An Investigation into the Perspectives of Parents who have Children with Regressive Autism: Experiences, Causes and Support

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Dissertation submitted for
BA (Honours) Special Educational Needs and Inclusion

April 2015

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Abstract

The purpose of this study was to gain an understanding of regressive autism and its impact on parents. Previous studies have investigated the phenomenon of autistic regression, but little has been found regarding the direct accounts of how autistic regression affects parents and how these manifest into family life. Using an interpretive framework, a case study of parents of children with regressive autism was developed through means of first-hand accounts. The methodology comprised of 15 questionnaires conducted with parents of children with autism, which led to the retrieval of 5 interviews of mothers whose children had experienced regression. The data was then explored thematically in order to examine the experiences of parents who have had a child with regressive autism, their opinions of what may have caused it and the support they had received. The findings reveal that the experiences of regression may make it harder to accept the child’s autism. Additionally, it was evident that all parents had an opinion of what had caused the regression with the predominant view being the MMR vaccination. In terms of support, parents had mainly negative experiences with professionals, conversely, parent to parent support was seen as the most successful. All findings indicate areas of need for further investigation.

Key words:

Autism, Regression, Regressive Autism, Parent Perspectives, MMR Vaccination, Causes, Support
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Chapter 1 Introduction

1.1 Rationale

The intended study aims to advance the knowledge around the understanding of regressive autism through exploring the perspectives of parents. Regressive autism has been described as a pattern of normal development followed by a loss of previously acquired behaviours or skills (Lainhart et al., 2002, p. 231). In studies focusing on regression it has been identified that parents are the first to witness the changes in their child (Fombonne and Chakrabati, 2001), yet the perspectives and impacts on the parent are narrowly researched. Therefore, this research intends to retrieve information from parents who have experienced the phenomenon of regression. This area is of interest due to the experience of having a family member who had displayed autistic regression and the knowledge of how it can impact on the family, particularly the parents.

1.2 Research Questions

Research already conducted on parental perceptions found that mothers were more likely to express guilt and have explanations for the causes of regression (Davidovitch et al., 2000, p. 113). Thus far, this seems to be the only piece of regressive autism research that considers the views of the parents. Consequently, it is significant to research this area due to a lack of existing research as well as the importance of acknowledging the views of parents. A range of issues emerged from my own experiences and the existing literature; these were then developed into the proposed research questions which are:

- What are the experiences of parents who have children with regressive autism?
What views do parents have on the causes of autistic regression?

What support do parents of children with regressive autism receive?

According to Roth (2010) the presence of autism can cause complex stress for parents (p.251). Consequently, I have hypothesised that stress could be heightened by the regression due to the loss of skills as well as the commencement of autism. The first research question identified intends to examine the impact of regressive autism as opposed to autism from birth. In studies it was also recognised that parents are inclined to search for explanations for the regression (Davidovitch et al., 2000: Rogers, 2004), therefore the second question aims to listen to the views of parents and what they think may have triggered it. The third question seeks to identify the support a parent receives/or does not receive if their child has had a regression.

1.3 Overview

The existing literature is reviewed further in chapter 2 followed by the explanation and justification of the methods in chapter 3. Furthermore, the results of the study will be presented and discussed in chapter 4 and subsequently, the study will be summarised and concluded in chapter 5. This research has the potential to be used by parents who have had similar experiences, and for professionals who are involved with families of children with autism; this research should create an insight into how regression impacts on parents as well as what support is or should be available.
Chapter 2 Literature Review

2.1 Introduction

Despite on-going research into the phenomenon of regressive autism, the existing research lacks qualitative data around the experiences of parents who have had children with regressive autism. Parents are the first to witness the changes in their child which occur during developmental regression (Fombonne and Chakrabarti, 2001), therefore the experiences and voices of parents should be considered and valued. Due to the research around the specific topic being narrow, this review critically evaluates the literature surrounding the topic, starting with the literature regarding the autism spectrum and parental experiences, followed by analysis of current research focusing on regression in children with autism and the parental experiences of having a child with regressive autism.

2.2 Research on Autism

Knowledge, understanding and awareness of autism has evolved over time. Recent data suggests that there has been a much higher prevalence of the condition (Fombonne et al., 2011) which has resulted in a significant growth in research evidence (Elsabbagh et al., 2012). Autism is a developmental disorder characterised by difficulties in three core areas identified by Wing and Gould (1979) as the triad of impairments, these include impaired functioning in communication, social interaction and social imagination. The DSM-5 diagnostic criteria refined the triad into two key sets of criteria: 1. Impairments in social interaction and communication 2. Repetitive and restricted behaviours, activities and interests (APA, 2013). However, difficulties vary in each individual, Frith (2008) states that autism comes in degrees from mild to severe (p.4) and therefore mirrors the idea that autism is known as a spectrum or ‘continuum’ (Grandin, 1995 p.137).
Within the categorizations of the triad of impairments there are a number of common characteristics often displayed by individuals on the autistic spectrum. Haney (2013) identifies that people with autism may have difficulties with the earliest forms of human communication such as: facial imitation, eye contact, joint attention and body language. One of the first red flags is difficulties in communication (Perepa, 2013, p.47), these differences include: non-verbal behaviours, failure to develop peer relationships, lack of social or emotional reciprocity, inability to sustain or initiate conversations and echolalia or idiosyncratic language (Boucher, 2009; Jordan and Jones, 1999).

Difficulties in social interaction interrelate with communication difficulties; individuals on the autistic spectrum may have difficulties interpreting social cues and norms (Heavey et al. 2000; Yong Hwee and Poon, 2011). Yong Hwee and Poon (2011) argue that those with autism rely on personal experiences and idiosyncrasies to guide decision making in social situations rather than their instinct (p. 186). Wing and Gould (1979) describes 4 types of social behaviours commonly observed: the aloof who is withdrawn, the passive who has an indifferent acceptance of social responses, the active but odd who makes social mistakes and has a lack of social inhibition and the stilted who has overformal social approaches. Stone (2004) argues that all of these subcategories may be exerted by the same individual at different times depending on different circumstances or contexts. Stone (2004) also criticises the use of the term aloof which they viewed as following the medical model of disability; this is the view that disabilities are problems intrinsic to the individual, overlooking the roles that society and the environment play in the individual’s ability to function (Falvo, 2014, p.1).

In addition to these differences people on the spectrum are often likely to experience distress with sensory experiences. Johnson and Myers (2007) identify that people with autism may be hyposensitive or hypersensitive to stimuli e.g. light. These difficulties correlate with
restricted and repetitive behaviours stated in the DSM -5 criteria including: repetitive speech and behaviours, excessive adherence to routine, ritualised behaviour, resistance to change and restricted interests (APA, 2013). These behaviours could all be triggered by sensory stimulation (Haney, 2013).

Theories to explain differences in behaviours in those with autism were first thought to be brain based. Kanner (1943) suggested that autism was an innate inability to form usual contact with people which should be biologically provided. Psychodynamic theories acclaimed the undeveloped social skills were due to disturbed mother-child relationships (Mahler, 1952; Bettelheim, 1967). However these theories have received much critique as the theory implies the disorder is the fault of the parent (Mercer, 2010). An iconic theory in the autism field has been the model that people with autism lack a ‘Theory of Mind’ (ToM). Baron-Cohen et al. (1985) hypothesised that children with autism had an inability to impute the beliefs of others and therefore lacked ToM. Further research conducted by Baron-Cohen et al., (1997) suggested that the test opposed the hypothesis when the participants were adults with autism or had Asperger’s syndrome. Frith (1989) also criticised the ToM terminology as the theory suggests conscious meaning whereas human thought is usually unconscious.

An alternative explanation for social difference is Hobson’s (1993; 2002) theory which associates with mutual emotional relatedness; it derives from Kanner’s concept that humans are social beings with a biological function to relate to others. Hobson (1993; 2002) argues that rather than processing information to determine the thoughts and emotions of others as mentioned in ToM theories, typically developing people have an early developing and intuitive understanding of other people’s feelings and empathy (Roth, 2010, p.118). Consequently Hobson’s theory suggests empathy involves the understanding of the self and of others around them and thus identifies the lack of emotional relatedness in individuals with autism as the primary difficulty. Roth (2010) argues that the theory does not involve
explanations for the non-social deficits and focuses on difficulties as opposed to skills. It is also unclear that the lack of emotional relatedness is universal for infants with autism. In a study by Frith and Soares (1993) it was concluded that only two thirds of the mothers of children with ASD had expressed worry concerning their child’s behaviour in the first year. This study also links to the concept of autistic regression as parents often notice differences in behaviour after the infant appears to be typically developing.

2.3 Parents’ and Families Experiences of Autism

Autism is usually detected when the individual is around two years old (Frith, 2008; Roth, 2010; Charwarska et al., 2007) and therefore, differences in behaviour in comparison to a neurotypical infant are usually first noticed by the parents. According to Roth (2010) diagnosis varies considerably depending on the individual or professional and can cause problems, delays and stress for parents. According to Gray (2003) a study showed that mothers were likely to claim the diagnosis affected their emotional well-being. It is highlighted by Randall and Parker (1999) that there are many factors which contribute to the complex stress which intensifies from the time of seeking diagnosis onward; these include the toleration of difficult behaviours exerted by the child in addition to the fragmentary professional services which can be obstructive and difficult to obtain (p.1). Stressors mentioned in the research include: late diagnosis, especially in children with only subtle differences (Howlin and Asgharian, 1999), the delay between the parent’s first concern and the diagnosis (Howlin and Moore, 1997) and lack of clarity over the diagnosis (Brogan and Knussen, 2003). Dale et al. (2006) also state that the controversy and debate surrounding the cause of autism adds to the stress. This is considered in a study by Dale et al. (2006) who discovered that the nature of mothers’ attributions regarding diagnosis reflected uncertainties concerning cause and prognosis. However, this study was only conducted on a small sample of participants which calls for further research obtaining the opinions of more mothers concerning the cause of autism.
Gray (2003) found that mothers may even express guilt relating to their child’s autism, thinking they are in some way to blame. Nissenbaum et al. (2002) also indicated that parents worry about how their friends and relatives will react to such diagnosis. There are also issues with the acceptance of diagnosis; Myers et al., (2009) reported that some family members live in denial and do not want to believe that their child has autism (p.680).

Conversely, Howlin (2000) found that diagnosis may trigger support and access to information. The research concluded that good experiences of diagnosis had a positive impression on families. For parents, diagnosis may explain why their child behaves differently to their peers (Roth, 2010). Nonetheless, due to the stressful experiences it is evident that support should be available and accessible to parents in order for them to cope with the difficulties surrounding autism. National Initiative for Autism: Screening and Assessment (NIASA) (2003) stressed the need to provide information and to involve families through the assessment process. This is supported by research which identified that parents who received more social support had lower scores of depression, anxiety and anger (Gray and Holdren, 1992).

The occurrence of autism has also been found to influence the rest of the immediate family. Studies have found that fathers react differently to mothers regarding the diagnoses of their child; fathers are more likely to work resulting in mothers taking the role of raising the child resulting in mothers expressing more worry (Gray, 2003; Hartley and Schultz, 2014). In some cases, the child’s problems may lead to relationship breakdowns between the parents (Roth, 2010, p.251). However, studies have implied that there is no evidence for an increased risk of parent separation for children with autism in comparison to children without autism (Freedman et al., 2012; Baezer-Velasco et al., 2013). Siblings have been found to exert a range of emotions such as jealousy, neglect, worry or hurt (Myers et al., 2009), but have also been found to gain interpersonal and care-giving skills as a result (Roth, 2010, p. 253). Grandparents have been said to be a
source of support (Myers et al., 2009; Margetts et al., 2006), however, some reports showed that grandparents can have an unaccepting view of the disorder, thinking it can somehow be ‘fixed’ (Myers et al., 2009, p. 680)

2.4 Regressive Autism

In some circumstances children with autism may have experienced a loss of skills they had previously gained which may result in even higher levels of stress for a parent, this loss of skills is described as autistic regression. Lainhart et al., (2002) defines the regressive pattern as a period of typical or normal development for the first one to two years of life followed by an alteration or loss of previously acquired behaviours or skills (p.231), then the commencement of autistic characteristics is evident (Kurita, 1985). According to Barger et al., (2013) approximately one in three autistic children display an abrupt developmental regression. It has been reported that loss of language is the most commonly described manifestation of regression (Lord et al., 2004). Reports of regression mention loss of language, social interest, initiative, involvement, social skills and play which is observed mainly between ages 1-3 (Tuchman and Rapin, 1997; Frith, 2008; Rogers, 2004). Therefore most parents experienced an infant who was developing normally then changed rapidly over the course of weeks or months; thus meaning the typically developing toddler evolves into a child who has the full condition of autism. However, an argument that exists is that the infants may have already demonstrated social deficits and markers for autism prior to the onset of regression. In a study conducted by Osnoff et al. (2005) it was found that over 50 percent of the children who experienced regression had revealed early signs of autism during their first 12 months of life, long before regression was established. In addition, according to Davidovitch et al. (2000) some parents were reported to have found ‘an abnormal acquisition of developmental milestones, prior to the regression’ (p.113). Frith (2008) also questions whether it should be
classed as regression and should instead be referred to as a lack of progress towards another stage of development.

A definite cause of autistic regression has not been found, although various theories have been developed. Some studies have suggested a genetic predisposition in the development of autism (Silverman et al., 2002; Chakrabarti et al., 2009). However, hypotheses for autistic regression suggest it could be triggered by external factors. One theory is that autistic regression is caused by complications of infection (Gupta et al., 1984), another encompasses the idea that epilepsy or subclinical epileptiform discharges are the cause (Stefanatos et al., 2002) or even environmentally mediated exposures such as mercury (Bernard et al., 2001). It has also been suggested that the measles-mumps-rubella (MMR) vaccine can trigger regression due to the exposure to the measles antigen in immunologically vulnerable children (Wakefield et al., 1998). The MMR study has been a topic of controversy within the autism field as parents have reported their child was ‘normal’ before the MMR vaccine (Roth, 2010). However, the study by Wakefield et al. (1998) has since been discredited as it did not provide scientific evidence for such a link. The publicity of the anti-MMR campaign led to a fall of 60% of vaccinations which posed a health risk to infants (Roth, 2010, p.140). Studies have demonstrated that the rise in cases of autism started before the introduction of the MMR vaccine in 1988 and therefore shows that it is not responsible for the increase in cases of autism (Frith, 2008). Taylor et al., (1999) found that the number of children diagnosed with autism had increased steadily from 1979-1992 in all the districts of London. Additionally, Honda et al., (2005) examined the cases of autism in over 31,000 children in the city of Yokohama in Japan which showed that after the vaccine was withdrawn the number of cases continued to follow an upward trend. The conclusions to these studies were that the MMR could not have caused the rise in the prevalence of autism.
2.5 Parents Experiences of Regressive Autism

Research already conducted on parental perceptions of developmental regressive autism has provided an insight into how mothers feel. In a study on maternal perceptions of developmental regression it was found that:

More mothers of children who regressed than those of children who did not, expressed guilt feelings regarding the development of autism, and almost all of them had an ‘explanation’ for the possible mechanisms that might have influenced their children’s developmental course. (Davidovitch et al., 2000, p.113)

It was also found in this study that mothers were in a stage of denial and avoided using the term autism to describe their child. Rogers (2004) found that some parents’ experiences of their child’s regression led them to: question their own child care skills, search for explanations and examine their child’s history. This is common for parents of children with autism; we as humans attempt to make sense of unusual and stressful occurrences by making assumptions about what caused them (Antshel et al., 2004). Due to the onset of regression, parents experience an agonising change and have an opinion that something external must have caused it (Frith, 2008). Parents of children with autism already tend to be unsettled by the uncertainties of what caused autism (Dale et al., 2006), consequently these curiosities are heightened by the contrast in behaviours before and after regression commences.

2.6 Conclusion

In conclusion, from the existing literature there is a clear lack of data concerning the parents own ideas around regressive autism. For the purpose of this study, the first research question is ‘what are the experiences of parents who have children with regressive autism?’ This research will build on and extend the narrow existing data regarding the feelings of parents of children with regressive autism. This will be
attained by gaining a holistic view of the experiences of parents which will include their experiences of observing the regression and their subsequent experiences of diagnosis. This is due to the identification of the research that suggests diagnosis is the point where parents experience the most stress and change. This study also considers the individual opinions and ‘explanations’ which parents have for the causes of autistic regression which are mentioned in the study by Davidovitch et al., (2000), although it is not expanded upon. Therefore the second research question seeks to expand upon and listen to the parent’s opinions and explanations by asking ‘what views do parents have on the causes of autistic regression?’ The third research question reflects upon how parents can be supported when experiencing having a child who has regressed by asking ‘what support do parents of children with regressive autism receive?’ This question relates to the literature which states the emotional well-being is better for those who receive support (Gray and Holdren, 1992); however this study will focus particularly on parents of children who have regressed. Additionally, this research could be advantageous to inform other parents who are in similar situations about any support which aids parents in understanding the nature of their child’s regression.
Chapter 3 Methodology

3.1 Introduction

This chapter presents the discussion of the research methods utilised for the study and why they were applicable in response to the research questions introduced in Chapter 1. The research questions informed the use of the specific methods in the study, these questions are:

- What are the experiences of parents who have children with regressive autism?
- What views do parents have on the causes of autistic regression?
- What support do parents of children with regressive autism receive?

These questions stem from a desire to understand the experiences, thoughts and views of parents of children with regressive autism. Therefore, this research takes the form of an interpretivist paradigm; this ontological position allows the researcher to look from a subjective point of view at ‘perceptions, feelings, thoughts and ideas’ (Thomas, 2013, p.111). This chapter comprises of: the type of approach the study has taken the form of; the participants of the study; the methods of research used; how the study has adhered to ethical protocols; and the process, description and justification of each method related to the literature.

3.2 The Approach

This study incorporates a case study approach because it investigates the phenomenon of regression and autism and therefore mirrors Yin’s (2014) definition of a case study which investigates a ‘contemporary phenomenon in its real world context’ (p.2). According to Thomas
(2013) a case study comprises of two parts: a subject and an analytical frame (p.150). When dissecting this study into two components, the subject refers to parents of children with autism and the analytical frame refers to the impact of regressive autism on parents. However, although choosing a restricted sample enables rich detail, it is at the expense of being able to make generalisations to the broader population (Hammersley, 1992). This criticism is supported by Denscombe (2010) who claims that the extent to which a case study can be generalised depends on how the example is similar to others of its type (p.60).

**3.3 Methods of Research Used**

The methods used were questionnaires and interviews and aimed to provide a qualitative perspective, this perspective is concerned with understanding individuals’ perceptions of the world (Bell and Waters, 2014). The combining of methods is an important aspect of a case study approach as the ‘aim is to gain a rich, detailed understanding by examining aspects of the case in detail’ (Thomas, 2013, p. 150). Questionnaires and interviews relate to the research questions’ purposes which are to interpret the views of parents. These methods encompass information directly from the parents themselves to gain a primary perspective. The participants of the questionnaire consisted of 15 parents who had children with autism. Using questionnaires led to the retrieval of the participants who had experienced having a child with autistic regression. This method then subsequently informed the sample for the interview phase which consisted of 5 parents of children who had regressive autism. This mix of methods reflects the triangulation approach which ‘is defined as the mixture of data or methods’ (Olsen, 2004, p.3).The key to the approach is to ‘see the same thing from different perspectives and thus be able to confirm or challenge the finding of one method with those of another’ (Laws et al., 2013, p.143). The use of both questionnaires and interviews provided data related to the research questions, providing written and verbal perspectives.
3.4 Reliability and Validity

Within interpretive research reliability is uncertain due to an inability to control certain variables. Thomas (2013) argues that reliability is ‘irrelevant’ in interpretative research due to the researcher’s positionality and on the basis that you are interviewing as yourself, interviewing someone else being themselves (p.139). However, to control certain aspects of the study, it was ensured that all questionnaires were given to parents of children with autism and each parent was provided with the same questions. Questions in individual interviews were also carefully considered to ensure there were no leading questions or bias. To ensure validity, all questions, both in the questionnaire and interview phase, were directly related to the research questions and general purpose of the study. This ensured that the method measured what it intended to measure (Thomas, 2013).

3.5 Ethical Considerations

The first phase of retrieving data was to collect responses via an online questionnaire (see appendix 4). In order to adhere to the ethical protocols informed by the British Educational Research Association (BERA) (2011), informed consent was obtained through a statement at the start of the questionnaire which informed the participants of the ethical considerations including informed consent, right to withdraw, anonymity and confidentiality. The statement said that ‘by completing the questionnaire you give informed consent’ (see appendix 1). The second phase which comprised of individual interviews adhered to ethical protocols in relation to BERA (2011). This was evident through the information leaflet (see appendix 2) which was given to each individual parent who participated in the interview process. This leaflet contained all the relevant information related to the study and a consent section at the end to obtain informed consent. The leaflet was in addition to an ethical statement (see appendix 3) which informed parents of the ethical code. There was also the option for them to
circle I agree or I do not agree to be recorded during the interview so I could gain informed consent to record telephone or face to face interviews. All participants consented to being recorded and were informed that recordings would be destroyed after use.

### 3.6 The Questionnaire Phase

The questionnaire research method was the preliminary foundation to precede and inform the next method of collecting data, Gillham (2008) supports this by suggesting that one method is rarely adequate and requires more methods to produce greater confidence in findings (p.2). Using the questionnaire method was advantageous because it meant getting a range of data in a short period of time which was 58 days and was flexible for the respondents who were all parents who have other commitments. Gillham (2008) supports this and says that respondents can answer at their own pace (p.7). However, a disadvantage of a questionnaire which was evident in the research was that respondents ‘may leave the item blank, or even abandon the questionnaire’ (Bell and Waters, 2014, p. 161). This was evident in that although there were originally 17 respondents, there were 15 fully completed questionnaires. However, 15 of 17 respondents is a substantial proportion of completed questionnaires, this could be due to the need for parents to voice their views and opinions. The questionnaire phase was an extremely important segment of the research as it led to the sample of parents who had experienced having a child with autistic regression.

It was important to gain a sample of parents of children with autism due to the difficulty in finding a direct sample of parents of children with regressive autism. The questionnaire also ensured the definition of regression was clear and questions associated with regression were written in an understandable and coherent manner. The participants for the questionnaire were gathered as an opportunity sample which are common in small-scale research (Bell and Waters, 2014). This was as a result of the link to the online questionnaire being sent to
different autism-related charity organisations located in both the midlands and the south of England and was thus passed on through word-of-mouth. The limitations of the sample were that it was a relatively small and therefore harder to generalise. However, Thomas (2013) believes that a case study approach is not created in order to understand others, but to understand it as itself (p.150). This is supported by Oakley (2000) who believes interpretive research can contribute to building a framework of multiple realities (p. 111).

Using online data collection was the most suitable way of collecting the specific sample. It was suggested by a charity for autism that the best way to reach parents was through social media. Bell and Waters (2014) claim that social media platforms can save you time and expense during data collection (p. 153). Social media was used so autism charities could post the link to the online questionnaire to their profile page. Links were also emailed to known parents of children with autism. In addition to web-based surveys being more time and cost effective (Lefever et al., 2006), online data collection protects against the loss of data and simplifies the analysis of data (Carbonaro and Bainbridge, 2000; Ilieva et al., 2002). The online questionnaire was designed in a way that could be understandable and approachable for parents and was presented in a way that was quick and easy to complete, Carbonaro and Bainbridge (2000) indicate that easy access to surveys for all participants is essential. Limitations to web-administered surveys include: participants access to a computer, technical difficulties and fraudulent responses (Lefever et al., 2006). In order to confront the risk of fraudulent responses, it was ensured the link was only sent to autism organisations/charities or directly to parents of children with autism via email.

The web-based questionnaire consisted of a range of question types which gave a variety of responses, some open-ended which presented qualitative data and some closed, which provided data which could be quantifiable. Closed questions demand a particular response (Thomas, 2013, p. 196). Some closed questions used were dichotomous,
Thomas (2013) describes dichotomous questions as screening questions to separate respondents into groups (p.209). Dichotomous questions consist of two fixed responses, the ‘screening’ dichotomous question of most importance was the question that determined which parents had children who had regressed; this question was ‘did your child lose any skills they previously had?’, to which the response was either yes or no. Other types of closed questions were multiple choice or rating scales. For the rating scale question which was, ‘how did you find the process of getting your son/daughter diagnosed?’ the responses followed the ‘semantic differential scale’ (Thomas, 2013, p. 214) which used opposite adjectives (e.g. It was a really bad experience/ It was a really good experience) and the rank in between. The multiple choice questions involved fixed responses such as: yes, no and maybe. The open-ended questions allowed the respondents to elaborate on experiences, views and opinions which are prominent specifications in the research questions. However, Bell and Waters (2014) also argue that questions that ask for opinions may be different at different times and may be difficult to analyse or compare. The structure of the web-based questionnaire involved the first page which introduced the study and ethical details, and then the last page requested the parents’ participation in an interview by asking if they would be willing to take part. The results obtained from these questions established the presentation, format and questions used for the interview phase.

Due to the nature of the study it was important to consider possible risks. In relation to the data focusing specifically on views, there is a risk that parents may not divulge all of their opinions over fears that they may be ‘wrong’ or may be judged. Due to this risk it was important to maintain a polite and friendly manner throughout the content of the questionnaire as well as highlighting my own interest and experience associated with the subject; sharing your personal experience helps to establish a rapport and elicits trust with the respondents (Dundon and Ryan, 2010, p. 565). Additionally, I had to
consider how my own researcher identity and positioning had an impact on the research. It was essential that my own opinions and views were not expressed, therefore ensuring that the questions were neutral. Bell and Waters (2014) state that you should avoid leading questions which might contain emotive language to influence a respondent (p.163). They also mention avoiding presuming questions that hold the researchers strong views which overlooks the fact that everyone may feel different (Bell and Waters, 2014, p.164). Another risk in the research was the gaps in the responses of the questionnaire due to the respondents’ freedom to skip questions; however, I felt this freedom was an important aspect in relation to ethics.

3.7 The Interview Phase

The interview phase was subsequent to the retrieval of the questionnaire responses. This phase enabled the research to yield rich responses in order to put ‘flesh on the bones of the questionnaire’ (Bell and Waters, 2014, p. 178). After the analysis of the questionnaire responses, it was essential that some of the data retrieved was extended in greater detail; therefore, the interview method was the most appropriate method for gaining more descriptive answers to the research questions. Bell and Waters (2014) determine that one of the most significant advantages of an interview is adaptability, which allows the researcher to follow up ideas and probe responses which you cannot do in a questionnaire (p.178). This is supported by Thomas (2013) who states that they will respond to you in an entirely different way to the questionnaire (p.194). This is due to the ability to watch and listen out for nuances in their behaviour to give important clues about how they feel (Thomas, 2013); the tone of voice, facial expression, hesitation etc. can be concealed by written responses (Bell and Waters, 2014). However, a disadvantage to interviews is that they can be very time consuming (Bell and Waters, 2014). This was evident in the preparation of the interviews which consisted of making initial contact with the parents, organising an appropriate time and date for
the interview, gaining informed consent, devising the interviews and in some cases travelling further afield to conduct the interviews.

Participants were collected through information provided at the end of the online questionnaire. It stated that anyone who had answered yes to the question regarding loss of skills (regression) and who would like to participate in an interview could contact the researcher with the details provided (see appendix 4). It was then fortunate that 5 of the 6 parents, who had answered yes to the ‘has your child lost any skills they previously had’ question from the questionnaire, contacted me to organise an interview. Due to the interview process being time consuming it is highly likely that you will have a relatively small sample (Bell and Waters, 2014); therefore, a sample size of 5 participants was a reasonable number to elicit a good range of information. 2 of the 5 interviews were conducted face to face whereas the other 3 were conducted via telephone, this was due to the participants’ living too far away to meet in physical presence. Telephone interviews have been said to compromise rapport and exclude non-verbal cues, though telephones have also been said to make respondents more relaxed (Novick, 2008). This being said, relationships were still built during interviews due to sharing my own experiences of regression. The participants of the interview phase were all mothers, and all of the participants’ children who had displayed regression were male; the gender bias of the sample was due to coincidence.

The interview procedure took a semi-structured form, Thomas (2014) refers to this form as the combination of a structural list of themes to be covered and the freedom to follow up points if necessary (p.198). For the specific focus of this study, it was important to have the freedom to follow up and probe certain questions to stimulate detailed answers in relation to the research questions. It was equally as significant to have a list of questions to ensure that all the important topics specific to the study were covered. The combination of ‘structure’ and ‘follow up’ allowed the interview to take a less formal
conversational form to enable the participants to feel more comfortable. It also meant the data retrieved wasn’t restricted to specific answers. The structure took the form of an interview schedule (see appendix 5), which provides a list of issues to investigate (Thomas, 2013). The schedule I used was a grid which had a column containing the issues and topics to be covered, a column for possible questions, and a column for possible follow up questions. The schedule was used as a guide, Thomas (2013) recommends interview schedules because you can deviate from them as necessary (p.199). Most of the questions formulated for the schedule were as a result of the information provided in the questionnaire responses; this meant the answers could be elaborated. The recording of the interviews allowed the format of the interview to be less formal, Bell and Waters (2014) state that recording allows eye contact between the interviewer and interviewee and ensures accuracy when writing about the responses (p184). However, transcription of recorded interviews proved very time consuming, Bell and Waters (2014) also argue that recording may inhibit honest responses due to the awareness of being recorded (p.184).

The risks of the interview are similar to the risks associated with questionnaires, participants may be equally as worried to disclose their views over fear that they are wrong, or simply because they may not know what will be asked of them. Therefore, for this study it was an important consideration to allow participants to view the questions before the interview so they could be prepared for questions. Another risk is that interviews are a highly subjective method, so there is always a risk of bias (Bell and Waters, 2014). However, interpretivist research involves the positionality of the researcher and participants, Thomas (2013) states that the researcher’s position will always affect the interpretation (p.139).

3.8 Summary
In summation, the methodology for this study took the form of two phases: questionnaires and interviews, and therefore took on the triangulation approach which involves mixed methods. Due to the study focusing on a phenomenon in a specific context, investigating regression and parental experiences meant the research took the form of a case study. Procedures were conducted and adhered to, to ensure the ethics of the study were met. The methods used were the most appropriate methods for eliciting the material most suitable for the research questions. Although there were challenges associated with the methods of choice, the literature concerning the uses of these methods justified why they were selected. The strategy for analysis was developed during the design process, this is stated in chapter 4.
Chapter 4 Results and Discussion

4.1 Introduction

The strategy for analysis of the data retrieved took the form of a thematic approach as suggested by Cresswell (2014, p. 197). After the examination of the questionnaire results combined with the outcomes of the five interview transcripts, a number of sub-themes have developed from the data (see appendix 6 for questionnaire results and appendix 7 for an interview transcript sample). By using the constant comparative method as demonstrated by Thomas (2013) each sub-theme was then compared to see how they interrelate (p.235). Then the themes were linked in accordance with research questions of the study and have consequently been organised in relation to the relevance of these. These categories are: the experiences of parents of children with regressive autism, the parents’ opinions of what caused the regression and the support parents of children with regressive autism have received. Lastly, the chapter will demonstrate the limitations and implications of the findings.

4.2 The Experiences of Parents of Children with Regressive Autism

*Gender, ages and co-morbidity of the child with autism*

**Table 4.2.1 facts about interviewees’ children who have regressive autism**

<table>
<thead>
<tr>
<th>Interview Participants (mothers) (pseudonyms)</th>
<th>The gender of their child who has been diagnosed</th>
<th>Their child’s approximate age of regression (to the)</th>
<th>Their child’s age of diagnosis of autism (to the)</th>
<th>Their child’s age currently</th>
<th>Any other conditions their child has</th>
</tr>
</thead>
</table>
In the questionnaire phase it was not specified whether the parent respondents were male or female. However, as shown in table 4.2.1, the interviewee respondents were all mothers and therefore reflected other studies which determine that mothers tend to be: more involved in the lives of their child with autism; are more likely to discuss their thoughts, feelings and views; and are more likely to seek support (Gray, 2003; Hartley and Schultz, 2014). It is also evident in table 4.2.1 that all the offspring of the interview participants’ who had experienced regression were male. This mirrors a population-based study which found that males were more likely to have documented regression than girls (Wiggins et al., 2009), but contradicts a study that indicates that males and females have an equal risk of regression (Barger et al., 2013).
In the data present in table 4.2.1, the ages of regression have differentiated from those identified in the literature. Regression has most commonly been reported when the infant is around 24 months of age (Tuchman and Rapin, 1997; Frith, 2008; Rogers, 2004; Wiggins et al., 2009). In the interviews with participants Julie and Lynn, the reported ages of regression were at 7 and 4 years old. This suggests that although these may be anomalies, regression could occur at any stage of childhood. However, in the study by Wiggins et al., (2009) there is considerable variation around the mean (which was 28.2 months), ranging from 1-91 months of age (p.364). The data in the table also indicates that one parent (Lynn) had a substantial gap between the onset of regression and the age of diagnosis. This indication could be as a result of the co-morbidity of Lynn’s child who has a mental health difficulty in addition to autism, which could have inhibited the ability to identify the ASD.

Experiences of regression

![Chart showing percentages of respondents' children who had/hadn't lost previously acquired skills.]

Figure 4.2.1 Questionnaire results for the percentage of respondents whose children had/hadn’t lost previously acquired skills
In the questionnaire data it was evident that approximately a third of the 15 respondents had experienced their child having a loss of previously acquired skills, and thus experienced regression (see figure 4.2.1). This figure supports the approximation by Barger et al., (2013) that around 1 in 3 autism cases are regressive. Lord et al., (2004) reported that loss of language is the most commonly reported characteristic of regression. This was evident for 4 of the 6 parents who had children with regressive autism in the questionnaire data. All 5 interviewee respondents recounted issues with loss of speech in addition to various other indications of regression. Here are some examples:

'I remember him saying two words together... he lost those words... He was lying on the floor and it seemed like he was staring into space.' (Sarah)

'He just stopped playing with things, stopped playing with us. And he started spinning things instead, like plates and things’ (Samantha)

This correlates with research that suggests that the main skills lost are associated with speech, social interest, involvement, social skills and play (Tuchman and Rapin, 1997; Frith, 2008; Rogers, 2004). The findings from the interviews suggest that these losses occurred as well as the commencement of autistic characteristics which have been established in the DSM-5 (APA, 2013), for example in Samantha’s account the repetitive behaviour of spinning things is reported after the regression occurred.

Due to the argument that exists that infants may have demonstrated signs of autism prior to the regression (Ozonoff et al., 2005), parents were asked whether any signs of autism were presented before the onset of regression. There were mixed results; two parents specified that there weren’t any markers for autism before, two indicated that there were elements of autism before, and one parent was unsure:
‘None that I observed. He was absolutely normal... He was really smiley’ (Sarah)

‘I didn’t think he was, I didn’t know much about it... He may have had elements’ (Julie)

‘Yeah, I don’t think he was 100% okay. He never pointed. I have some really nice footage... with really nice eye contact. And I also remember him being about 6 months old and I couldn’t make eye contact with him’ (Samantha)

This data challenges Hobson’s (1993; 2002) theory that people with autism are born without emotional relatedness, as Sarah described a smiley child who engaged with her before the regression. These results also challenge the phenomenon of regression as being considered a regression if there were signs beforehand. Resultantly, it could potentially be seen as a lack of progress towards another developmental milestone as argued by Frith (2008). The term regression was also opposed by one of the parents who expressed:

‘I don’t think it is regression as such, I just think it (autism) manifests itself more and more’ (Sarah)

Experiences with education and healthcare

The majority of the participants’ experiences with healthcare were associated with the child’s diagnosis of autism rather than the regression.
In the questionnaire data, parents provided varied reviews about the process of their child’s diagnosis as shown in Figure 4.2.2. Many of the respondents expressed relief because it allowed them to understand their child and enabled them access to help; this reflects Roth (2010) who suggested diagnosis offers an explanation as to why their child behaves differently (p.247). However, the relief was also coinciding with other feelings such as sadness or an inability to accept the autism which has been identified in previous research (Myers et al., 2009; Davidovitch et al., 2000). The comments regarding the process of diagnosis with healthcare professionals were predominantly negative due to it being a slow and long process with recurring appointments. The extensive process of diagnosis had been said to contribute to complex stress affecting emotional well-being (Randall and Parker, 1999; Gray, 2003; Roth, 2010).

The interview participants disclosed mainly negative experiences in healthcare during diagnosis due to a lack of knowledge and information:
‘The doctor diagnosed him and gave some information... it wasn’t a lot’ (Julie)

‘I remember sitting in front of that consultant and he said your son is autistic... He said “So what you need to do now is go on the internet”’ (Lynn)

‘The first thing was being reassured (that nothing was wrong with him)’ ‘They said he wasn’t assessable because they would ask him to do things and he wouldn’t do them’ (Samantha)

The comments from the parents share a common lack of clarity from professionals over the diagnosis (Brogan and Knussen, 2003). Davis and Gavidia-Payne (2009) found that professionals being provided with information and services in an organised way contributed to positive family outcomes (p.159). However, it is evident that in healthcare, the participants’ needs had not been met in terms of accessing information.

Two of the participants (Julie and Lynn) had children at school age at the time of regression. Julie’s son’s regression meant a change in schooling from mainstream to special education. Lynn’s experiences in education were due to her son’s behaviour which meant educational professionals were focusing on her as a parent, rather than helping her son; this may clarify why there was a significant gap of approximately 7 years between the regression and the diagnosis. It was stated in chapter 2 that the delay between the first concern and diagnosis was a ‘stressor’ (Howlin and Moore, 1997), however 7 years is a tremendous gap which had caused a large amount of stress. In addition to the delay, the parent was falsely blamed for her child’s behaviour; this reflects historical ideologies that acclaimed that mothers were to blame for undeveloped social skills (Mahler, 1952; Bettelheim, 1967). This raises the issue that outdated ideologies may still be apparent.

Impact on the individual and their families
The narrow data surrounding parental impact has distinguished that parents are 'confronted with a dramatic negative change' (Davidovitch et al., 2000, p. 118). Nevertheless, the extent to which this change impacts has not been illuminated. Results of the questionnaires revealed that regression had a distressing impact on parents. Words such as ‘awful’, ‘upsetting’ and ‘devastating’ were used to describe their emotions during their child’s regression. It was evident that these feelings accumulated due to feelings of loss and powerlessness:

‘It was awful seeing your child regress as if he had a brain disease ... no one could do anything’ (Questionnaire respondent 5)

‘To watch your child disappear in front of your eyes is the worst thing in the world’ (Questionnaire respondent 3)

Interview results indicated that the onset of regression made the autism harder to accept due to it not being present beforehand. The interviews allowed the further understanding of the impact of regression on the family members; these were immediate family members such as siblings, partners or grandparents. One parent expressed a difference in impact between her and her husband due to him not being actively involved in meeting professionals, therefore resulting in it being hard for him to understand. This reflects studies that conclude fathers have dissimilar coping strategies (Gray, 2003; Hartley and Schultz, 2014). She also reported the father being able to escape responsibility through working, this has also been reported by Myers et al., (2009) who found fathers used avoidance to cope (p.677). Similarly another parent expressed their husband’s difficulty in accepting the autism, which has previously presented itself in studies on families of children with autism (Myers et al., 2009; Davidovitch et al., 2000). A parent who had a younger sibling to her child with autism described the main impact of regression:

‘I don’t know what it was like (for the sister) being younger than him and him having more skills initially, then she overtakes him after only a short time really’ (Julie)
However, other parents with additional children expressed the impact to be the autism rather than regression itself:

‘His brothers are close in age, I suppose it is the impact of the autism really that they felt, you know, coping with a sibling with severe autism and challenging behaviour, so that’s how it’s impacted on them’ (Janet)

The previous existing research suggests that siblings can exert a range of negative feelings resulting from having a sibling with autism this could be associated with jealousy, worry, neglect or hurt (Myers et al., 2009). However, from this study, siblings as described by their parents seemed to be very accepting of their sibling’s condition, but rather impacted by the behaviour of their sibling. Perhaps the acceptance could be due to the regression, seeing their sibling before and after and understanding why they may need more attention from their parents.

Grandparents were described to have feelings of sadness and loss similar to the impact on the parents. However, parents described a clear lack of understanding and difficulties with acceptance; this may be a generational effect. Myers et al., (2009) found that their generational ideologies could stem from the idea that the parents are to blame for the ‘bad’ behaviour of the child (p. 680)
4.3 The Parents’ Opinions of what Caused the Regression

From Figure 4.3.1 it was evident that all the parents who had a child with regressive autism had an opinion or an idea of what may have caused the loss of skills. This reflects the research identified in chapter 2 which found that parents were more likely to search for explanations and have opinions of what had caused it (Davidovitch et al., 2000; Frith, 2008).

**Genetic Predisposition**

In the literature there are theories that autism is hereditary (Silverman et al., 2002; Chakrabarti et al., 2009). However, parents had mixed views on whether autism had a genetic predisposition. In the questionnaire responses regarding their opinions of what caused the regression there were no comments to suggest they thought it was hereditary. Conversely, the interview data has produced an array of opinions of whether it could be genetic:
'In the research there may be a predisposition, I know there is dyslexia in the family... so there may be a genetic predisposition for autism’ (Sarah)

‘I’m not saying you don’t have the autism gene in the family, but the severity of my sons condition is not in the family, you can’t put it down to anybody’ (Janet)

It is evident that although parents have explanations for the causes as discussed by Davidovitch et al., (2000) there are still uncertainties. This is understandable due to the fact that although there are many theories, a definite cause has not been found in the research (NHS, 2015). This implicates difficulties with parents trying to make sense of why their child had regressed. It was evident that the professional stance was geared towards hereditary causes:

‘If you mention anything else (to the professionals), other than it being hereditary, they don’t want to know!’ (Janet)

This suggests that although parents’ opinions of what caused the regression haven’t been listened to, medical professionals may have opinions that support genetic theories. Should professionals divulge this information if it has not been proven as a definite cause?

Self-blame

It was evident that at the time of regression some of the parents had feelings of self-blame:

‘As a parent you kind of blame yourself, thinking you must have done something wrong.’ (Julie)

‘I believed it was me ... When I’ve got professionals saying it’s your fault’ (Lynn)

The participant Julie had feelings of self-blame due to a lack of knowledge around autism and the shock of the loss of the skills, whereas Lynn experienced these feelings due to professionals blaming her for her son’s behaviour. Feelings of blame preceding diagnosis
have been identified in the literature, parents reported being labelled as a ‘bad’ parent by professionals, friends and relatives before diagnosis (Osbourne and Reed, 2008, p. 315; Roth, 2010, p. 250).

Lack of Diagnosis

The participant ‘Lynn’ stipulated the lack of diagnosis as the cause of the regression:

‘Because he wasn’t diagnosed when he was younger ... When the doctor saw him, he couldn’t believe how unwell he was and he said he’d gone back to how you would act if you were 2. He said because he hadn’t had the treatment and therapy and he was left, that’s why he’s gone back to that age’ (Lynn)

Although this cannot be viewed as the definite cause, there has been research to suggest that early identification can improve the opportunities for children with autism to benefit from intervention strategies and decrease the stress put on parents (Zwaigenbaum et al., 2013).

Diet

Two of the parents, Julie and Samantha, mentioned gluten and dairy as a factor in the regression of their children:

‘He had a urine test and they said he may be sensitive to wheat and dairy, it may be due to the fact that he had a lot of wheat and dairy around the time of regression’ (Julie)

‘He didn’t have milk for a week and he was way better, he really improved. Doing the trial of no dairy or gluten is essential, because it makes a big difference to some people.’ (Samantha)

The parents discussed gluten and dairy in the diet as a possible contributor rather than an actual cause of the regression. The link between gluten free diets and autism has caused much debate. Results by Whiteley et al., (1999) suggested that children with autism that participated in a gluten free diet showed an improvement in a range of
behaviours. However, it has been argued that research is not conclusive, a study by Harrison Elder et al., (2006) reported no significant findings. This implicates a need for further research.

The MMR Vaccination

5 of the 6 respondents of the questionnaire who had experienced regression mentioned the MMR vaccination as a possible cause for the regression of their child. Similarly 4 of the 5 interviewees also determined the MMR as a potential contributor, these were the reasons for this conclusion:

'I think there is enough evidence to say it contributed ... there was a lot going around about this guy Andrew Wakefield and I think his evidence back then was quite compelling ... I think if you put all these ingredients together... so I’m not saying the MMR didn’t have an effect, but I’m also not saying it did and I’ll never know probably’ (Sarah)

‘Other parents pointed to the MMR ... So I looked in my diary and found he started regressing in the March... and the MMR booster vaccination was in the Feb and he had a funny turn 3 days after the vaccination, he went blue round the hands and mouth and he was crying and had a temperature’ (Julie)

‘It could have been having chicken pox so young due to his immune system being so low, and giving him the MMR, was that too much for him? ... One point after the vaccination my son went delirious’ (Janet)

‘He was about 14 months (when he had his MMR) and about a month after we noticed ... Other people started to say he wasn’t like that before his MMR and then when I finally read up on the MMR ... it kind of made sense’ (Samantha)

It was interesting to find similarities in accounts of the MMR vaccination and that two had reported a similar reaction of ‘deliriousness’ a short time after the vaccination in both Julie and Janet’s accounts. Although studies to support the MMR as a possible cause have been discredited and studies have been said to disprove
the claim (Taylor et al., 1999; Honda et al., 2005), they focus on the prevalence of autism as a population, rather than focusing on cases of reported regression following the MMR. This indicates a need for further research, especially in order for parents to make sense of regression and the MMR.

4.4 The Support Parents of Children with Regressive Autism have received

*Parent to parent support*

During the interview process, it was prominent when discussing the support each parent had gained, that talking to other parents in similar situations was the most successful approach. Within the data, each parent had found success in different contexts. These included local national autistic societies, courses, charities, churches and online communities. Parents described how contact with other parents of children with autism was instrumental to their support:

‘*The input from other parents was invaluable … Other parents are the biggest source of help*’ (Julie)

‘*Nobody wants to know, except the people who have been through it*’ (Janet)

It was apparent that this form of help was successful; the majority of the participants identified that talking to others resulted in not feeling alone. The parents also gained ideas from other parents about how to make use of funding and advising on good places to go to. Similar conclusions were drawn from a study by McCabe (2008) who found that parent to parent support allowed equal relationships, learning from one another and moral support. However, some parents did not feel comfortable in support groups, for example:

‘*I went to a national autistic society group, but they were really not my type of people, they were just very negative about autism, saying they’ll have an awful life and there’s nothing you can do.*’ (Samantha)
This suggests that parents are not homogenous when it comes to support and that ‘interventions for parents … that are focused on meeting the needs identified by participating parents may be most effective’ (Clifford and Minnes, 2013, p.179). Samantha found more success talking to ‘like-minded’ parents through online communities. Similarly, a study found that online support groups can provide personal empowerment due to a disinhibition to express themselves more openly (Barak et al., 2008).

Despite the reviews of finding support from support groups and other means, most parents reported that at the time of regression the support was scarce due to a lack of understanding of what was occurring. Finding support only commenced either once the diagnosis was given or a considerable time after.

**Professionals**

It was important to investigate the role of professionals in the support of parents of children with regressive autism due to studies such as Davis and Gavidia-Payne (2009) concluding that professional support was a means for positive outcomes. The interviews examined whether professionals gave sufficient information surrounding regressive autism, especially considering the impact it has on the parents as identified previously. There were mixed responses regarding professional support. Some parents’ referred to supportive professionals:

‘There are certain professionals that really do make a difference’
(Sarah)

However all of the 5 parents had reported memories concerning professionals’ lack of support and information, Lynn reported:

‘Staff from school used to say they couldn’t cope, they sent me on behaviour courses but I wasn’t the one with the problem … They didn’t refer him to a specialist… I did’ (Lynn)
These results reflected a study by Woodgate et al., (2008) which found parents had experiences with unsupportive professionals with a lack of knowledge of autism coinciding with limited resources to support the parent or child.

All the parents of this study made indications for more accessible information for parents in the future. Suggestions were to provide more information around the regression; to point them in the direction of more information and specialists; and to point them in the direction of a parent who had been in a similar situation and didn’t mind being contacted.

In the reports from the parents in this investigation, professionals’ knowledge of regression was even scarcer and the results showed that professionals either ignored or rejected the parents’ fears over the MMR:

’I don’t think with the whole MMR anyone takes you seriously ... when you start talking about regression nobody wants to know. They say no! You can’t believe that, it’s not true’ (Janet)

’I said to them the MMR might have caused it and they never said anything’ (Samantha)

Due to the MMR controversy, many studies have looked into why parents chosen not to have the vaccination (e.g. Casiday et al., 2006; Evans et al., 2001; Bellaby, 2003), these studies have shown that parents displayed a significant level of distrust towards the professionals and the government. However, the research lacked the opinions of parents who had actually thought the MMR had induced autism. In this research, parents established that the professionals’ opinions/lack of opinions were due to fear of being professionally condemned. Unexpectedly, some professionals showed signs that they may not be totally comfortable with the safety of the MMR vaccinations:
'I remember explaining that I thought the MMR was safe because the initial vaccination didn’t cause any problems and she (autism specialist) said “ah but you don’t know” … she wasn’t discounting the MMR as possibility’ (Julie)

'When my son had his MMR, when I came out of the room, the health visitor turned round and said to me " make sure you write that down in your book in case of anything” because she obviously wasn’t happy with it’ (Janet)

This distinguishes how confusing the MMR vaccination can be in its relation to regression. If professionals contradict their own judgments on the safety of the MMR, how can a parent trust that a vaccination is safe? The uncertainty parents feel around the cause of autism and regression is an added stress to parents (Dale et al., 2006).

Research and Self-help

It was evident in the results data that from the combination of the questionnaires and interviews, research and self-help was one of the most common forms of support. This was unforeseen, due to the idea that support is usually external, with social support being identified as the most frequent form of support (Luther et al., 2005). This evidence may suggest that the desire to research was predominantly due to the parents’ lack of support during the time of regression and diagnosis:

‘I went into practical mode and thought, let me research this, you find the support yourself really … I read books by other parents of children with autism, so you don’t feel so alone’ (Sarah)

‘As soon as he got the diagnosis I was reading books... Once you know about PEC boards and routine, life became a lot easier’ (Lynn)

The term self-help is used broadly to describe the parents drive to find help for their children. One parent funded her own therapy programme for her son, other parents voluntarily attended courses and lectures. Other parents got actively involved in setting up societies for parents or involving themselves in courses for autism strategies. It is evident
that self-help and research was vital in finding the best possible solutions for their children. But as emphasised by Lynn, the support is usually fought for:

‘I feel like all I’ve done is fought for everything’ (Lynn)

This ‘fight’ theme has been explored by Woodgate et al., (2008) who found that parents fight to improve the system for their own children and other families with autism to prevent other families experiencing the same feelings of isolation (p.1081).

4.5 Limitations and Implications

It is clear that a limitation to this study is that the issues generated from this investigation are not explored as in depth as they could be; this suggests implications for further research in to the sub-topics which have arisen from the parents perspectives of regression. Furthermore, the study only represents the views of a small sample which means findings cannot be generalised. However, all parents’ experiences of regression will be inevitably different, which mirrors the idea that a case study’s significance is to gain greater detail of a restricted sample rather than to generalise (Thomas, 2013, p. 150). Resultantly, the purpose of the study is to understand it as itself and to build on and contribute to the existing research (Thomas, 2013; Oakley, 2000). A suggestion for further research could be a replication of this study with a much larger sample to increase the likelihood of generalisation. In addition to this, the methodology could have been improved if the three participants who had partaken in the telephone interviews could have instead been face-to-face, to allow more depth into their views and to observe gestural cues which are only evident in physical presence (Thomas, 2013, p. 194). However, this was the best possible approach due to participants living further afield.

Despite these limitations, the study yields rich information concerning the perspectives of the parent in three different areas: their experiences of regression, their opinions of the causes of regression
and the support they received. The study highlights many issues that should be investigated into in further detail. Firstly, the implications of autism before the occurrence of regression, as identified in the literature, could suggest that autism may have always been apparent but in a smaller degree. Another implication is that regression can heighten the difficulties of the understanding of professionals and family members, due to them being seen as ‘fine’ before the onset of regression. This could be a trend for further investigation. In terms of support it was evident that parent to parent contact was the preferred form of support although at the time of regression they mainly referred to researching and self-help. Professional support was predominantly negative, which implies that parents need to be given more information and direction surrounding regression. It seems as though this area has been neglected, Barger et al., (2013) indicated that around 1 in 3 cases are regressive, but there is still limited research on the parents’ views.

A significant implication is that parents should be taken more seriously by professionals. 4 of the 5 parents implied the MMR could have contributed, perhaps there should be more research into the views parents who think the MMR may have had an effect. Due to the research showing there is no link between the MMR and autism, there should be clearer information for parents; this is because it was suggested by the parents that some professionals seemed uncertain about it being a risk. It should also be taken into account that the parents’ children with regressive autism had the regression 10 or more years ago. This suggests that research should be conducted on parents who have recently experienced regression.
Chapter 5 Conclusion

5.1 Study Intentions

The study set out to examine the phenomenon of regressive autism through the voices of parents who have experienced it first-hand. The investigation has identified the existing research relating to autism and regression. It was evident that the general literature lacked vital discourse regarding direct evidence of parents’ experiences of regression, their views and the support available. Therefore, the study sought to answer three main questions:

- What are the experiences of parents who have children with regressive autism?
- What views do parents have on the causes of autistic regression?
- What support do parents of children with regressive autism receive?

5.2 Summary of Discoveries

The findings established in chapter 4 detailed the results of parental experiences of regression. Although the results cannot be generalised, some of the accounts do correlate with studies that suggest autism could be present before the onset of regression. It was evident that around a third of questionnaire respondents had experienced regression, and within the sample of parents who had experienced regression all children were male and the age of regression varied. The findings indicate a greater challenge for parents and families to accept the diagnosis of autism due to the difference before and after regression; this was accompanied by predominantly negative experiences with diagnosis.
Within the confines of a small sample, the majority of the participants were inclined to believe the MMR vaccination had contributed in some way to the regression of their child despite evidence to suggest there is no link. It was apparent that the lack of knowledge, uncertainty and sometimes ignorance displayed by professionals as well as the influence of other parents may have contributed to this belief.

Although it had been identified that there can be some supportive professionals, the attitude towards the support of professionals was largely negative. Parents had found more support from other parents who had experienced autism in the family and also from self-help and research.

**5.3 Recommendations for Future Practice and Suggestions for Further Research**

My research implies that professional support should favour parents’ views and suggests that professionals should be encouraged to provide better and clearer information surrounding regression, the MMR vaccination and further support. The complexity of the findings, which raise many issues, indicate the need for further research. Firstly, the study could be replicated in a larger scale to incorporate generalisations to other parents of children with regressive autism. The study could also be replicated with an addition of a control group of parents with children who have autism which is non-regressive, this way it would be useful to compare the impact of both in order to assess whether the impact is greater on parents who have experienced regression. The final suggestion for further research would be to investigate the experiences of parents whose children have recently regressed due to the participants in this study having children who regressed a decade ago or longer. This would be interesting to evaluate whether experiences, views of causes and support available has altered since then.
5.4 Final Conclusion

The study provides a detailed insight into the experiences of parents of children with regressive autism using an interpretive paradigm to provide an understanding of a small group of individuals. However, this was at the expense of being able to generalise the findings to the broader population of parents who have experienced regression in their child. Additionally all of the interviews could have been executed in physical presence rather than a mixture of face-to-face and telephone discussions. Nonetheless, this research should be useful for other professionals and individuals in the field to help understand how regressive autism impacts on a parent. Although you cannot make assumptions that these experiences may occur for other parents, this study acknowledges parents views as extremely significant. Therefore, this study may be a catalyst for further research based on parental views.
References


Appendix 1 – Statement Appearing on the First Page of the Online Questionnaire

Welcome to My Survey

Dear parents and guardians,

I am a student at the University of Northampton and I am studying a BA(Hons) Special Educational Needs and Inclusion degree. For my dissertation I am studying the experiences of parents who have children with regressive autism (who have lost skills they had previously acquired). All information will be subject to a code of ethics. Any personal information will be anonymous and the information gathered will be used for the purposes of the study only. By completing and submitting this questionnaire you give informed consent for the researcher to use the data collected for the purposes of the study. However, you have the right to withdraw at any time, and you can do this by contacting the researcher at the email address provided. Thank you for participating in this survey, your participation is sincerely appreciated. If you have any questions please do not hesitate to contact me.

Sincerely,

Sara Yos
The University of Northampton

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The University of Northampton
Appendix 2- Information Leaflet with Consent Form for Interviews

Did your child lose skills they had previously acquired?  
For example: loss of spoken language
Are you interested in this research project on the experiences of parents of children with regressive autism? If so please read inside for more details.

A Study on the Perspectives and Experiences of Parents who have Children with Regressive Autism

Definition of Regressive Autism: usually refers to a child where parents report an early history of normal development for 12-24 months which is followed by a loss of previously acquired skills.

Who is conducting the research?  
This investigation is being carried out by Sara Yoa as part of an undergraduate dissertation research study, and is supervised by senior lecturer Marie Howley, School of Education, University of Northampton. Having experienced a family member with regressive autism, this study looks at my own personal interest in regression and how it impacts the family. There has been a range of research into the possible causes and diagnosis of regressive autism and an even broader range of research on autism itself.

However, to date, there has been little research on the impact of regressive autism on parents and families. Therefore my study will delve into the perspectives, feelings and thoughts of parents who have experienced the phenomenon of regressive autism.

Research Purpose
The purpose of this research is to:

i) identify existing research on regressive autism, and how autism affects the family and ii) determine the experiences, opinions and coping strategies of parents who have a child with regressive autism.

Research Questions
1) What are the experiences of parents with a child who has regressive autism?
2) How do parents cope when a child has regressive autism and what are the coping strategies?
3) What views do parents have on the causes or contributory factors of regressive autism?

How will information be gathered?
- Questionnaires to parents of children with autism
- Interviews with parents who have experienced having a child with regression.
- Consideration of relevant documentation and literature

All information collected as part of the study will be subject to a code of ethics and will be treated in the strictest confidence. The ethical statement enclosed informs you of the storage of data, confidentiality and your right to withdraw at any time.

Thank you for your consideration, and your contribution is greatly valued.

If you require any further information, please contact me at:
Email: [email protected]
A Study Focusing on the Perspectives and Experiences of Parents who have Children with Regressive Autism

If you are willing to take part in this research, please complete the consent form below and return to Sara Yos.

I am willing to take part in this research and have been made aware of the purpose of the research and the ethical code. I understand that I have the right to withdraw at any time and that all information provided by me will be confidential. Your personal information will be anonymous.

I agree/ I do not agree (please circle) to be audio recorded during the interview process.

Signed ___________________________ Date ________________________
Appendix 3- Ethical Statement

This ethical statement is informed by BERA (2011) ethical guidelines for educational research.

The researcher recognises and respects the rights of all those involved in the study, including parents and the children; their confidentiality will be protected at all times. All the personal details of the participants will remain anonymous throughout the study.

Informed consent will be sought from all participants.

Participants have the right to withdraw at any time.

The purpose of the study is to examine the experiences, views and coping strategies of parents who have children with regressive autism. The rights of the participants included in the study remain a significant concern to the researcher and will be protected at all times.

The researcher will report accurately and fairly any information obtained through interviews.

The researcher will report upon the procedures, results, analysis and findings of the research accurately and truthfully, and in sufficient detail to enable other researchers and professionals to understand and interpret them.

The researcher will be available to discuss issues arising from the research with any interested party. The researcher will share research outcomes with participants when requested.

All data obtained from this research will be kept securely and will only be used for the purposes of the dissertation.

The researcher will at all times represent the interests of the University of Northampton and will abide by its policies and regulations.
Appendix 4- Questionnaire

Question 1

1. What is the gender of your child with autism?
   - Female
   - Male

Question 2

2. How old was your son/daughter when they were diagnosed with autism?

Question 3

3. What were the first signs that your son/daughter had autism? (e.g., lack of eye contact)

Question 4

4. How did you feel about your child’s diagnosis of autism?

Question 5

5. How did you find the process of getting your son/daughter diagnosed?
   - It was a really bad experience
   - It was neither a bad or good experience
   - It was a really good experience
   Other (please specify)

Question 6

6. Did your son/daughter lose any skills they had previously learned? (e.g., loss of speech)
   - Yes
   - No

   If you answered yes what skills did they lose? If you answered no, the survey ends here. Please click next until you reach the end of the survey.

Question 7

7. If you answered yes to question 6, do you have an opinion of what may have caused the loss of previously gained skills?
   - Yes
   - No
   - Maybe

   If you answered Yes or Maybe please specify what your thoughts are.
The last page of the questionnaire states:

If you have answered yes to question 6, would you be interested in taking part in an interview? An interview would allow me to gain a deeper understanding of your thoughts, feelings and experiences as a parent with a child who has lost skills they previously had (regressive autism). If you are interested please contact me via email and your participation would be highly valued.
## Appendix 5- Interview Schedule

<table>
<thead>
<tr>
<th>Issue/Topic</th>
<th>Possible questions</th>
<th>Possible follow-up questions/probes</th>
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<tbody>
<tr>
<td><strong>Experiences</strong></td>
<td>Gender?</td>
<td>Did it take a certain length of time before the regression stopped?</td>
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<td></td>
<td>At what age did your child regress?</td>
<td>Or do you feel it is continuing?</td>
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<td></td>
<td>What age were they diagnosed?</td>
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<td></td>
<td>Who diagnosed them?</td>
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<td></td>
<td>What were the main signs of regression?</td>
<td>What is your story? Did your child show any signs at all before the regression occurred?</td>
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<td></td>
<td>Were they in education at the time? Nursery/school</td>
<td>What were your experiences in education and health care – relating to regression?</td>
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<td></td>
<td>What impact did the regression have on you?</td>
<td>What impact did it have on the family? partners/siblings/grandparents</td>
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<tr>
<td><strong>Causes</strong></td>
<td>What do you think caused the regression?</td>
<td>How did you come to this conclusion?</td>
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<td>If MMR- how long after the vaccine did the regression occur</td>
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<tr>
<td><strong>Support</strong></td>
<td>Where did you gain any support?</td>
<td>Research- what did professionals say about the MMR?</td>
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<tr>
<td>Question</td>
<td>Answer</td>
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<td>Did professionals have information on regression? Did they have enough information?</td>
<td>What did professionals tell you were possible causes of regression?</td>
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<tr>
<td>What did professionals tell you were possible causes of regression?</td>
<td>What do you think about the research around the MMR and regression?</td>
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<tr>
<td>Research- what did you find out?</td>
<td>Was this useful, did the research help you in anyway?</td>
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<td>Was this useful, did the research help you in anyway?</td>
<td>Was there any information that was particularly useful?</td>
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<td>Was there any information that was particularly useful?</td>
<td>Do you think there should be more accessible information? What ways could information be made more available?</td>
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<tr>
<td>Do you think there should be more accessible information? What ways could information be made more available?</td>
<td>Did you go to any support groups?</td>
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<td>Did you go to any support groups?</td>
<td>Do you know/have contact with other families whose child has regressed?</td>
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<td>Did funding help?</td>
<td>Were your family supportive? How were they supportive?</td>
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<td>Were your family supportive? How were they supportive?</td>
<td>Any other forms of support?</td>
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<td>Any other forms of support?</td>
<td>If another parent was in the same position, what advice would you offer them?</td>
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<td>If another parent was in the same position, what advice would you offer them?</td>
<td>Do you get any support now?</td>
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<td>Do you get any support now?</td>
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<td>Do you get any support now?</td>
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<tr>
<td>Any more comments or views you want to express?</td>
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</table>
Appendix 6- Questionnaire Results

Quantitative data

Is your child with autism male or female?

Gender of Child with Autism

- 3, 18% Female
- 14, 82% Male

How old was your child when they were diagnosed with autism?
How did you find the process of getting your son/daughter diagnosed?

Did your son/daughter lose any skills they had previously learned?
If you answered yes to question 6, do you have an opinion of what may have cause the loss of previously gained skills?

For parents of children who lost skills, whether they had an opinion of what caused the loss

Qualitative data

What were the first signs that your son/daughter had autism? (e.g. lack of eye contact)
1. Flapping

2. He regressed at 15 months, lost speech, stopped interacting with us, stopped playing and taking an interest in the world, became unreachable. He began screaming in pain, developed horrific bowel problems, became a fussy eater, developed reflux (diagnosed by NHS), went from being a great sleeper to a terrible sleeper, became unhappy. I could go on.

3. Unsocial able Lack of eye contact Extreme meltdowns Extreme behaviour in school

4. In hind sight, bowel differences from day 1. Hated going to day care nursery etc. Didn't interact with other children. Sensory issues screamed at bright shop lights, perfume counters, too much noise.

5. Didn't talk except for the odd word

6. A lack of social interaction, not responding to her name, not looking at anyone, seemingly unable to hear or respond to us when we talked to her. Indeed the first investigations were around whether or not she could hear us, we thought she was deaf.

7. sensory issues, selective mutism, unable to engage with other children, very restricted diet, unable to make choices

8. lack of social skills being literal

9. Literally no crying as a baby (but I didn’t realise this could be a sign) He was slow to speak The first real sign came at first
school when he would go into a trance like state during story time, around this time I noticed his lack of eye contact

10. Staring into space lining up trains Loss of single words he had learnt

11. did not want to do one to one work with me, lack of response, regression in reading, speech and signing, could not join in class activities, sitting in a chair flapping a sock

12. My child showed no signs of autism until he had the MMR vaccine and then he began exhibiting certain behaviours such as repetitive movements, the humming and the clapping and flapping of the arms.

13. Communication skills, lack of language, poor eye contact, apparent ‘bad’ behaviour in school, being frustrated.

**How did you feel about your child’s diagnosis of autism?**

1. Relieved, we knew that there was something wrong

2. I don't understand the question I'm sorry. Is this specifically about the fact that he was diagnosed or is it about the fact that he regressed and I lost him. If the latter, I was and am utterly devastated. He has suffered a lot with bowel pain and headaches and I want to help him. I am petrified about his future. I want him to be happy and ok. If the question is about the fact that he’s diagnosed, do you mean - did that go ok? If so, no - it took a year and I was reassured that he was fine by too many professionals who should have known better. If the question is about the actual diagnosis then I don’t feel much because the feelings are not about that.
3. It was relief because my son had been like this since 2 years & I had no help so didn't know how to deal with situations. He was written off as bad behaviour & everything was down to my parenting.

4. It answered a lot of questions, gave her a reason for being different and finding difficulties she couldn't understand.

5. Although I didn't understand what Autism was at the time I really didn't want my son to be diagnosed with the condition.

6. Some relief because I knew something was wrong and a diagnosis enabled me to work out how to help him and sad because I knew that he wouldn't be a 'typical' child.

7. Relieved (as up till the point he was diagnosed we were believing we were bad parents. upset cross worried sad scared

8. He didn't get a diagnosis till he was 17, until then he had been told he showed symptoms of autism so it was a total relief to have a diagnosis Even then the doctor was in my opinion quite ineffectual and told my son his diagnosis is Atypical Autism

9. I thought initially I would be able to 'fix' it - also I didn't know the severity at the time. Nor did I understand the reality and what it would mean. At 2.5 years he wasn't that different I felt to other children.

10. I felt very sad for him and his teaching assistant had tears in her eyes. But also it was very helpful to have a diagnosis in December 1997 and a direction to go in to help him after he had been regressing since March 1997 but I had questions like how/why/when did he become autistic and how could he be helped and what would his future be? It meant a complete change in his schooling from fighting for him to be at mainstream to wanting him to go to a special school where his needs could be better met.
11. I did not want to accept that my child had autism. I still find it hard to deal with now as I know he isn’t a “normal” child.

12. Had an elder child with Asperger’s already, so not surprised, frustrated that diagnosis took long time (originally assessed at age 8 diagnosis not till 11) was told he wasn’t autistic so fought to get him reassessed as we were sure he was so almost a relief to be ‘proved right’.

Comments from Rating Scale question: **How did you find the process of getting your son/daughter diagnosed?**

1. (Rated ‘It was a really bad experience’) It was too slow and I hate the attitude of most autism so-called experts.

2. (Rated Other please specify) The process was good in as much as my son had a MDA which is really important. But I did find it really hard going with so many appointments, so many questions, and not always understanding what was going on. This was because I wasn’t sure what was going on or because of how I was coping at the time.

3. (Rated Other please specify) It was useful to get a diagnosis so we could get her more help, but also devastating to know this was lifelong.

Comments of **If you answered yes what skills did they lose?**

1. connection, his relationship with us and the world around him, the ability to feed himself, the ability to play and enjoy life, the ability to sleep at night, the ability to smile and light up etc.
2. By age of 11 my son became mute & was so dramatised by experiences. It was a tough which ended in him having serve mental health resulting in being section.

3. Yes but hard to explain as he was so young

4. Some speech he had

5. loss of speech, loss of ability to read (he had been on level 5 of the Oxford Reading Tree scheme) and loss of ability to sign and respond to instructions such as 'touch your toes', 'touch your nose', loss of eye contact and relationship, not able to join in class activities

6. After the MMR vaccine his speech was impaired and it was like he was a totally different child.

Comments of **What is your opinion of what cause the loss of skills?**

1. MMR

2. Too much stress of trying to deal with a mainstream school then being left by local authority with no education for 3 years.

3. My son had his MMR at the age of around 7 months along with a booster jab. He had contacted chicken pox at around 4 to 5 months. His 3 older brothers also had chicken pox so there was not a lot I could do to prevent this. They all then went down with what seemed like a chest infection. By the time my son had his MMR his immune system I feel would be very low. When I took my son for his booster the doctor informed me that they were also giving the children the MMR. I didn't question this but
really wish I had. When I came out of the room the health visitor said to me make sure you record what's happened in your red book. Clearly she was not happy with what had happened. Speaking out about this is difficult nobody wants to listen. Just to let you know that my son then had his check up about 8 months and they were concerned about him. No problems before this. I then moved. If I stayed where I was I should think he would have been diagnosed earlier.

4. I wasn't - and am still not sure- if MMR had an effect

5. His teaching assistant and I thought he started to regress in March 1997 (when he was 6 nearly 7) then I looked up in my diary when he had had the MMR booster vaccination as so many parents had mentioned it but I had dismissed it as safe. I found he had had it in February 1997 and he had had a strange episode afterwards which I did not associate with the vaccine at the time. I also think that food intolerances/allergies may be involved as well as I discovered he was sensitive to wheat and dairy in Feb/March 1998. In the summer of 1996 I had been advised by a nutritionist (not NHS) to put him on a wheat and dairy free diet to help against candida and glue ear but I had not done it. (There was an idea going round in 1998 that an inflamed gut was more susceptible to the MMR viruses allowing toxins into the brain.) My son had been having cranial osteopathy before the vaccination when he was about 5/6 years old then he saw the osteopath again when he was 7 in 1998 (after the vaccination) and he found he had definite damage to his central nervous system at the back of his head at the top of his neck but he did not want to be quoted. The research institute who discovered the food sensitivities also did not want to be quoted. I think this is because anyone challenging the drug companies and 'the establishment' would be vilified.
6. MMR vaccine

**How did you feel when your child lost previously acquired skills?**

1. How do you think? This is a ridiculous question. I love him so I was devastated. I want to help him.

2. Very upset I couldn't see the old person coming back and watching him so distress was the worst experience a parent can witness.

3. It was awful and upsetting to say the least to watch your child disappear in front of your eyes is the worst thing in the world.

4. Didn't realise it recognise till near diagnosis

5. Devastated. It was awful seeing your child regress as if he had a brain disease and no-one could do anything. It was worse than the diagnosis of Down’s syndrome and 2 holes in the heart soon after he was born. The lack of response and relationship was very hard but also that all that work I had done to encourage his skills was all gone. I remember feeling emotionally handicapped when talking to an educational psychologist at the ******** after he regressed and was diagnosed as autistic. She wanted me to continue working on encouraging his skills but I couldn't anymore, I was too handicapped myself. (She did not think that my son was autistic before the regression.)

6. Angry at the fact that something which is supposed to help my child has actually ruined his whole life
Were there any strategies you used to cope with your child's changes? (E.g. parent support groups)

1. I researched and still do as much as I can

2. I read up on everything I could get my hands on and had some input from speech and language but when she left no one else helped for years.

3. No just got on with it myself as there was no help really

4. My initial reaction was to research and contact NAS And doctors to try and help

5. Yes the Sussex Autistic Society was a great help. (not functioning now) Also Jesus helped me, and praying and sharing with Christian friends and our local church and helping others.

6. I did not go to any support groups.