children were in mainstream secondary school.

Materials

The researchers iPhone xs was used to conduct two interviews’, whilst using a voice recording application to record the interviews. The researcher’s MacBook Air was used to conduct six interviews using the Microsoft teams application, which records and transcribes calls. The researcher also used a MacBook air to transcribe the interviews. An interview guide containing open-ended questions was followed, which aimed to gather an in-depth understanding of parents of children with autism’s stress levels, what coping techniques they use, what supports are available to them as parents. At the start of the interview guide, there were demographic questions listed (See Appendix I).

Data Collection

A pilot study was conducted as the interviews were conducted through Microsoft teams. The pilot study allowed the researcher to ensure that there was a strong WIFI connection within the researcher's home, it also ensured that Microsoft word was dependable and that the interview questions guide allowed the interviewees to explore their experiences of parenting a child with ASD freely (See Appendix I). There were eight semi-structured interviews conducted with the participants individually, lasting approximately 25 to 60 minutes. At the beginning of the interview, the researcher asked some demographic questions, and then began asking questions to explore the experiences of parenting their child with ASD, including how themselves and their partners reacted and adjusted to the diagnosis of their child, which led to questions about the challenges they face daily as parents, to the positives they think there is to parenting a child with ASD, then to questions about their stress levels, what supports they have if any, and coping strategies they use to manage the stress. When the interview questions were finished, all participants were thanked and told how much their participation and time was appreciated, they were then provided with a debriefing sheet listing many help services and support groups available in Ireland (See Appendix V). All interviews were recorded and then transcribed (See Appendix VI, all other transcripts available on request).

Methodological Considerations

An inductive approach was used to identify the themes within this study, therefore the themes were strongly linked to the data (Braun & Clarke, 2006). As a close data analysis was conducted, the themes were identified through a semantic approach as the data was collected from the semantic memory of the participants (Braun & Clarke, 2006). This study delves into the lives of parents of children with ASD, focusing on words and phrases the participants use to describe their experiences. This study was conducted from a realist view, as the researcher was taking the data from the transcripts and using that data only (Maxwell, 2012).

Data Analysis

Data analysis was conducted using Braun and Clarke's (2006) six phases of thematic analysis. This allowed the researcher to analyse the data and identify themes based on common reoccurrences among the interview transcripts (See Appendix VI). Firstly, the researcher familiarises themselves with the data, which took place while transcribing the data from the recordings ensuring that the quality of writing was perfect, which gives the researcher a more accurate interpretation of what was being expressed in the transcripts when reading them. The researcher then re-read all the interview transcripts and start coding the data looking for any re-occurring similarities and differences between each of the participant’s interview transcripts. The researcher then generated these codes into potential themes. After further analysis of the codes and potential themes, the researcher then chose the themes and subthemes for this study. The chosen themes and subthemes were discussed in the results section. Please refer to appendix VII to see a detailed illustrative map including themes and subthemes.

Results

Figure 1. An illustrative map displaying Themes and Related Subthemes

The interview transcripts were analysed using Braun and Clarke's (2006) thematic analysis. As shown in Figure 1, during the process of data analysis, four key themes were identified: 'Shock, Denial, Disbelief': Initial Response to Diagnosis, The Learning Curve, The ASD Journey, and Minding Yourself as a Parent of a Child with ASD. See Appendix VII, to view a detailed illustrative map displaying these themes and related subthemes.

Theme 1: 'Shock, Denial, Disbelief': Initial Response to Diagnosis

The first theme identified from the data was 'Shock, Denial, Disbelief': Initial Response to Diagnosis. One subtheme was found within this theme such as, Perception of Partners Response. Having analysed the transcript's the data showed that the majority of parents' experienced negative initial responses to their child's diagnosis of ASD, "the two of us were a bit speechless. It was kind of like no one spoke, we were just shocked" (Participant 7). Participant 5 portrayed that she was "heartbroken".

After analysing the transcripts, the data demonstrated that there was a sense of disbelief and denial from a number of participants, initially they did not want to believe that their child had a disability, "I didn't believe it! I didn't think there was anything wrong with him" (Participant 6).

Several participants described that they felt a sense of loss, “you need to grieve for what you're going to lose because you are going to lose what you thought you had” (Participant 3).

Many participants expressed that they were also feeling quite scared due to a lack of direction and knowledge about autism. Participant 2 revealed,

> “I was terrified because I didn't know enough about it and I just thought the worst like I thought, I literally thought autism was the worst thing in the world. I didn't know it was a spectrum I didn't know I was just scared like, I didn't know enough about it and what to do next”

Similarly participant 8 noted, “it's like here's a diagnosis, your son has autism, now you go and do everything.”

Perception of Partners Response

Perception of Partners Response was determined as a subtheme in this section. After analysing the interview transcripts, seven of eight participants who were married or cohabiting, all perceived that their partner did not show their reaction as much as they did themselves, they felt that their partner was almost embarrassed at first and it took a while for their partner to adjust to the diagnosis of his child and open up about it. One participant shared,

> “I would say we both felt the same, but I just showed it a lot more he kind of, was a bit more like, nearly embarrassed to talk about it or say much at the time. So yes, he kind of didn't really talk about it, whereas I told everyone, and I cried to everyone. Like he

> eventually just got so fine with it, I mean now he would tell people before they even meet my child" (Participant 2)

The majority of female participants revealed that their male partner did not understand the extent of the diagnosis and how it may impact their child's life. One participant described,

> "I don't think he fully understood autism. He kind of didn't know what it was, so he kind of took on the chin. It was only when he sat down and read the report that he had tears in his eyes reading it because he realized then that it's a lifelong condition. So, I think once he read into it, he kind of understood more so at the time no he wouldn't have been the same as me. He kind of took a bit longer to realize" (Participant 8)

However, many of the partners were perceived as strong, they held their emotions together so that they could support the participants. Participant 3 noted that her husband was "much more level-headed". Similarly, participant 5 revealed, "My husband said to me, she's the child she was the minute before you were told that your daughter has autism, so she is the same child now."

Theme 2: The Learning Curve

The second theme to emerge from the data was The Learning Curve. There are three subthemes within this theme such as, Parenting, Social Perceptions, and Self-Discovery.

Parenting

Parenting was identified as a subtheme in this section. Analysis of the transcript showed that as a parent, when your child is first diagnosed with ASD, due to the lack of information and direction received, you must educate yourself about ASD, about the impacts of the diagnosis on your child, how you can meet their needs, and support them as best you can. For instance, participant 2 mentioned:

> “I didn't even know an autistic school was a thing and I didn't even know there were special classes, back when my child was diagnosed. I just thought he was never going to school ever, like it was so bad” (Participant 2)

Parents must prepare for their whole life to change, which several participants described as a huge stressor, “it was a struggle,” (Participant 7). The lifestyle change was hard on both the parents and the siblings. One participant revealed:

> “She doesn't like a lot of noise. So, we kind of have to be quiet no singing, you can’t cheer or anything like that and so there’s certain things, so you kind of have to be mindful of that (…) if one of the other kids might start singing a song and it would set her off, so it’s kind of stressful, but you also don’t want to be not letting the other kids sing. So, your always mindful of what’s going to set her off” (Participant 5)

The majority of participants learned how different it is going out with a child with ASD:

> “If I wanted to go to the, to the shop. It's kind of like I have to plan the whole journey and tell him before, and when I get there, he is constantly screaming and looking to run off and stuff like that” (Participant 8)

However, many participants portrayed that they had learned many positives while parenting a child with autism, “I think it really opened my mind to how clever people with autism are” (Participant 2). “They're all like their own individuals” (Participant 1).

Many participants mentioned that they had learned how loving and caring children with ASD are. One participant revealed:

> “it's a real different kind of love (…) people will never understand the love you get from your kids with autism like when they come over and just give you a hug or a kiss, they really mean it, whereas like, my other little one will give you a hug and a kiss, every five minutes just for any reason or so she can have a sweet or get something, you know, but when he gives one it’s just so meaningful it's just, I don't know, it's a real like raw true form of love” (Participant 2)

Similarly, another participant described her child with ASD as a special gift,

> “They are all a special gift, but it is just amazing to see that not one child with autism is the same they are all their own individuals, and the love and care my son shows in his own way is so special to us all, he is the most caring person in the house” (Participant 4)

Social Perceptions

Social Perceptions was chosen as a second subheading within this theme. Analysis of the transcripts demonstrated that adjustment to the judgement received when in public with their child with ASD was extremely stressful for participants, “people do tend to stair and judge, that's quite stressful” (Participant 7). This judgement has also caused fear for many participants, “we didn't go on holiday until he was, I think nearly six because I was terrified to sit on an airplane with him because of people's reactions” (Participant 7).

All participants mentioned that they received judgement in public places, which brought some participants sadness and others anger. For instance, two participants stated:

> “They look down on him because he’s different, he does not look different, but he is very socially awkward, self-conscious, and his hands can fidget a lot, he also can be in his own head sometimes and would be laughing to himself. For example, in the shops, he’d start to laugh to himself thinking of something in his head, which others find weird and look at him strangely, but the way I see it is who are they to judge? leave him alone he’s happy!” (Participant 6)

> “I find the biggest thing for me is being out in public. When people are staring with the noises, sometimes my child makes the stimming noises, (…), but it wouldn't even be children staring it's more the adults, and if he's having a meltdown, they just kind of tend to like talk, give us looks and roll their eyes, and they don't understand! I find that the hardest. Even if he was just having a bold day and he didn't have autism, like who are they to judge?” (Participant 8)

Self-Discovery

‘Self-Discovery’ was identified as the third subtheme within this section. After analysing the transcripts, it was evident that all participants had discovered many things about themselves throughout this learning process. One participant mentioned, “it’s made me stronger as a parent” (Participant 2). When asked what advice they would give to a parent with a newly diagnosed child with ASD, participant 7 stated, “don't give up”. Similarly, participant 2 said “just keep fighting” and “don't be afraid”. A number of participants mentioned that they have to fight for everything which is incredibly stressful, participant 8 described it as “a constant battle”.

From the analysis of the transcripts, it was clear that throughout the learning process all participants learned many similar things about themselves, one being resilience, they learned that they had to fight for their child no matter what, and not to ever give up. For instance, one participant shared, “Fight! don't sit back and just take yes we'll have you on a waiting list, (…) fight to get all the help for your child’s needs, and never give up!” (Participant 4).

Another common discovery which was learned throughout the learning process was patience. Many parents noted that you need to have a lot of patients with your child, “have patients, be strong, and keep fighting for the supports your child needs” (Participant 6).

Theme 3: The ASD Journey

The ASD Journey was the third theme discovered from the analysis of the data. This theme consists of three subthemes: Accessing Services for your Child, Dependence, and Fear for the Future.

Accessing Services for your Child

Accessing Services for your Child was identified as the first subtheme within this section. Analysis of the transcript showed a huge lack of support services for children with ASD, and for the parents, “there's just not enough support” (Participant 7).

There is a lot of uncertainty around support services, many participants mentioned that they have been on waiting lists for years. For instance, participant 8 described:

> "Support would be a big stress for me, but I just think that there is always going to be waiting lists, so there is actually not much you can do about it, just research and try and enforce the stuff you're learning online at home" (Participant 8)

The majority of participants mentioned how long the waiting lists can be, one participant mentioned:

> "He has been on a waiting list again since he was 10 for occupational therapy, and he more needs speech and language which he also hasn't had since he was 10, and now is almost 16, and still hasn't gotten any, and there finishing with him because of his age and referring him on to the another team to see if they can facilitate him better. But we might not even get seen to because of covid, so we don't know, and I feel like I'm just lost in their records at this stage" (Participant 4)

Similarly, another participant stated, "they don't care, they leave you on waiting lists for years" (Participant 6). While participant 7 revealed, "you have nowhere to turn if, if you're struggling."

The data collected shows that lack of supports is a huge experience within the ASD journey, a number of the participants shared that when they finally got their first appointment with a support service, they were relieved, to then be disappointed,

> "The speech and language therapy he got on great with one of the girls, that helped him a lot. And then she left, and he hasn't had any since and they didn't put him with someone else, they just left him and when we asked about it, we are told were on a list again" (Participant 4)

Similarly, another participant mentioned, “I feel like the little, tiny bit of work that they were given us or help, now they're just like taking that back,” (Participant 7).

During the interviews participants spoke about how it would be a significant help if there were also supports put in place for the parents. Participant 3 shared:

> “I think there should be something that parents have, whether it's access to counselling or whether it’s sessions that are parent only, as in you know, how to deal with stress or how to understand that it is ok to feel sad, or even sessions that might empower parents. So, it's okay to feel bad but here's what can happen, or you know, here's why we're doing what we're doing” (Participant 3)

Dependence

The second subtheme identified within this section was Dependence. Having analysed the interview transcripts, it was found that children with ASD are more dependent on their main caregiver compared to other children with no disabilities, “you’ve to spend more time with them than other children with no disability” (Participant 6). Similarly, another participant explained, “she’d have to be watched a lot because she would run, so if we leave the door open, she’d run out the door. We have to watch her a lot more than her siblings” (Participant 5).

The majority of the participants described that they must do everything for their child with ASD, participant 8 shared,

> “I dress him, I bathe him, I feed him. I teach him things, I sit him down and teach him how to do his alphabet, his letters, his numbers, everything like that (…) I'm his voice, I'm his teacher, I'm everything to him”

The participants with older children with ASD, mentioned that their children with ASD are still quite dependent on them, however, it is important that they have some independence, one participant explained:

> “I do an awful lot for him you know, it just comes natural to you, but he’s a teenager now so that’s why we have to let him do things for himself, for a bit of independence, but we will always have to still fix what he does, but it is a progress” (Participant 4)

During the interviews, it was common among many participants that their children can be quite mischievous, so they must be watched all the time, “he's mischievous like he gets up to all sorts I have to watch him all the time” (Participant 8). Similarly, participant 2 shared:

> “keeping him safe is a challenge like he climbs the counters daily and I have to make sure the doors are always locked (…) So yeah it's just, like, keeping him safe and, and eating is so much easier with our toddler that does not have a disability”.

After analysing the transcripts, it is evident that caring for a child with ASD is a bit more stressful than caring for a child of typical development “taking care of any child would increase stress levels, but it is a bit more stressful taking care of a child with autism because they need a lot more care” (Participant 1).

Fear for Future

Fear for Future was found as the third subtheme within this section. Analysis of the transcript demonstrated that the majority of the participants feared for their child’s future. Participant 2 described:

> “I know the both of us stress and worry every day and especially about the future like you just can't help but think about the future all the time, worrying about what way he'll be or where he'll be and stuff like that, so it definitely, definitely increases our stress levels at home, and in regard to the future.”

Despite the majority of the participants being fearful for the future, some mentioned that they are also hopeful, as they are seeing their child develop daily and learn new things, so they hope that when their child grows older, they will continue to learn and hopefully be independent. One participant revealed:

> “Even for my child’s future, I’m terrified in one sense. Because obviously, I don't know. But at the same time, I'm also quite hopeful because, from the child, we had to the little girl we have now there's been huge leaps and bounds” (Participant 3)

During the interview’s, several participants shared that a lot of their fear was because they will not be around forever to care for their child with ASD and that the future is out of their control, “I fear for his future, like the things that you can’t control” (Participant 3). Similarly, another participant whose child with ASD suffers from anxiety and depression said, “that's the worst and scariest challenge because you don't know what's coming up and what he's going to do” (Participant 4).

Theme 4: Minding Yourself as a Parent of a Child with ASD

The fourth theme to emerge from the data was, Minding Yourself as a Parent of a Child with ASD. This theme consists of two subthemes, Positive Attitudes, and Social Supports.

Positive Attitudes

Positive Attitudes was identified as a subtheme within this section. After analysing the transcript, the data showed that parents of children with ASD face challenges daily which causes them major stress. Therefore, the parents that participated in this study described that for them to cope, they must think positive.

The majority of participants explained that when they are in a stressful situation with their child, they stay calm and think positively. For instance, one participant shared, "I stay calm and try to think as positive as I can, and need to make sure he is ok before my stress levels go down" (Participant 4). Similarly, another participant mentioned, "there's no point in me being crazy and stressed out when he's he really can't help how he is, but I can, I can control how I'm feeling where's he can't" (Participant 8).

However, for the participants to stay positive through all the challenges and stressful situations, they need to have a lot of patience. One participant described:

> "Take a step back and try not lose the plot, so basically be calm, and also try to think positive and remember that he does have a disability which is why he needs extra time to learn or understand things, so you need to be very patient" (Participant 6)

Social Supports

Social Supports was found within the data as the second subtheme within this section. Analysis of the transcripts showed that several participants cope with the support of their partner, family, and other parents of children with ASD.

The data demonstrated that many of the participants rely on their partners to help them cope, “we're very good like as a husband and wife and like recognizing if the other person is stressed like I could say, (…), I need to get out of here” (Participant 7).

Throughout the interviews, the majority of participants mentioned that they could not cope without the help of their partners and family members. For instance, one participant explained, “if I didn't have my family around and my child’s dad, there's no other people that I can go out with, like no other people that have autistic kids” (Participant 1).

Having analysed the transcripts, some participants shared, that by finding other parents that have children with ASD, helps them cope with the stress, because the other parents understand as they have experienced the same challenges. Participant 2 described:

> “When I found the school, I found great support in the parents there, (…) so it definitely helps to find those supports in other people who are going through the same, because you feel normal again by hearing, you know you can talk to other parents, whereas I can't talk to my other mommy mates who just have kids without autism because they just don’t understand, they don't know what we're going through, so it's so much easier to find other families, that definitely helps me”

Many participants coped with the help of social supports, now those participants help other parents of children with ASD. One participant shared, “please talk to me like ask me questions, ask other parents questions they are the ones who know the best. They know all information” (Participant 2).

Discussion

This study used a qualitative approach to explore the experiences of parenting a child with ASD, to get an in-depth understanding of the challenges faced by parents, their stressors, coping strategies, how they reacted and adjusted, and their perception of their partners reaction and adjustment to the diagnosis of their child. A thematic analysis of interviews conducted, identified four key themes: 'Shock, Denial, Disbelief': Initial Response to Diagnosis, The Learning Curve, The ASD Journey, and Minding Yourself as a Parent of a Child with ASD.

Regarding the first theme identified in this study 'Shock, Denial, Disbelief': Initial Response to Diagnosis, similarly to Wachtel and Carter (2008), all participants experienced a negative initial reaction to their child's diagnosis, and their perceptions of their partners' reactions were also negative, although they did not initially show their emotions as much as the mother. It was found that female participants' perceptions of their male partners' initial response, was that they controlled their emotions to portray as the strong parent to support their partner, and they did not understand the diagnosis. Parents receiving such shocking information about their child, which they lacked knowledge about, affected them tremendously, they felt that they received a diagnosis for their child with little information and direction (Salleh et al., 2020). Consistent with Shilubane and Mazibuko (2020), this study suggests that professionals need to be more aware of ASD, to help parents understand autism. Similarly, Shrestha et al. (2021) highlighted the urgent need for autism awareness programs to be put in place, to raise parents understanding of autism.

Denial and Disbelief, were two of many reactions discussed by parents. The findings suggest that denial may have been an attempt to cope with the shocking diagnosis of their child. Denial may have acted as a defence mechanism against the news of the diagnosis, as the truth was too painful and overwhelming at the time, therefore the parents would not believe what they were being told. Greif was also mentioned, as parents have wishes for their children during pregnancy and when their child is young, however, when parents received their child's diagnosis, they initially felt a sense of loss. They knew their child may not be capable of the things a parent would wish for. These findings corresponded with previous studies (Bravo-Benítez et al., 2019; Gentles et al., 2019).

In regard to the second theme, The Learning Curve, parents expressed many stressful challenges faced while adjusting to life parenting a child with ASD, including educating themselves about autism and how to meet the needs of their child, learning to cope with judgements in public places, and discovering many positives about themselves and their child. This study found that adjusting to living with a child with ASD had an impact on both the parents and siblings, which highlighted the importance of professional supports for the family, such as family-centred interventions and individual parental supports tailored to their needs (Meyer et al., 2011; Cassidy et al., 2008; Dardas, 2014). Similarly, to Ryan (2010), this study revealed that when parents wanted to go out, they had to learn to prepare their child with ASD to avoid meltdowns, involving giving the child much notice and explaining exactly where they are going, what for, and when they will be home.

Findings also discussed how both the children and parents experienced negative judgements, due to the behaviours of their child in public places, which is perceived by the public as a bold or a spoiled child due to lack of awareness about ASD (Salleh et al., 2020). This resulted in sadness, anger, and an addition of stress for parents (Farrugia, 2009; Schwartz, 2001). However, if the child was to identify their autism on an ASD ID card worn around their neck in which they can wear in public places, they may avoid negative judgements (Ryan, 2010). Although the parents' learning process was stressful, this study revealed that there were also positive things learned (Neely-Barnes et al., 2011). Participants mentioned that they learned that children with ASD are extremely loving and caring people, and that parenting their children with ASD has learned them to be resilient, as it has made them a stronger and better parent. Therefore, in the future instead of parents ‘adjusting’ to life parenting a child with autism, it should be referred to as ‘growth’ in a parent of a child with ASD (Waizbard-Bartov et al., 2018).

The third theme within the study, The ASD Journey, highlights the lack of support services for children with ASD which heavily impacts the parents’ stress levels. The participants explain their dreadful experiences in which they feel forgotten about. Many of them had no supports in place for their child, and the parents that did receive some supports for their child described how staff turnover is a huge problem, which led to two main problems, a huge gap between appointments, and waiting lists lasting years (Connolly & Gersch, 2013; (Loumidis & Shropshire, 1997). It was found that the lack of supports and constant fighting for supports impacted both the child and the parent negatively (Rivard et al., 2014; Connolly & Gersch, 2016). This study highlighted the importance of how children with ASD need certain supports depending on the severity of their condition, as it helps the children learn to cope with the unique characteristics of their diagnosis, and without those supports put in place it negatively impacts the child, and heavily impacts the parents’ stress levels (Ingersoll & Hambrick, 2011). The findings also revealed that parents need supports before their child’s diagnosis, during the process of diagnosis and throughout their journey caring for their child, as it can have an extreme impact on their psychological wellbeing (Murphy & Tierney, 2006; Reddy et al., 2019; Hartley & Schultz, 2014).

Similarly, to Myers et al. (2009) and Reddy et al. (2019), this study highlights how children with ASD are more dependent on their parents compared to children without a disability. Depending on the severity of their child’s diagnosis, the parents do everything for their child and have to constantly watch and protect them, which causes fear and severe stress for parents as ASD is a condition which requires life-long care and commitment. In correspondence with Watson et al. (2013) parents all feared for their child's future due to not knowing what will happen to their child when they are not able to provide care for them, and whether their child will progress to have some independence. However some parents remained hopeful that their child will progress. This highlights the importance of life skills intervention programmes for adolescents diagnosed with ASD, for them to gain a bit of independence which would benefit both the children and the parents.

Similarly, to Mount & Dillon (2014), findings within the theme Minding Yourself as a Parent of a Child with ASD, suggested that positive attitudes and social supports help parents cope throughout their time caring for their child. Similarly, to Robertson and Frydenberg (2011) and Dardas (2014), this study found that thinking positively in challenging times helps parents look at the bigger picture rather than how bad the situation is in that moment, and to separate the behaviour from the individual. This helps them stay calm and have patience, which de-escalates the situation. In correspondence with the findings of Lai and Oei (2014), this study found that parents heavily rely on social supports to cope with their challenges. Participants would be lost without help from their partners and parents, and they also confide in other parents of children with ASD as they can understand what each other are going through. Other parents of children with ASD can help as emotional support as well as advising them how to manage challenging difficulties.

Overall, this study highlights the challenges faced daily by parents of children with autism, and how stressful these challenges are which is similar to findings by Cappe et al. (2020). It showed that parents of children with ASD face a tremendous amount of stress, which parents with a child of typical development and parents of children with other disabilities may not face (Bonis, 2016; Dunn et al., 2001; Rivard et al., 2014). Similar to Cassidy et al. (2008) and Dardas (2014), this study highlights the importance of professional supports and interventions put in place for both the child with autism and the family as the family’s psychological well-being will be reflected upon the child. These findings should be considered by healthcare professionals to make themselves more aware of ASD (Salleh et al., 2020) and to put in place family-centred sessions educating the family about ASD, and how to cope with the stress (Dardas, 2014).

Clinical Implications and Future Direction

The findings from this study highlighted many clinical implications. Similarly, to Shrestha et al. (2021), the current study found that for professionals to provide beneficial support to parents of children with ASD upon the diagnosis and throughout their journey, they must have more awareness about ASD. The lack of knowledge about ASD from professionals was evident, which caused a major stress increase and fear for the parents. It was also revealed that participants found support in other parents of children with ASD, who provided each other with advice and emotional support, as they could understand and relate to what each other was going through.

However, there are boundaries as to how much personal information a parent would share with another parent, such as the impact that the diagnosis and the challenges are having on their partner and other family members well-being. Therefore, there should be family-centred services put in place for the families, such as counselling. Counselling would help the family members by providing them the tools they need mentally to manage the stress and guide them through the challenging behaviours. It would help parents realize that it is ok to feel sad and exhausted at times and advise them as to how they can manage those feelings.

Future research may develop this study further, by increasing the sample size, to get a broader insight into the lives of parents of children with ASD and comparing the parents’ experiences by age group of their child, and by who receives support and who struggles to receive any supports. This insight would gain more understanding of the challenges faced by parents over the years, and if there was a common age group found to be the toughest for parents. Future research should also consider comparing male and female participants, and recruiting one-parent families, as in the current study only one participant was a lone-parent.

Strengths and Limitations

One strength was that this qualitative study adds to many other standing qualitative evidence, which provides more experiences of parents of children with ASD from different perspectives. The use of a thematic analysis allowed flexibility within the data analysis and interpretation of the data. Another strength of this study was the one-to-one interviews as it gave the researcher the opportunity to receive detailed answers, which may not have been provided in a group setting.

However, there were some limitations to this study. The number of participants was limited as the researcher had to stay within certain time restrictions. Another limitation of this study worth considering is that due to the current government restrictions, interviews had to be conducted online, and some participants had WIFI connection issues, therefore the researcher resorted in conducting those interviews over the phone. If it was possible to be physically face to face with the participants, it would have allowed the researcher to capture non-verbal ques. Participation in this study had no direct advantage to participants, which was a concern in regard to recruitment for the study. However, the researcher did not struggle to find participants, as many people were willing to share their experiences. It was considered that the participants may not give in-depth and truthful answers due to how emotional their answers may have been, however, this was not a problem. All of the interview questions contributed to the strength of this study.

Conclusion

In conclusion, the current study has contributed to research concerning parenting a child with ASD, the stressful challenges faced by the families, and how they cope. This research shows that there is a great amount of knowledge about ASD to be learned by both individuals within the society, and professionals, which will positively impact both the parents and children diagnosed with ASD. The findings also revealed that the parents lived stressful challenging lives, in which they received little supports, therefore, they had to experience this lifelong journey without much direction or advice from professionals. This study highlights the importance of professional supports for children with ASD and their families, starting when the parent first expresses worries about their child, through the process of diagnosis, and after their child’s diagnosis. It calls attention to the importance of ASD interventions to be put in place, and it also revealed the positives to parenting a child with autism. It adds to the insufficient amount of literature regarding parents' reactions to their child’s diagnosis and their perception of their partners reaction. The researcher wishes to expand this study further in the future, as there was a multitude of data collected.

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Appendices

Appendix I - Interview Questions Guide

General and demographic questions:

1. What age are you?
2. What is your marital status?
3. How many children do you have? What child has autism (as in eldest, youngest middle) and what age are they now?
4. What age was your child when diagnosed with ASD?
5. Are you the main caregiver?
6. Do you have a partner? Or did you at the time of your child diagnosis? If yes, what age? (If answered no, skip Q's 8 & 17)

Experiences – stress, coping, supports:

7. How did you feel when you first learned your child was diagnosed with autism?
8. Skip Did yourself and your partner react and adjust to the diagnosis in different ways? If yes, can you give an example of the different ways?
9. What does your average day consist of caring for a child with autism?
10. Are there any difficulties/challenges that you come across daily?
11. Tell me a bit about your experience of having a child with autism.
12. What positives are there to parenting a child with ASD?
13. In your opinion does caring for a child with ASD cause an increase to stress levels for parents? If so, why?
14. Do you have an example of a situation where your stress levels were increased?
15. What are the main factors you find stressful?
16. Are there particular strategies you use to cope?
17. Skip Do you and your partner cope with these stress levels and challenges differently? If yes, can you give an example of how they cope differently?
18. Do you feel that there is helpful support available to parents with children diagnosed with ASD? Who/what are your key sources of support?
19. Can you tell me about an experience where you felt there was no support? And a time you received helpful support?
20. What are the most important supports to have available to you as a parent of a child with ASD?
21. How do you think other family members, friends, and people in the community view children with autism?
22. Lastly if you could give advice to a parent with a newly diagnosed child with ASD what would it be?

Appendix II – Study Information Sheet

The experiences of parenting a child with autism.
My name is Katie Kelly Foran, I am a final year BA psychology student in the National College of Ireland. As part of our degree as a psychology student, we must conduct an independent research project. The research project in which I have chosen to do is the experiences of parenting a child with autism. For this research project I am looking to recruit parents/caregivers of children diagnosed with autism spectrum disorder (ASD) to take part in an interview. The aims of this study are to get an in depth understanding of the life experiences of parents caring for children with ASD and explore parents stress levels and the coping strategies they use, and if mothers and fathers cope differently. We also aim to look at supports available to the parents if there is enough and if they are helpful to parents. This research project has been approved by the Psychology Research Ethics Committee.

What will taking part in this study involve?
In this study, if you decide to participate you will be asked to take part in an interview over the phone/computer (your own preference), at a time that suits you. The interviews will take approximately 30/40 minutes. The interview questions will be about your life experiences caring for

a child with autism. The interviews will be recorded by an app, and then transcribed, so that I can collect the data.

Who can take part in this study?
All participants must be parents aged 18 years or over, and have a child diagnosed with ASD for at least 12 months.

Participants' rights:
Participation in this study is voluntary. It is completely your choice whether to take part or not, and if you decide not to take part there will be no consequences. If you do decide to take part in this study, you may decide to stop being a part of the research study at any time during the interview without explanation. You have the right to ask that any data you have supplied to be withdrawn/destroyed up until the interview is completed and transcribed, as the data will be unidentifiable after it is transcribed, and all identifiable information is deleted.
You have the right to have your questions about the procedures answered (unless answering these questions would interfere with the study's outcome). If you have any questions as a result of reading this information sheet, you should ask the researcher before the study begins.

Benefits and risks of taking part in this study:
There are no known benefits for you in this study. However, the information gathered in this study may be beneficial to future research within this topic and may contribute to a greater understanding of this topic.
There is a possibility that some participants may experience minor distress, if the interview questions cause them to discuss certain upsetting experiences they have had. If any participant feels upset for any reason, they can take a break, or can stop the interview. Whether participants complete the interview or not they will be emailed a debriefing form with information for mental health organisations and information for parent support groups in Ireland for parenting children with ASD.

Confidentiality/Anonymity:
All of the information given will be completely confidential. The interviews will be one on one with the researcher over the phone/computer. The data collected will be potentially identifiable, the researcher will not be collecting any names or addresses of participants, however, the researcher will see the participants email or number throughout the interview process. Therefore, all emails/numbers will be deleted as soon as the interview is completed and transcribed. Any identifying information mentioned throughout the interviews will be edited in the transcriptions. Therefore, from the time the interview is completed and transcribed, the information will then be unidentifiable. The interview transcriptions will be labelled as participant 1, participant 2 etc… If participants mention any identifiable information throughout the interviews, i.e., names of child, partner, school, area etc., that identifiable information will be edited in the transcriptions, so that the information will be completely unidentifiable after the interviews are transcribed.
The only people that will have access to the data collected will be the researcher and the researcher's academic supervisor. However, in the unlikely event that either the researcher or the academic supervisor feels that the participant or another individual is at risk of harm or danger, or a law has been broken, they would be required to share this information with the authorities. This would be very unlikely to happen, if it does happen, the researcher will contact you and discuss this with you first, but they may have to breach the confidentiality with or without your permission.
The recordings of the interviews will be stored in a password encrypted file on the researcher's computer, which will also be password protected. Once all the recordings are transcribed, they will be deleted. Consent forms and Interview transcripts will be stored securely as electronic, password-protected files on a password protected computer, where only the researcher can access them. Interview transcripts and consent forms will be stored for 5 years in accordance with the NCI data retention policy.
Data protection officer: Niamh Scannell
Contact email: Niamh.scannell@ncirl.ie

Results of this study:
The results of this study will be presented in my final dissertation, which will be submitted to National College of Ireland. As this is a qualitative study, direct quotes from the interviews may be included in the presentation of results, these quotes will be identified as Participant 1, Participant 2 etc... The results of the project may be presented at conferences within the college and at a national level or submitted to an academic journal for publication.

If you would like further information me or my supervisor would be happy to answer any questions you have. You may contact:
Katie Kelly Foran
Undergraduate researcher
National College of Ireland
Email – KatieKellyForanNCI@gmail.com
Research Supervisor: Dr Conor Nolan
Research Supervisor email: Conor.Nolan@ncirl.ie

Appendix III – Consent Form

The Experiences of Parenting a Child with Autism

- I agree on a voluntary basis to participate in the research project; The experiences of parenting a child with Autism.
- I agree that I am 18 years old or over.
- I agree to participate knowing that I have a right to withdraw at any stage during the interview without any penalties incurred.
- The study has been clearly explained to me and I have been given the opportunity to ask any questions I have in relation to the study.
- I understand that participation involves a semi-structured interview that will last 30-40 minutes in duration.
- I understand that I will not benefit directly from participating in this research.
- I agree to my interview being audio-recorded and once this the data is transcribed that the audio files will be deleted.
- I understand that all information I provide for this study will be treated confidentially and will be un-identifiable in the final year project.
- I understand that parts from my interview may be quoted in a final year project and that it may or may not be published. These quotes will be labelled as participant 1, participant 2 etc…
- I understand that after the interviews are transcribed, I will not be able to withdraw my participation as all identifiable information will be deleted, and labelled as participant 1, participant 2 etc… Therefore, from then on, the information will be unidentifiable.
- I understand that the researcher is obliged to report to the relevant authorities any information that Is given that may be a potential risk to me or another party. They may do this with or without my permission.
- I understand that consent forms and interview transcripts will be stored in secure storage for 5 years, in accordance with the NCI data retention policy.
- I understand that both the researcher and academic supervisor are available for me to speak with if required.

By ticking the box below 'I agree', you are agreeing that: (1) you have read and understood the Participant Information Sheet, (2) questions about your participation in this study have been answered satisfactorily, (3) you are aware of the potential risks (if any), (4) you are giving your full consent to partake in this study, and (5) you are taking part in this research study voluntarily (without coercion). If you are happy agree and click the 'I agree' button, then please click the 'submit' button below to submit your consent form.

I agree ☐

Appendix IV – Recruitment Poster and Blog

Recruitment Poster

NATIONAL COLLEGE OF IRELAND

DO YOU HAVE A CHILD DIAGNOSED WITH AUTISM?

IS THE CHILD UNDER THE AGE OF 18?

ARE YOU OVER THE AGE OF 18?

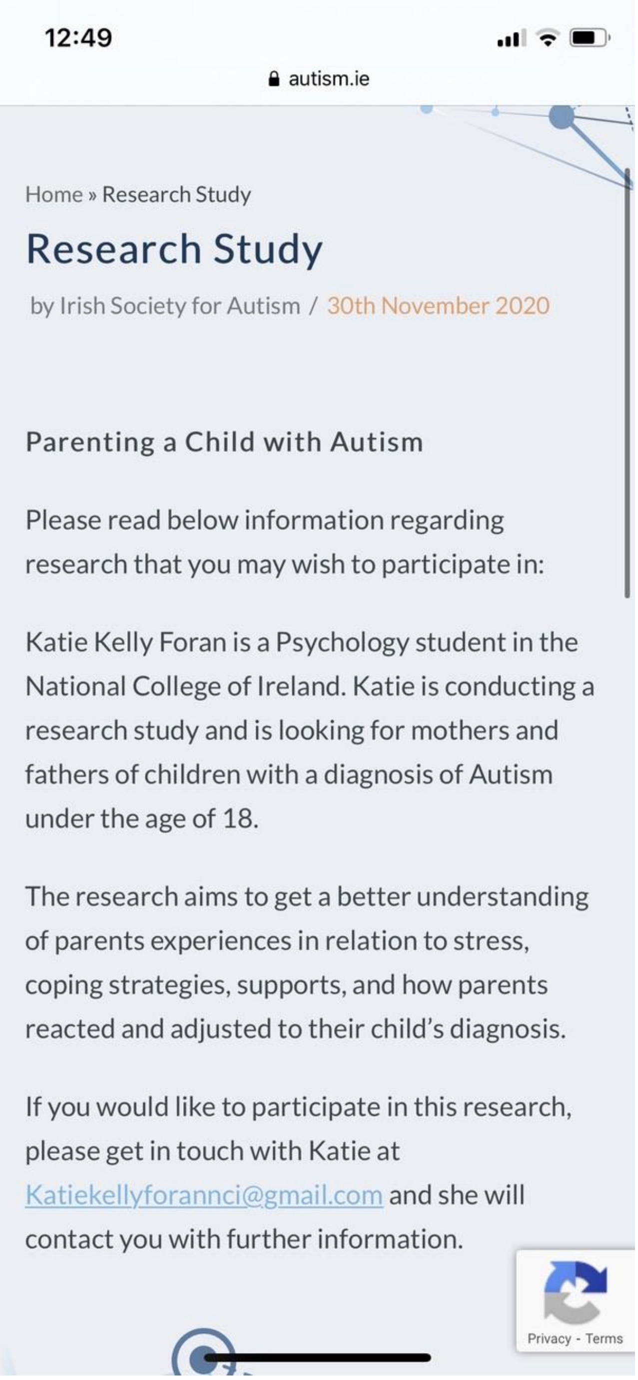
WE ARE CURRENTLY LOOKING FOR MOTHERS AND FATHERS OF CHILDREN WITH ASD TO PARTICIPATE IN A RESEARCH STUDY.

We want to get a better understanding of parents experiences in relation to stress, coping strategies, supports avaliable to you, and how mothers and fathers reacted and adjusted to their child's diagnosis

If you are interested in taking part in this study please contact the researcher at KatieKellyForanNCI@gmail.com and she will send futher information

Researcher : Katie Kelly Foran
BA (hons) Psychology

Recruitment Blog on the 'Irish Society for Autism' Website



Home » Research Study

Research Study

by Irish Society for Autism / 30th November 2020

Parenting a Child with Autism

Please read below information regarding research that you may wish to participate in:

Katie Kelly Foran is a Psychology student in the National College of Ireland. Katie is conducting a research study and is looking for mothers and fathers of children with a diagnosis of Autism under the age of 18.

The research aims to get a better understanding of parents experiences in relation to stress, coping strategies, supports, and how parents reacted and adjusted to their child's diagnosis.

If you would like to participate in this research, please get in touch with Katie at Katiekellyforannci@gmail.com and she will contact you with further information.

Appendix V - Debriefing Sheet

Thank you for taking the time to participate in the study 'The experiences of parenting a child with autism'. This study aims to investigate the understanding of the stressors involved in the lives of parents caring for children with autism. Which we hope will result in more awareness of the experiences they encounter daily and that parents need more helpful supports available to them.
Thank you so much for your cooperation.
If you have any questions at all regarding this study you may contact Katie, the researcher, at x18313533@student.ncirl.ie.
If you feel distressed or in harm there are many mental health helplines listed below, that you can contact for free to help you with your struggles. If you feel you need more support as a parent of a

child with ASD, I have also listed many support groups throughout Ireland for parents of children with autism.

Mental health helplines:
SAMARITANS IRELAND: 116 123 or visit Samaritans.org.
PIETA HOUSE
1800 247 247 or visit http://pieta.ie/.
AWARE: 1800 80 48 48 or visit Aware.ie.
JIGSAW.IE: Visit Jigsaw.ie
GROW.IE: 1890 474 474 or visit Grow.ie.
YOURMENTALHEALTH.IE: Visit Yourmentalhealth.ie.
SHINE.IE: Visit Shine.ie.

Support groups among Ireland for parents of children with autism:
Dublin:
The Tallaght Autism Parents Support Group – Email: tpasg.info@gmail.com
Social Circle (Tallaght) - https://www.facebook.com/SocialcircleASD/?epa=SEARCH_BOX
Snowflakes (Swords) - https://www.facebook.com/Snowflakesautismsupport/
Ripples - https://www.facebook.com/pg/Ripples-279047178893332/about/?ref=page_internal
Prism (Dun Laoghaire) - https://www.facebook.com/prismdlr/
Jump - https://www.facebook.com/JumpAutismSupport/
Open Spectrum - https://www.facebook.com/groups/1076855992350419/
South Dublin ADHD and ASD Parent Support Group - https://www.facebook.com/pg/asdadhdsouthside/about/?ref=page_internal
Ausome Support Dublin – Bridging the Gap - https://www.facebook.com/ausomeautismdublin/
Gravity Autism Support – www. http://gravityautismsupport.simplesite.com/ / https://www.facebook.com/pg/gravityautismsupport/about/?ref=page_internal
Parent Led Autism Network - https://www.facebook.com/groups/160757657944743/announcements/
Lucan Autism Network - https://www.facebook.com/pg/lucanautismnetwork/about/?ref=page_internal
Friends of Autism and ADHD Ireland - https://www.facebook.com/pg/friendsofautismadhdltd/about/?ref=page_internal
D8 & Bluebell Parents Association for Autism Inclusion - https://www.facebook.com/pg/D8andBluebell.P.A.A.I/about/?ref=page_internal
Spectrum Kids Fitness - https://www.facebook.com/pg/spectrumkidsfitness/about/?ref=page_internal
Autism Support Dublin North - https://www.facebook.com/autismsupportdublinnorth

Carlow:
Carlow Autism Support - https://www.facebook.com/pg/Carlow-Autism-Support-1431876660429730/about/?ref=page_internal
Galway:
The Galway Autism Partnership (GAP) - https://www.facebook.com/galwayautismpartnership/
Cork:
The Rainbow Club - https://www.facebook.com/rainbowclubcork/
Shine Centre for Autism - https://shineireland.com/
Limerick:
Limerick Autism Group - https://www.facebook.com/limerickautismgroup/
Dochas - https://www.facebook.com/dochasautism/
Wicklow:
Triple A - https://www.facebook.com/triplea.wicklow/
Wexford:
Cottage Autism Network (CAN) - https://www.facebook.com/CottageAutismNetwork/
Advocates for Autism - http://advocatesforautism.ie/
Laois/Offaly:

Laois/Offaly Families for Autism (LOFFA) - http://www.loffa.ie/
Tipperary:
South Tipperary Autism Support Group - https://www.facebook.com/South-Tipperary-Autism-Support-Group-368478421557/
Tipperary Advocacy Supporting ADHD, Autism, Dyspraxia, Dyslexia - https://www.facebook.com/pg/ntlp.ie/about/?ref=page_internal
Autism Awareness Roscrea - https://www.facebook.com/Autism-Awareness-Roscrea-201770293775384
Clare:
Ennis Voices for Autism - https://www.facebook.com/eva.clare.5/
The Clare Crusaders - https://www.facebook.com/pg/The-Clare-Crusaders-640634146039485/about/?ref=page_internal
Cavan:
Cavan Autism Parents Support Group - https://www.facebook.com/CavanAutismParentsSupportGroup/
Louth/Meath:
Drogheda Abacus Autism Support - https://www.facebook.com/DroghedaABACASSchool/
Meath:
Athboy Autism Support Group - https://www.facebook.com/athboyautismsupportgroup/
Meath Autism Network - https://www.facebook.com/pg/meathautism/about/?ref=page_internal
Mayo:
Mayo Autism Support Association - https://www.facebook.com/pg/mayoautismsupportassociation/about/?ref=page_internal
Kildare:
Kildare Autism Network : https://www.facebook.com/KildareAutismNetwork/
Donegal:
Autism Family Support Group Letterkenny – www.autismlk.com
General:
Autism Activities - https://www.facebook.com/pg/autismactivities.ie/about/?ref=page_internal
MWB Autism Support - https://www.facebook.com/pg/longfordautismgroup/about/?ref=page_internal
Sensory Fun With Friends - https://www.facebook.com/pg/sensoryfunwithfriends/about/?ref=page_internal
Autism and Aspergers Support Group - https://www.facebook.com/Autism-and-Aspergers-Syndrome-Support-Group-166387396775119
The Autism Mammy – https://www.theautismmammy.com/

Appendix VI – Participant 2 Interview Transcript (All transcripts available upon request)

General and demographic questions:

Interviewer: What age are you?
Interviewee: I am 30.
Interviewer: 30, Perfect, and what is your marital status?
Interviewee: I'm cohabiting.
Interviewer: How many children do you have? What child has autism (as in eldest, youngest middle) and what age are they now?
Interviewee: I have two children, the eldest is autistic and he is five and a half.
Interviewer: And what age was he when he was diagnosed?
Interviewee: He was diagnosed at two years and nine months. Now I sent him in for referral at 15 months because I was really concerned about how he was developing. So, thank god we got in early and sorted things early. I'm one of a few that got sorted early, I think.
Interviewer: Yes, exactly! And are you the main caregiver?
Interviewee: Yes, I am
Interviewer: And you mentioned you had a partner, so what age is your partner?
Interviewee: My partner is 29.

Interviewer: 29, perfect

Experiences – stress, coping, supports:

Interviewer: And when you first learned your child was diagnosed with autism, how did you feel?

Interviewee: Em, I was terrified because I didn't know enough about it and I just thought the worst like I thought, I literally thought autism was the worst thing in the world. I didn't know it was a spectrum I didn't know I was just scared like; I didn't know enough about it and what to do next.

Interviewer: Did yourself and your partner react and adjust to the diagnosis in different ways? If yes, can you give an example of the different ways?

Interviewee: I would say we both felt the same, but I just showed it a lot more he kind of, was a bit more like nearly embarrassed to talk about it or say much at the time. So yes, he kind of didn't really talk about it, whereas I told everyone, and I cried to everyone. Like he eventually just got so fine with it like I mean now he would tell people before they even meet my child

Interviewer: What does your average day consist of caring for a child with autism?

Interviewee: In this house like keeping him safe is a challenge, like he climbs the counters daily and I have to make sure the doors are always locked. Like even this morning he got out the door and ran in front of his bus. And I nearly had a heart attack, like he's usually quite good and will wait and he's used to his routine. But this morning I spent a bit longer away from him in the kitchen doing something, and he heard the bus, and he was gone. So, I found him out on the road at the bus in the middle of the road. So, I was mortified.

So yes, it's just, like, keeping him safe and, and eating is so much easier with our toddler that does not have a disability, like our youngest you'll just give her the food and shell have anything, but with my child with autism you have to kind of hope that he will eat, so you've to make the same stuff every day and you have to sit and spoon feed him, because otherwise he won't really eat much. And he's not that bad in regards to clothes so thankfully he will like, keep his clothes on, although sometimes he likes to strip off the trampoline, so we do be out chasing him putting his clothes back on, but he's not that bad with clothes or materials like he seems to be ok. But I think he definitely likes the sensory feeling of not having clothes on some day's ha ha, oh and he's also ok with sound. Now he used to be really bad, or he I think he's nearly gotten used to it, like he won't wear the ear defenders no matter how much we tried when he was quite sensitive to sound, he still wouldn't wear it like he would just hold his ears, but he is a bit better now.

Interviewer: and is your child verbal?

Interviewee: No, I would say pre-verbal, I used to always say non-verbal thinking my child would never ever speak but he does definitely try, like he can sound out what he wants to say, or he just struggles to say actual words, but I think he's definitely trying.

Interviewer: That's great! So, can you tell me a bit about your experience of having a child with autism?

Interviewee: I feel like I haven't really experienced much of the judgement when I'm in public and I definitely think it's because he's still quite young. I do fear for when he's older. I think a lot more people kind of excuse his behaviour or tantrums because of how young he is, thinking he is cute and say, "aw look at him like he's only a little fella". He doesn't really have that many tantrums but when he does people just think aw 'god love him' or something like, it's like they know, so his age definitely comes into it. But as he gets older, now I am scared that looks will turn from like 'aw cute' to judgement or like 'you think he'd cop on' or 'god he's out of control' because I definitely think it's a lot harder when they're older in regards to judgement in public. So far, I haven't really experienced any bad experiences yet.

Interviewer: Yes, that's really good to hear! So what positives are there to parenting a child with ASD?

Interviewee: Em, I just think it really opens up your mind, like I feel like if I didn't know about it, like I'd be very close minded person and I would just assume, like autism is a disability that is terrible, like id more so feel sorry for parents of children with autism, but it has showed me that my child with autism is actually is able for things, like it just shows me that although he's different in one way, like, he still very like his sibling in other way, and is still a normal child he's still able to go to school and do everything. Like he is still able to learn, that was my biggest concern I thought it right he has autism like he's not going to understand anything like I just assumed it affected him in that way as well. But it doesn't like he's well able to learn and I think it really opened my mind to how clever people with autism are, but it's just for me it's a real eye opener, like, and I'm glad, well not glad, I always say I wish I could take his autism away like just for him, but I'm glad because of how it’s made me stronger as a parent, it's opened my eyes to be a lot more open and it's just, like, it's a real different kind of love, as well it's so funny, I'm like, people will never understand the love you get from your kids with autism like when they come over and just give you a hug or a kiss, they really mean it, whereas like, my other little one will give you a hug and a kiss, every five minutes just for any reason or so she can have a sweet or get something, you know, but when he gives one it’s just so meaningful it's just, I don't know, it's a real like raw true form of love, and I love it.

Interviewer: Aw that’s so nice! And In your opinion does caring for a child with ASD cause an increase to stress levels for parents? If so, why?

Interviewee: Definitely like, although I don't know if I just sugar-coat it and say aw, he's grand, he’s not that hard work. But I definitely do stress, whether it's privately or I just hide it, but even as a parent in that relationship like I know the both of us stress and worry every day and especially about the future like you just can't help but think about the future all the time, worrying about what way he'll be or where he'll be and stuff like that, so it definitely, definitely increases our stress levels at home, and in regards to the future.

Interviewer: So, the main stress factor that you'd find would be thinking about the future?

Interviewee: Yes, thinking of the future and how he will progress because at the minute, he's been the same for a long time, so that’s really stressful, because of COVID there has been no support at all, so we just don't know what’s going to happen, because he's kind of stayed the same for the last year or so and without much improvement, so I don't know how he will manage. I feel with no supports during covid its holding him back.

Interviewer: Yes, and are there particular strategies you use to cope?

Interviewee: Yes definitely, I think when I find other parents are going through it it's much easier, so like I scoured the internet for like support groups and mommy groups, and even like finding a school, because I didn't even know an autistic school was a thing and I didn't even know there were special classes, back when my child was diagnosed. I just thought he was never going to school ever, like it was so bad, but then when I found the school, I found great support in the parents there, and I found out like a lot of people even from here have children with autism that I never knew about. So, it definitely helps to find those supports in other people who are going through the same, because you feel normal again by hearing, you know you can talk to other parents, whereas I can't talk to my other mommy mates who just have kids without autism because they just don’t understand, they don't know what we're going through so it's so much easier to find other families that definitely helps me.

Interviewer: Do you feel that there is helpful support available to parents with children diagnosed with ASD? Who/what are your key sources of support?

Interviewee: In regards to my child, he needs a lot of speech and language therapy and occupational therapy and we really don't get any of it, and even if, I know they say the public waiting list is terrible, but we did have him with a service here, and the appointments were so scarce, and then with covid then they just never happened. Even privately like I think there's such a lack of understanding, with private therapists, like, there's not enough support with autism or like they don't have enough experience with ASD. There's so many private speech therapists out there but I can't find ones that are actually really good with young kids with autism like they just, they just do their normal techniques, and it just doesn't suit. So, I feel his best support has been his school placement, like being in an ASD unit has really helped him. And one of the best things we did as well when he was younger was finding a home tutor. So, I didn't really know about home tutors either and so, and until he got a diagnosis and only for my friends again like no one really told us until I found other parents who explained it to me. And then we found my child a Home tutor and she was like, the best start for him before he started school.

Interviewer: Ok perfect, and my next question was do you think that other family members or friends and people in the community view children with autism differently? But you've mentioned that because your child is young, you think that they don't judge as much, but you do fear for him being judged in the future?

Interviewee: Definitely, yes.

Interviewer: Ok, and so my last question would be, if you could give advice to a parent with a newly diagnosed child with ASD what would it be?

Interviewee: I would say find other parents that have children diagnosed with ASD, like, I like, I always tell people, even if I hear someone who has a newly diagnosed child or think they might be diagnosed, I'm literally like please talk to me like ask me questions, ask other parents questions they are the ones who know the best. They know all information, like I could ask this the special education needs officer questions, but I found, talking to other parents of children with ASD, 1000 times more helpful. And so, I would just say like find your support and other parents, and just get to know all your rights, and all the supports that are available, like you don't want to miss out on anything. And just keep fighting like Don't be afraid. I know, I think at the time when your child is first diagnosed It's nearly like a grey area like you're a little scared you're a little bit nervous, you don't want to say too much or ask too much, but just do ask everything there and then and just make sure you have a list of everything you're entitled to and all the help that you might get.

Appendix VII – An illustrative Map of the Four Key Themes along with Subthemes that Emerged from the Data