

THE COPING STRATEGIES OF FAMILIES WHO  
HAVE MORE THAN ONE CHILD WITH AUTISM:  
A QUALITATIVE STUDY

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## Abstract

How do families with more than one child with autism manage to cope and do they risk family disintegration or demonstrate resilience?

Although there is extensive literature on coping with children with disabilities, no previous study has examined the effect of living with two or more children with autism. Eleven families including parents, siblings, and verbal children with autism, (45individuals) were interviewed to ascertain their coping strategies. Using Grounded Theory, the semi-structured interview typescripts were analysed, and a theory emerged that all families cope, but they go through different periods of perilous coping and buoyant coping. The various factors which lead to each type of coping are demonstrated, and discussed.

Practical suggestions to improve coping are given by the families. Their message to the non autistic world was that they do not want to be pitied. The results showed a remarkable degree of resilience in all the families. Family and extended family were the most significant source of support. Perilous coping was associated with a number of intervening factors.

The families showed real warmth and love towards the affected children and in spite of concerns about the future, the non affected siblings were confident they would look after their disabled siblings when the parents were no longer able to do so. Children with autism had a fascinating range of perceptions about autism.

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## CHAPTER ONE INTRODUCTION

### 1.0 Preface: Inspiration for the study

This study was first conceived when the researcher was in clinical practice as a Consultant Paediatrician and had responsibility for the diagnosis and management of children with autism. Over an eighteen year period in one geographical area, some families presented with two or more autistic children. It was intriguing that, in spite of the literature about stress in families with autism, these families appeared not only to remain intact, but to cope at least as well as families with only one autistic child. The author was keen to find out if this observation had any validity and this prompted the present study.

The nature of the disorder, known as autism, or Autistic Spectrum disorder (ASD), is that it is life-long and is associated with several different medical co-morbidities. These are co-existing conditions. The role of the paediatrician is to diagnose, manage and treat these problems as they arise. A long term relationship between doctor and family is therefore established, and medical insight into the family and its vicissitudes becomes central to the successful management of complex family difficulties. In this study, a complete change of role from physician to researcher occurred. Using the background

knowledge of some of these families to guide the development of the interview questions, the previous clinical relationship having been terminated, the new persona of the researcher emerged to enable an entirely different set of insights to be obtained.

### 1.1 Reasons for the study

There is a paucity of literature about coping strategies in these families with more than one affected child, with no study devoted entirely to families with two or more autistic children. The evidence about stress in families with a single child with autism suggests that it is more stressful than coping with a child with a learning disability, or one with Down's syndrome.<sup>1, 2</sup> Could it be the case that having two or more children with autism increased the stress two or threefold? If this were the case, how is it that these families with several autistic children manage to remain as a family unit and continue to derive happiness from their children?

There is a perception that the prevalence of autism is rising. This may not be the case, as will be discussed later, but certainly there are many more individuals being recognised who have this disorder. Therefore, there is an urgent need to find out about ways of promoting coping and securing a future for these individuals based in their families. The cost of caring for adults with autism, especially within institutions, is very high<sup>3, 4</sup> and therefore any strategies that can be employed to promote family cohesion should be explored, although in Knapp's study he found that the costs accrued by the parents were also very high.

Little is known about the thoughts of the children with autism, about their concepts of ASD, and whether this might influence family coping. The siblings also play a key role in family life and although there are studies<sup>5</sup> about siblings and their perception of autism, this study will explore their role in these multiplex families where the normal sibling is sometimes in a minority.

With these themes in mind, Chapter 1 will be arranged under the following headings:

An overview of autism

Stress, coping and resilience

Personality and its impact on coping

Well-being and quality of life,

    Siblings and autistic individuals own understanding of their condition.

The research questions which have arisen from the epistemology.

## 1.2 Overview of Autism

### 1.2.1 Definition of Autism

Autism is a complex disorder of neurodevelopment described as a triad of impairments which consist of problems with communication, difficulties with social interaction and a lack of imagination associated with rigid thought patterns and repetitive behaviours.<sup>6</sup> The condition is life-long, but the presentation and manifestations of autism do vary in severity according to the

developmental stage of the individual. The symptoms of each part of the triad can also vary in severity. Communication problems can present as a complete and persistent absence of verbal communication, at one extreme, and at the other, normal fluency of speech, but an inability to use speech in a socially appropriate and reciprocal manner. The difficulties in social interaction can be severe, such that an individual cannot bear to be in a room with strangers at the lower end, but merely exhibits a mild social gaucheness at the other. The rigidity of thought and repetitive actions can also vary along a spectrum from obsessions which limit daily activities, to a preference for extreme order and systematisation. This is why autism is now commonly referred to as 'Autistic Spectrum Disorder' (ASD).<sup>7</sup>

The World Health Organisation International Classification of Diseases version 10 (ICD10)<sup>8</sup> describes autism as a 'Pervasive Development Disorder' with various subtypes including classical autism as described by Kanner,<sup>9-11</sup> autism-not otherwise specified-(NOS) and Asperger's syndrome. Some years later than Kanner, in Germany, Asperger<sup>12, 13</sup> described a syndrome of verbally able individuals who had social deficits. This work went unrecognised for years -possibly because it was published in German in 1949 when the world was recovering from World War 2. It was not until Wing<sup>14, 15</sup> wrote about the condition in 1981 that the clinical picture became known to a wider audience as 'Asperger's Syndrome'.

The American classification system DSM 1V<sup>16</sup> describes autism slightly differently but the same groups of problems apply in both classifications.

There is a revision in process at the moment and it is likely that the term Autism Spectrum Disorder (ASD) will be the main diagnostic category, as at the moment the different subgroups are not thought to be helpful in terms of outcome or treatment.

Throughout this thesis the term ASD will be used except where the breakdown of the different categories has been tabulated or where an example is best illustrated using the more precise diagnosis.

### 1.2.2 The Incidence and Prevalence of Autism

The true incidence of ASD in the UK is unknown. This is because incidence is a measure of the number of new cases per person-year, of an entire population. In autism, there are many cases in any one year that are as yet undiagnosed, because autism presents at different ages. The prevalence of autism, which is the proportion of people who have a condition at any one time, appears to be rising. In the author's own experience, the number of referrals for assessment of possible ASD, in a secondary referral unit at a District General Hospital, rose from six or seven per year in 1992, to two or more per week by 2008.<sup>17</sup> However, detailed studies of prevalence<sup>18</sup> have shown that it is the increased awareness of autism in the general population which has led to this rise rather than a true increase in prevalence.

Nevertheless, widely differing prevalence rates have been quoted depending on the dates of the particular study, for example a study in the USA<sup>19</sup> showed that the prevalence in the year 2000 was at 34 per 10,000, but Frombonne<sup>20</sup> writing in an editorial suggested that this was likely to be an underestimate.

More recent prevalence studies<sup>21</sup> have suggested that the prevalence rate is still rising with earlier diagnosis being one factor. Gurney<sup>22</sup> looked at the rising trend of prevalence over time. In his study, which was based on an age-period-birth cohort of special educational disability data; which was gathered using school ascertainment of children who require extra support, he found a rising trend in cases of ASD as a primary educational disability which showed no sign of diminishing starting from the year 1991.

There does not appear to be significant differences in prevalence between different countries in the developed world. A Danish<sup>23</sup> study showed that the trend for rising prevalence had continued in Denmark in spite of eliminating Thimerosal, a chemical that was used in the manufacture of immunisations, which was thought to be a causative factor in autism and a possible reason for the increase in prevalence. A more recent study, using a total population study, suggested that the prevalence in South Korea<sup>24</sup> was even higher.

The commonly accepted prevalence rate at the moment, in the UK, is about 1 in 100 children.<sup>25</sup> The referral rate to the child development centre used in this study had this prevalence level.

### 1.2.3 The Diagnosis of Autism

There has been considerable debate over the nature of the diagnosis because there are no clinical or diagnostic tests which conclusively give an unequivocal diagnosis of ASD. The diagnosis is always based on a thorough history from a parent and detailed observation of the affected child. When the

children in this study were diagnosed (up to twenty years ago in some cases) the use of diagnostic questionnaires such as the Autism Diagnostic Inventory-Revised (ADI-R)<sup>26, 27</sup> screening devices such as the Checklist for Autism in Toddlers (CHAT),<sup>28, 29</sup> and other diagnostic tools such as the Autism Diagnostic Observation Schedule (ADOS)<sup>26, 30, 31</sup> and the tool developed by Wing et al,<sup>32</sup> the Diagnostic Interview for Social and Communication Disorders (DISCO), had not been invented. Recent evaluation of these diagnostic aides is still ongoing.<sup>31, 33, 34</sup> Although these tools are now the standard way of confirming a diagnosis; the multidisciplinary assessment was the 'gold standard' twenty years ago and is still highly valued today. This assessment consists of a diagnostic interview by a paediatrician or psychiatrist, combined with observation of the child's behaviour, and then further assessments by other professionals such as clinical psychologists, speech therapists, occupational therapists and nurse specialists. This is the method used for the assessment of all the participating children in this study. The more recently diagnosed children also had the benefit of further confirmation using the ADOS and ADI, or the DISCO.

#### 1.2.4 Causes of Autism

The aetiology of autism is unknown, although there have been numerous attempts to develop hypotheses about its causes. Currently, different models have been used to try and understand the condition. These include two main branches of research. Firstly, psychological theories have tried to explain deficits in brain functioning; and secondly, biological models of causation, which have examined genetic causes, environmental factors, or anatomical

abnormalities. The latter research projects try to identify particular structural or chemical abnormalities in areas of the brain using imaging techniques.

The various biological aetiologies are not necessarily exclusive, and may eventually be shown to have components of genetics, environmental and anatomical anomalies as part of the aetiology.

These areas of possible causality will be discussed further below. The main psychological theories will be discussed, then, the biological theories will be explored.

#### 1.2.4.1 Psychological theories of causation

The paradigm of ‘information processing’ is the background to the development of psychological theories which have been proposed to explain autism. Information processing theory is concerned with the way the human brain takes in information, via the senses, and then uses and processes this information to make it available for logical thought and output in the form of actions, words and motor activity, as well as complex behaviours and memory. The model is based on the premise that the brain can be thought to work like a computer with increasing levels of complexity. The model is central to understanding the basis of several mental illnesses and therapeutic approaches to treatment. Information processing is discussed by Ingram,<sup>35</sup> who follows the history of the development of this paradigm from early beginnings in animal behaviourist experimentation, via Alan Turing’s<sup>36</sup> computational theories, to the relatively recent use of cognitive/behavioural approaches to the understanding and treatment of pathological behaviours.

The paradigm, as applied to the autistic brain, suggests that there could be an abnormality at any point in the process from altered sensory input, via changed sensory perception, to difficulties in storing sensory information leading to bizarre behaviour. Ingram concentrates on the possibility of altered sensory perception as being a major factor in disordered information processing in autism. While there is evidence of abnormalities of sensory perception in many children with autism; for example over sensitisation to smell or texture of food, or under-sensitisation to vestibular sensations, this is not universally present in the autistic child, and therefore does not explain all the aspects of disordered 'information processing' in the autistic mind.

A theory, based on 'information processing', that has been used to explain the central deficit in autism is the psychological model of a lack of 'theory of mind'. This is an inability to reflect and understand that another person has feelings that differ from one's own; and the ability to understand about one's own beliefs and those of others. The 'theory of mind' was first described in chimpanzees in 1978 by Premack.<sup>37</sup> This theory was probably developed from the philosophical writings of Hegel<sup>38</sup> in the nineteenth century, who wrote about the philosophy of mind. In the twentieth century, Baron-Cohen,<sup>39</sup> and others first raised the possibility that difficulties with 'theory of mind' were associated with autism. In a series of ingenious experiments, they showed that children with autism had significantly more problems with understanding that other people have different thoughts from their own, than a group of normal children or children with lower IQs. He had previously noticed that autistic children had a particular problem with understanding other children's

likes and dislikes and indeed were frequently not really interested in other children at all. Later, he went on to suggest that the development of shared attention in others was a precursor to demonstrating that a child had developed a ‘theory of mind’.<sup>40</sup> Shared attention, which can be demonstrated by being able to look at a distant object which is pointed at by another person, (and thus share the attention with another person) is often severely delayed in the autistic child and is one of the earliest signs of autism in the pre-verbal child. Autistic children sometimes lack the ability to use finger pointing at all, a form of communication which most normal children can achieve by one year of age.

The problem with theory of mind is that although many children with autism do have difficulties with tests for theory of mind using the standard tools such as the false belief tests and the Sally-Anne test,<sup>41, 42</sup> a considerable number of autistic children do go on to pass the tests at a basic level, and some at a higher order of understanding, although they often develop this much later than children with the same IQ. There is therefore insufficient evidence of an absolute problem with the theory of mind, rather a deviation or delay in the development of the perception of other people’s feelings.

A second theory about the causation of autism, arising from the ‘information processing’ paradigm is that it is a problem with executive functioning, which is a difficulty performing complex tasks which require coordination and planning involving several different parts of the cerebral cortex. Executive function has been defined by Ozonoff<sup>43</sup> as “the ability to maintain an

appropriate problem-solving set for attainment of a future goal; it includes behaviours such as planning, impulse control, inhibition of pre-potent but irrelevant responses, set maintenance, organised search and flexibility of thought and action.” (p 1083) Ozonoff argued that executive functioning problems are the core deficit in autism and that problems with theory of mind might be explained by the lack of executive functioning. People with autism certainly demonstrate difficulties with executive function but so do people with other conditions such as Attention Deficit Hyperactivity Disorder (ADHD),<sup>44</sup> and learning difficulties. While it is part of the picture of the cognitive defect in autism it cannot be the sole responsible factor. However, it is of interest that children with ASD also frequently have severe symptoms of ADHD. It is debatable whether the poor attention skills in children with ASD are a core deficit or whether the lack of attention is an added co-morbidity, as not all children with ASD have ADHD as well. Whichever is the correct hypothesis anecdotal evidence suggests that children with ASD often respond well to the same medications that are used in the treatment of ADHD (personal experience)

A third psychological theory is that there is a lack of central coherence which is an inability to understand the wider picture while concentrating on detail.<sup>45</sup> This theory, as advocated by Happe,<sup>46</sup> was used to explain why some people with ASD were brilliant mathematicians or artists but seemed to lack a more general perception of the world and where they were in a social context. She found that people with different levels of ability on theory of mind tests, nevertheless, all showed a lack of central coherence.<sup>47</sup> This lack of central

coherence is much more evident in some children with autism than others, and while it helps to explain some of the features of the 'autistic savant', it is hard to reconcile this theory as being the central cognitive deficit.

A fourth theory of the cause of autism suggests that autism is in fact an extension of the male brain. This theory has arisen because autism is much more common in boys than girls, usually of the order of 4 boys to 1 girl.

Baron-Cohen<sup>48</sup> argues, with good evidence, that boys are much better at systematising, prefer spatial perceptual activities, and perform less well on emotional intelligence tasks than girls. He also shows that girls with autism have many more of the male attributes. Perhaps the autistic individual is just a more exaggerated form of normal males. There are certainly advantages in employment for having these skills and being single minded and not spending time on relationships in the workplace. These advantages might explain, from an evolutionary viewpoint, why people with autism succeed and continue to reproduce. Although this does not apply to the severe form of autism as these individuals are so socially isolated, they rarely form sexual partnerships, and can therefore be viewed as carrying genes which do not reproduce into the next generation.

#### 1.2.4.2 Biological theories of causation

In addition to the psychological theories, there are biological approaches to the understanding of autism. The fact that the condition is definitely heritable was demonstrated by early identical twin studies<sup>49</sup>, which showed that in monozygotic twins( identical twins) the chance of the second twin being

diagnosed with an autistic spectrum disorder was approximately 92%, whereas the risk in dizygotic (non identical) twins was much lower. This fact led to a search to find a single gene that might cause autism. There have been several single genes that have been identified and implicated in certain families. A review of the genetic studies which have implicated certain genes has been undertaken by Freitag.<sup>50</sup> Some of the syndromes associated with autism such as the Fragile X syndrome, a condition mainly occurring in males, although carried by females and associated with intellectual disabilities and certain physical characteristics, has a particular mutation on the X chromosome. The Frax A gene is now readily identifiable in clinical practice, but this type of autism only accounts for less than 2% of children with autism. As yet no single gene has been found that could explain the wide spectrum of presentation, and differing phenotypes. The fact that several single genes have been implicated in various syndromes associated with autism means that it is extremely unlikely that autism will be found to be a single gene disorder. It is almost certainly polygenic.<sup>51</sup> (Involving several genes)

There have also been numerous studies of brain imaging to try and identify a particular abnormal anatomical site. A recent symposium<sup>52</sup> reviewed several of these approaches and tried to summarise the current state of knowledge. Firstly, the symposium examined various anatomical sites such as the frontal lobes or the parietal area or the corpus callosum which have all been implicated in different studies. There was agreement that there was inconsistency in the results and the only universal finding was that people

with autism have large brains, which might suggest a brain with more synapses, but there is not a single part of the cortex which is abnormal in all people with autism. The latest proposal was that abnormal genes have an effect on the development of synapses between the neurones of the brain.

Keen<sup>53</sup> has shown that there are probably environmental factors which are important in the aetiology of autism. She showed that the risk of having a child with autism was at least three times higher in the same ethnic group (Afro-Caribbean) from mothers who had recently immigrated into the UK rather than those who were also Afro-Caribbean but had been born in the UK. Earlier, Gillberg,<sup>54</sup> in a much smaller population study, in Sweden, demonstrated that immigrant mothers from Uganda were several times more likely to have a child with autism than a native Swedish mother. This suggests that although genetic factors are important in the aetiology there are likely to be significant environmental factors which play a part. Just exactly what these are has not yet been determined.

It is evident that although there are many theories of the causation of autism, the present state of knowledge does not give clarity about which, if any, of the theories discussed above, really explain autism which is such a diverse spectrum. This study does not propose to try and clarify causation. However theories about causation can have a profound effect on the way families cope. This was born out in the 1980s when a misinterpretation of Kanner<sup>10</sup> suggested that parents who were rather cold and detached were the cause of

their child's autism. It is therefore important to consider which type of causation a particular family favours when discussing coping strategies.

### 1.2.5 Outcomes in Autism

There have been various outcome studies looking at both people with mild and severe intellectual disabilities that have examined life expectancy in autism, as well as the possibility of independent living, and attendance at University or obtaining employment. The studies of the more able individuals with ASD have been reviewed by Howlin<sup>55</sup>. She found that there was no significant worsening of life expectancy for these individuals unless they had an additional diagnosis such as epilepsy. Gillberg<sup>56</sup> found that the commonest type of epilepsy in people with ASD was complex partial seizures, and individuals with epilepsy were more likely to have a worse prognosis. The author would agree that complex partial seizures were very common from her own clinical experience.

In another study, Gillberg<sup>57</sup> found that individuals with a lower IQ had a worse prognosis for life expectancy. However, it is likely that people with a lower IQ had more medical complications relating to their underlying condition which may have influenced their prognosis. More recently, Billstedt's<sup>58</sup> prospective study of 120 individuals with autism found that the psycho-social outcome may have been worse than had previously been believed, for individuals born in the 1960s -1980s.

Whether the families in this study were aware of these factors and whether the knowledge about outcomes influenced their ability to cope seems unlikely, but questions about the family's views of the future was one area that has been examined in this study.

### 1.2.6 Heterogeneity in Autism

Family heterogeneity, that is the presentation of different types of autism within one family, is normal.<sup>59</sup> The present author had experience, in clinical practice, of several families who had more than one autistic child, and they often showed heterogeneity of the spectrum within their family. In fact it was more unusual for a family with several affected children to have children with identical presentations of autism. Although Konstantareas has shown<sup>60</sup> that symptom severity is inversely related to coping, there are differences of opinion on this, and it was thought that all degrees of severity could be included in this study to test this point within the same family.

The possibility that these families often showed considerable resilience and perhaps even coped better than families with one autistic child was a spur to this study and led to a question of whether there was some factor inherent in autism that promoted coping in both the parents and siblings of these multiplex families.

## 1.3. Stress, Coping and Resilience

### 1.3.1 Definitions

The Oxford English Dictionary defines stress as 'an effort or demand upon physical or mental energy'.<sup>61</sup> 'Stress' has been used loosely in many ways with a variety of slightly different meanings particularly in the context of stress in the work-place. This has complicated many studies which have tried to assess levels of stress. In this thesis the above definition will be used.

Lazarus<sup>62</sup> wrote about the effects of stress on families. He defined how stress leads on to coping and is the trigger which leads to the emergence of coping behaviours. His work has been seminal in the development of studies on stress and how different types of coping develop from different stressors. Lazarus<sup>63</sup> also had a definition of coping which alluded to the cognitive and behavioural efforts needed to surmount taxing demands which would normally be beyond the resources of the individual. Turning to families, McCubbin<sup>64</sup> gave a description of coping involving behavioural and cognitive efforts used by families to reduce demands on the family system. In this thesis the coping strategies employed by parents will be explored and analysed.

Families who become stronger in spite of adversity are said to be showing 'resilience', which has been described by Rutter.<sup>65, 66</sup> His definition is "Resilience describes a process whereby people bounce back from adversity and go on with their lives. It is a dynamic process highly influenced by

protective factors. Protective factors are specific competencies that are necessary for the process of resilience to occur." (p. 626)

### 1.3.2 Stress

In spite of the difficulties with definition, there is an extensive literature on measuring stress in families with children with different disabilities. Abidin<sup>67</sup> first developed a way of measuring stress using a questionnaire called the Parenting Stress Index. This tool has subsequently been used by many researchers. McCreary<sup>68</sup> reviewed several different measurement tools for examining stress, including the Parenting Stress Index, and she found that the measurement tools were a valid measure of stressors but that there was inconsistency across different studies in the findings about stress. However, she came to the conclusion that stress was an important cause of psychopathology in children.

Most authors agree with Dabrowska,<sup>1</sup> that having a child with autism causes a higher level of stress than looking after a child with Down's syndrome or other developmental delay. Although Dabrowska's study was done in Poland, and although the quantitative tools for measuring stress were revalidated on a Polish population, only pre-school aged children were included and therefore the results might not be applicable to older children and adults. The other problem about the measurement of stress in a quantitative way is that measures in questionnaires dictate a forced choice response (e.g. yes or no in response to a set question), and as a consequence, some really significant stressors may be inadvertently missed. The findings from Dabrowska's study

suggest that parenting a child with autism is more stressful than parenting a typically developing one, or a child with Down's syndrome.

Sharpley,<sup>69</sup> in the introduction to his study, comments that other authors had suggested that there were three main reasons for the stress caused by autism; firstly, the relatively poor understanding of the condition by the general population, compared to other developmental delays; secondly, the inappropriate behaviours shown by autistic children; and thirdly, the knowledge that the condition is life-long with no cure. Sharpley's study, which used questionnaires to measure stress, parental anxiety and depression, had a very low return rate which may have biased the results. He demonstrated that the behavioural problems of the children were the major management problem for the parents, and that 81% of the parents had been stretched beyond their limits at some time. The mothers reported elevated levels of anxiety and depression. Those who had access to other family members for support had lower levels of daily stress, although this did not reach statistical significance. Sharpley's findings about the child's behavioural problems being the main cause of stress in the parents are confirmed by two other studies. Firstly, Freeman,<sup>70</sup> who validated the use of a measurement tool called the Childhood Autism Rating Scale (CARS)<sup>71</sup> as a method of measuring stress, and secondly, Dumas<sup>2</sup>. Both studies showed that parenting stress is associated with high levels of psychological distress and depression, and that child behavioural problems were a source of unhappiness in parents.

Further exploration of sources of parenting stress was undertaken by Phetrasuwan,<sup>72</sup> who used postal questionnaires, in a descriptive study that measured parenting stress, depression, and psychological well-being. She found a correlation between higher parenting stress and depression. This seems almost a tautology because parents who are depressed are likely to score stressful symptoms higher. Another problem with this study was the fact that one of the tools used for measuring parental stress, the Parental Stressor Scale: Developmental Disabilities (PSS:DD) had not been adequately validated. Several different ethnic groups were included in the study and the uptake from replies to questionnaires was 45%, which is high for a postal questionnaire study. They did show that managing demanding behaviours was a significant source of stress. These findings were consistent with those of Dumas<sup>2</sup> and Tomanik.<sup>73</sup>

Tomanik,<sup>73</sup> argued that many previous studies of stress were flawed because they measured very broad domains of behaviour and may not have measured behaviours typical of autism. She also correctly surmises that stress in parents of children with autism may be due to their child's poor adaptive skills, rather than poor behaviour per se. She examined specific autistic adaptive and maladaptive behaviour and maternal stress. Her sample was from a well educated and middle class background. She used questionnaires to measure stress and looked at a sample of children aged 2-7 with pervasive development disorders. She reported that two thirds of the parents were stressed, and the child's aberrant and adaptive behaviour was the main responsible factor. This study had the advantage of being

specifically designed to look at autistic behaviours and suggested that having an autistic child is indeed very stressful to parents.

Hastings<sup>74</sup> has shown that there are different experiences of stress in families with children with autism, and that the effects of stress can lead to maternal depression as well as adversely affecting the siblings. Tehee<sup>75</sup> has looked at the factors contributing to stress including parental gender. He found that mothers tended to be more stressed than fathers possibly due to the fact that they normally have more of the burden of care. Konstantareus<sup>60</sup> found that symptom severity and the level of functioning of the autistic child were related to parental stress. Specifically, high activity and lower mental functioning were associated with higher parental stress levels. Other studies have also reported a relationship between parenting a child with autism and parental stress. For example, Rao<sup>76</sup> reported that parenting high functioning children with autism was more stressful than parenting normal children of a similar intellectual level, and more recently, (2008) Davis,<sup>77</sup> demonstrated that stress is prevalent in parents of newly diagnosed children and is largely associated with typical autistic behaviour.

While it is useful to have established that autism and its symptoms contribute to a very stressful environment for the affected families, it is even more important to investigate methods of reducing stress, to improve coping, and to examine factors that lead to resilience and a good quality of life. This present study investigates how a potentially extremely stressful situation that of having more than one autistic child might either be overwhelming, or might

alternatively lead to improvements in coping and long term resilience and a better quality of life. All the studies discussed above used quantitative measures for stress and symptom severity. These cannot capture the full range of behaviours, or the nature of the stress, felt by the parent. One reason for using qualitative methodology in this study was to try and understand the full picture of the different causes of stress, and the coping strategies employed by the parents.

### 1.3.3 Coping

Having defined coping as in 1.3.1, Lazarus<sup>62</sup> went on to describe the response to stress as consisting of three processes. The first process is the perception of the threat. The second process is that of the evaluation of the resources available in response to a threat, and the understanding of the effectiveness of a particular coping strategy. The third process is of reappraisal. Coping is the way of completing these processes.

Coping is not a static process. It continues to evolve as new threats are perceived and reappraisal of the process occurs. Coping can also be a multiple set of responses to the stressor.<sup>62</sup> Coping has been described as falling into two major categories; emotional focused coping, which is a way of changing the emotional response to the stress; and problem focused coping, which is a practical way of altering the problem.<sup>78</sup> These categories of coping are not completely separate nor is one method of coping superior. However various authors have looked at outcomes for families, in terms of quality of life, related to the two approaches.

Mancil,<sup>79</sup> in a review of the current literature, summarised the stress related studies pertaining to coping strategies that were effective in reducing stress. The authors found that of the fifty articles retrieved from their search, only nineteen met their review criteria, and of these, only two mentioned the mental age or IQ of the child. They felt that there was indeed evidence that parents of children with autism did experience a high level of stress, but that the coping strategies from the various studies were not consistent; perhaps because the study populations varied a great deal, and the studies made use of differing measures. It can be argued that the complexity of family life is such that developing universally applicable coping strategies is an unrealistic aim. Mancil<sup>79</sup> suggested that future studies should have more consistent populations and that more control and comparison groups need to be used.

Erguner<sup>80</sup> included a control group within an interventional study that looked at coping following a parent instruction group, compared to no intervention. He showed that the intervention group had less hopelessness, and the parents used more social support, but the groups were quite small and the children's ages varied considerably. It is possible that the effect would have been greater if the study had been undertaken immediately after diagnosis.

Lyons<sup>81</sup> reversed the question by asking whether the impact of autism severity and parental coping strategies had an effect on stress, rather than examining stress and whether this led to coping. She suggested that severity of autism was related to the level of stress. This study used a sample of highly educated parents selected from a parent support group and was cross

sectional so might not be applicable to all families with ASD. She did report that emotion-focused coping was related to more family problems than task orientated coping. However, the sample was biased towards mother's views and did not take account of the views of siblings or fathers.

There are now a number of studies which have examined coping specifically in families with children with autism. For example, in 2005 Hastings<sup>74</sup> did a study involving two types of families, those with pre-school aged children with autism and those with school aged children with autism. Initially, he described how there were few studies specifically investigating coping in families with children with autism. He then measured coping within the two types of families, using the COPE inventory<sup>82</sup> to explore whether the age of the child or the gender of the parent had a significant effect on coping style. The brief COPE inventory has twenty eight items in the form of statements and respondents are asked to rate whether they have used that type of coping or not on a four point scale from 'not at all' to 'doing this a lot'. He also examined whether there was an association between parental coping strategies and stress or mental health. He measured mental health using the Hospital Anxiety and Depression Scale which has been shown to have good reliability. Stress was measured using the questionnaire on Resources and Stress-Freidrich short form (QRS-F: Freidrich et al.1983)<sup>83</sup> and parents had to answer true or false to a series of questions such as 'other family members have to do without things because of N'. Applying factor analysis to the brief COPE items he devised four coping scales. Factor 1(active avoidance coping) which included subscales for substance abuse, self blame and venting of emotions, which he concluded demonstrated an attempt to

avoid the stressor. Factor 2 (problem-focused coping) which included items for planning, active coping and seeking social support. Factor 3 (positive coping) included items such as use of humour, positive reframing and acceptance. Factor 4 (religious /denial coping) which was a mixed group. These new coping scales were reported to have an acceptable internal consistency.<sup>84</sup> Using these new factors, he showed that mothers were more likely to use active avoidance coping and this was associated with stress, anxiety, and depression. The age of the child was not significantly associated with coping style. The use of alcohol and social withdrawal was associated with active avoidance coping .One wonders whether parents who use alcohol and social withdrawal more, do not have more mental health problems anyway, and these may not be related solely to stress associated with having a child with autism. It is also possible that those who made use of positive coping were more likely to be optimists or have a higher self-efficacy. He observed that parents did better with less avoidance coping and suggested that more positive coping leads to better outcomes.

Coping has been conceptualised in several ways, and the measurement of coping has been described by Dalrymple<sup>85</sup> who summarised these well, based on Carver et al<sup>86</sup>. It is useful to list these types of coping in order to consider them in the context of the rich information provided by the families who took part in the current study. These categories are an expansion of those used by Hastings.

1. Active coping: exerting effort to remove the stressor.

2. Planning: thinking about how to confront the stressor.
3. Seeking Instrumental Social Support: seeking assistance and advice.
4. Seeking emotional support: gaining empathy.
5. Suppression of competing activities: reducing attention to other activities in order to concentrate on dealing with the stressor.
6. Turning to religion.
7. Positive reinterpretation and growth: making the best of a situation by viewing it in a more favourable light.
8. Restraint coping: coping passively by holding back coping attempts until they can be of use.
9. Acceptance.
10. Venting of emotions: increased awareness of one's emotional distress and a simultaneous tendency to discharge feelings.
11. Denial
12. Mental disengagement: through day dreaming, sleep or distraction.
13. Behavioural disengagement: giving up
14. Alcohol/drug use.
15. Humour.

Is it important to be able to subdivide coping in order to measure it more accurately or is it better to listen to coping descriptions and interpret them accordingly? By quantifying types of coping, some of the essence of what contributes to the whole family perspective of coping may be lost. In the current study, families had the freedom to discuss whichever strategies they

found helpful, which gave a fuller description of the families' coping and resilience, or their problems.

Other authors have looked at coping over time. Gray<sup>87</sup>, in a longitudinal study, found that, over a ten year period, religion became a more important strategy. Additionally he found that emotional focused coping occurred more predominantly the longer the family had lived with the young person with autism. However, Twoy<sup>88</sup> examined how family adaptation might be influenced by coping styles, and found normal levels of family adaptation and less use of spiritual support in families with disabled children as compared to families without disabled children. The question about whether religion becomes a more significant factor over time will be addressed in this study.

Not all studies have reported that raising a child with autism has a wholly detrimental effect upon parental mental health. For example, Higgins<sup>89</sup>, in an Australian sample, found that care givers of a child with ASD had a healthy self-esteem in spite of lower levels of marital happiness. He suggested that coping strategies were not significant predictors of the outcomes concerning family functioning (adaptability and cohesion), self-esteem and marital satisfaction.

Recent publicity about ASD may have influenced the public's understanding of autism and this in turn may have changed parental coping strategies. The fact that ASD has become much more readily recognised in both the professional and lay population has probably had a significant effect on the

way families cope and adapt. In 1990 there were two papers by Rodrigue <sup>90</sup>,  
<sup>91</sup> which both gave a very gloomy outlook for families with children with autism, compared with other types of disability. In part, the lack of recognition of autism in the early 1990s would have meant that parents would have been totally unprepared for the diagnosis of autism and would therefore have had a much greater shock at the time of diagnosis than in the twenty first century. It is to be hoped that such findings would not occur if the studies were repeated today.

An often ignored construct that is related to coping in families with autism is attachment. Bowlby's <sup>92</sup> work on attachment theory was seminal in explaining the importance of the relationship between the child and his or her principal carer, usually the mother. He based this on studies of juvenile offenders who had very disruptive early attachments<sup>93</sup>. Although there was much criticism of attachment theory following the initial publication of his work, subsequent authors<sup>94, 95</sup> have generally accepted that there are different types of attachment in early infancy and that disrupted attachments do lead on to mental health problems in later life and relate to offending behaviour.

Howe<sup>96</sup> looked at an outline of attachment theory with reference to disabled children, and found that there was a complex picture between attachment and disability. He suggested that it was not the disabled child per se that caused the insecure attachment, but rather the carer's attitude towards disability that influenced the type of attachment. This suggestion has not been proven.

Van IJzendoorn et al<sup>97</sup> compared groups of children with autism, mental retardation, language delay and typical development, while examining their attachment and parental sensitivity to their needs. They found that the autism group had the most disordered attachment, but this was not related to parental sensitivity. They concluded that parental sensitivity is associated with security of attachment in children without autism but they could not confirm this for children with autism. They did not look at whether this was related to coping ability. Little is known about how attachment might be related to coping in children with autism.

Kuhaneck,<sup>98</sup> in a qualitative study on coping in eleven mothers of autistic children, found a number of helpful practical strategies such as 'my time', planning, knowledge, 'sharing the load', 'lifting the restraint of labels' and 'recognising the joys'. The author used a phenomenological approach, which is different from the methodology in the current study. However, the description of the way she used semi-structured interviews and the type of analysis was similar to the Grounded Theory methodology used in the present study. Her findings, although restricted to recruitment from a parent support group, are nevertheless relevant to the current study.

Vaughan<sup>99</sup> also examined the coping process through the content and structure of parental stories, in mothers of children with autism. She argued that her analysis of the narrative data, using a social constructionist framework, demonstrated that mothers were using cognitive coping

strategies, and she reported that discrete episodes of practical coping were particularly apparent. Her interviews took place in three phases. The first was a life story interview; the second was three stories chosen by each participant to illustrate stressful episodes in the last few weeks; and the third phase was to share the stories with all the participants to look for similarities and differences. While the stories are very interesting, they only reflect the mother's view point. The current study, by using the rigour of Grounded Theory, and the more comprehensive picture achieved by interviewing the whole family, hopes to produce a more rounded and valid assessment of coping.

A further series of authors have examined the adaptations that families made following the diagnosis of autism. Some have described the stages of adaptation as being very similar to the grief process after the death of a family member.<sup>100</sup> Others have looked at the impact on the whole family.<sup>101</sup> Mansell<sup>102</sup> examined reactions to the diagnosis of autism, using a postal survey. His study combined quantitative and qualitative methodologies to examine whether changes made to a local autism diagnostic service had been beneficial and whether the parent's attitude to the diagnosis changed over time. He found that special units and school were rated by parents as the most useful source of support and treatment. He also found that many parents were frustrated at the way they were regarded by lay people and other parents. As the study was examining one particular service, the results might not be generalisable, and the return rate for the questionnaires was low, which might have biased the results. However, there were some useful

pieces of information gathered particularly around the way a diagnosis is broken to parents which might have long term consequences for coping.

Trute<sup>103</sup> looked at long term adjustment, following a referral to a disability service. His cohort was therefore a mixture of different disabilities. He found that adjustment could be predicted by parental negative appraisal of the disability and also by self esteem. All these authors have looked at different aspects of family adaptation, but none have examined the effect in multiplex families. This study hopes to explore these particular families in more detail.

**In summary**, there have been a large number of studies that have looked at coping in families where a child has a disability, or has autism. Themes have emerged suggesting there are potentially two main types of coping, 1) emotion focused and 2) practical focused coping. Within these types are some subtypes, such as the use of spirituality within emotion focused coping,<sup>82</sup> and actively seeking information within practical coping. Several studies have shown that many families do adapt and cope over time. There is some debate about which personality types do so more easily, and the role played by parental self-esteem. There is also some controversy about which types of practical support are the most useful. The time of the diagnosis and its aftermath is generally agreed to be very stressful, and can be compared to a grieving process. The way the parents approach their adaptation to the reality of living with a child with autism is important in the long term coping strategy of the family.

In spite of all the literature on coping, there has not been a study which looks at coping strategies in families with more than one autistic child. This study hopes to address this issue. By studying families with more than one autistic child it will be possible to examine whether the same coping strategies apply to all the affected children in the family and whether the stressors vary between children. This may throw light on whether the concept of stress, as thought to be caused by autism, leads to coping, as proposed within the wider literature on coping, in families who have children with disabilities.

Studying a subject as complex as family life and coping, using quantitative methodologies, can be difficult, because of the nature of forced choice questionnaires. These inevitably are restrictive, in spite of trying to capture data by using the Likert scale<sup>104</sup> which measures severity of symptoms on a sliding scale. The answers given may not be the most important but rather those that have been validated within the instrument which is being used. As a consequence, this study uses a qualitative approach in order to enhance the richness of the data. In deriving the interview questions there were no pre-conceptions about types of coping. The open ended questions were used in such a way that families could describe themselves however they wished. During the course of analysis, emerging themes were then compared with the evidence from the literature, where this was relevant.

#### **1.3.4 Resilience.**

If families become stronger as the result of adversity what are the processes that lead from grief and depression into resilience? Patterson<sup>105</sup> wrote about the construct of family resilience, and commented that more recently, there

has been a greater emphasis on strengths within family research, and the psychological literature has also begun to look more at positive mental health. She cautioned that confusion has arisen around the concept of family resilience. Some practitioners concentrate on family strengths as opposed to deficits, whereas others concentrate on outcomes to explain unexpectedly competent functioning in families. However, she felt that there are some markers which define family resilience in terms of family systems outcomes. Firstly, the family unit must consist of at least two members; secondly, family adaptation occurred as a result of a crisis; thirdly, there is risk exposure, and fourthly, there are family protective processes. She felt that the whole topic of family resilience could be explained using a model known as FAAR- Family Adjustment and Adaptation Response.

Scorgie<sup>106</sup> explored transformations- significant positive changes- that occurred in families with children with a variety of disabilities. This study was executed in two phases: in the first qualitative phase, she studied a sample of parents who were apparently doing well according to parent support groups or professionals. From those results, nine themes emerged which described transformational outcomes. In the second quantitative phase, a survey of a different group of parents, also with a range of disabled children, was asked whether they agreed with the positive outcome statements found in the first group. Most of the results from the second survey showed a high level of agreement about the positive transformations statements. The two main types of transformation identified were, firstly, personal transformations such as: family members gaining new roles in the family, local community, or in

their careers, or new convictions and faith; secondly, relational transformations, which were changes in the way family members related to other people, including stronger marriages and extra friendships with other families with disabled children. Caution must be exercised however in the reliability of the results, as there was only one negative statement in the second phase survey and parents might have felt obliged to agree with the statements. Also, the group chosen for the quantitative phase was very diverse in terms of type and severity of disability. The results may not be generalisable to a group consisting of purely children with autism. However, she did show that unlike earlier studies, divorce rates in families with disabilities were actually lower than in families without disabilities.

Byatt,<sup>107</sup> firstly summarised the evidence about the existence of family resilience and commented that the topic had not been applied much to families with children with disabilities. He surveyed 175 parents of children with autism aged between 2-18. The sample was biased in favour of white upper-middle class families. The methodology required the participants to write their answers, thus excluding people who had literacy problems from the study. However, in spite of recruiting fewer participants than expected, and a somewhat biased sample, he demonstrated that family connectedness, closeness, positive meaning making, spiritual and personal growth are all possible in families with a child with autism. In a different study, Hastings (2002),<sup>108</sup> showed that parent's positive perceptions about the way they viewed the intellectual disability of their child could become a source of strength in the family.

Altieri,<sup>109</sup> in a qualitative study on fifty-two parents, consisting of twenty-six married couples, used semi-structured interviews to look at various aspects of living with autism. He used a Grounded Theory approach to look at the early development of the child, the social support within the family and the parent's beliefs about the cause of the autism. The positive factors that he identified were, increased support from the extended family, strengthening of the marriage, and better parenting; and a perception that their children with autism, were perceived as a gift. These findings will be compared with this current study's analysis.

Only two of the aforementioned studies, that of Bayat<sup>107</sup> and Altieri,<sup>109</sup> were specifically about autistic children. Clearly, there is a gap within the existing literature, and the current study hopes to enhance the understanding of resilience as applied to families with several autistic children.

#### 1.4 Personality, Self-Efficacy and Coping

The issue of personality is important for the current study, as it has been suggested that the outcomes for coping are dependent on the underlying personality type. Personalities have been divided into two broad and completely opposing groups, as either optimists, or pessimists.<sup>110</sup> Optimism, defined in the Oxford English Dictionary,<sup>61</sup> is 'a view that ultimately good must prevail over evil and therefore an optimist is one who is of a hopeful disposition and inclined to take a favourable view'. Conversely, pessimism is a tendency to look at the worst outcome, or to suppose that all things tend to

lead to evil, or to anticipate a poor outcome. Pessimists are therefore the opposite of optimists. There are two modifications of optimism and pessimism: firstly, that of the personality who has a tendency to always perceive the world positively which is referred to as dispositional optimism, and conversely for dispositional pessimism, and secondly, situational optimism which refers to hopes or expectations arising from a particular situation. Scheier<sup>111</sup> described how there may also be health benefits in dispositional optimism, as well as discussing the definition. Scheier,<sup>112</sup> in 1985, also looked at coping strategies associated with dispositional optimism and pessimism by examining how optimism might have a positive effect on symptom expression, psychological adjustment and health outcomes. It is likely that the individual maintains the disposition over time. In addition, Carver and Scheier<sup>113</sup> also looked at how optimism might be more related to problem-focused coping and seeking of social support. Pessimism was more likely to be related to denial and distancing from an event.

Dispositional optimism and pessimism are relevant to the current study because there are several different situations in which the families might find themselves, and overall coping may relate to the disposition of the individuals.

The concept of self-efficacy is also important in understanding the approach to coping. Self-efficacy, as discussed by Bandura,<sup>114</sup> can be described as the conviction that one can successfully execute the behaviour required to produce the outcome. Self-efficacy may be related to the level of optimism or

pessimism, but whereas dispositional optimism refers to an overall personality type, self-efficacy is a belief in one's ability to perform a task which can vary in different circumstances.<sup>115</sup> For example, an employee may have a high self-efficacy at work where he is good at concluding business deals but a low self-efficacy as a parent. Self-efficacy is important in the context of the current study as it may explain why some parents find coping easier than others and may determine their behaviour as in the 'health belief model' of Strecher.<sup>116</sup>

The 'health belief model' was first developed in the 1950s as a way of explaining why people make changes to their behaviour to help prevent some perceived health threat, for example, giving up smoking in order to prevent cancer. It is widely used in Public Health programmes to determine whether a campaign is likely to be successful. There are five components to the health belief model: the seriousness of the risk; the individual's perception of their susceptibility; the perceived benefits of the change in behaviour; the barriers to carrying out the change; and self-efficacy.

Maternal self-efficacy has been investigated as being related to the ability to change cognitively. Kuhn<sup>117</sup> noted that feelings of competency in the parental role were associated with wellbeing, but that knowledge about the condition on its own did not lead to greater self efficacy. The role of information about autism leading to a perceived increase in competency and knowledge which in turn leads to improved self-efficacy is relevant to the current study.

## 1.5. Well-being and Quality of Life

### 1.5.1 Well-being

Personality and self-efficacy may well be important components of well-being and quality of life. As well-being is part of successful coping, it is worth exploring this concept further. Well-being, as opposed to illness, was first described with the formation of the World health Organisation (WHO) in 1948 when the new WHO defined health in a new way as 'physical, mental and social well-being not merely the absence of disease or infirmity'.<sup>118</sup> The constitution was confirmed again in 2006<sup>119</sup>. This definition of the aims of the WHO was a heroic departure from the previous definitions of health as being an absence of ill-health. While the aim was revolutionary, the measurement of well-being has been much more difficult. Breslow<sup>120</sup> developed a method of measuring aspects of health by asking the study population questions about disability, chronic conditions, and symptoms and placing the population on a continuum so that any individual could be viewed as more healthy or less healthy than average. The same method was applied to mental health which resulted in a U shaped distribution of poor mental health in younger or older adults and a strong relationship with income level. There was also a positive association between physical health status and mental health status. In addition, he examined social health, as the degree to which an individual is a functioning member of the community, which included employability, educational achievement, marital satisfaction, sociability (number of friends) and community involvement. Social health was found to be strongly associated with income, race and area of residence. The summation of these measurements resulted in a health index for each individual.

However, the aims of the WHO are still hotly debated<sup>121</sup> and Jadad felt it was unrealistic to aim for a state of complete physical, mental and social well-being. He argued that it was futile to try and define 'health', because "health, like beauty, is in the eye of the beholder and that a definition cannot capture its complexity" (editorial: a2900). Although there are problems with definitions of well-being, the concept is one that is used so universally that to do a study on families and coping without exploring issues of well-being would be to render the study incomplete.

### 1.5.2 Quality of Life

In common with well-being, 'Quality of Life' is considered an important outcome of successful coping. Quality of Life is also difficult to define,<sup>122</sup> since like well-being, it encompasses physical well-being, mental well-being and in addition, a basic level of satisfaction and self-worth, and has both objective and subjective components. The present study has tried to capture aspects of Quality of Life by asking about the families' subjective feelings about their Quality of Life rather than trying to impose some objective measure. The measurement of Quality of Life has become an entire area of academic research,<sup>123</sup> but in spite of the inevitable subjectivity of the concept it is a useful one in the context of an outcome of coping strategies.

## 1.6 Siblings

Most studies on coping in families with disabilities have concentrated on the adults in the family. In the current study, a wider view of coping was taken, so

that the ideas of the autistic individuals themselves could be examined, and also those of their siblings, who do not have autism. It is to be hoped that the broader perspective of the whole family gives a less biased, and more complete view than that obtained from studies that only included adults. This is also necessary for a more holistic view of family resilience.

There have been many studies that have examined sibling well-being in families with children with disabilities.<sup>124-128</sup> These studies have reported mixed results. For example, Hastings<sup>129</sup> showed that the sibling of a disabled child is less well adjusted and has more mental health problems than the sibling of a normal child. The problem with this study was that it was only the mothers who were studied and the siblings in question were not asked for their views. Also the study sample included severely affected children, as all the autistic children had a low IQ, and this may have distorted the results.

In contrast, Findler<sup>130</sup> suggested that the presence of a disability in the family leads to greater psychological growth in the sibling. Findler's study was conducted in Israel and the findings might not be applicable to the UK. He studied teenage siblings and had no corroborative evidence from other members of the family. However, Hodapp<sup>131</sup> showed that the siblings of children with autism have less closeness to their sibling as an adult, than those with a sibling with Down's syndrome. Whereas, Eisenberg-Laurie<sup>132</sup> suggested that if the sibling lives away from home in a residential placement, the closeness of the adult siblings is compromised.<sup>132</sup>

Other authors have looked at which particular factors lead to sibling adjustment. Giallo,<sup>133</sup> found that parent and family factors, such as the family's level of risk taking, their socio-economic status and their resilience were better predictors of the sibling's coping ability than the sibling's own views. As family factors seem to be crucial in determining how the siblings view their disabled brother or sister, it is not surprising that other authors<sup>127</sup> have found that marital stress can be associated with poorer sibling outcomes. Also, other family factors, such as the temperament of the siblings, was examined by Rivers,<sup>128</sup> who found that persistence was the most important factor in improving the sibling relationship

Another study which analysed which factors contributed to siblings adjustment was that of Macks,<sup>134</sup> who compared two groups, one with siblings of children with autism, and one without, and used a range of different ages and a parental measure to corroborate the sibling's findings. He found that the sibling's psychological and emotional development was better in a sibling of an individual with autism, than a sibling of a normal child, if certain demographic factors were in place. These advantageous factors were: being female, having higher socio-economic status, having more than one sibling, and being younger than the affected family member, but if these factors were not present, then this finding was less obvious.

A further factor that was investigated by Orsmond,<sup>135</sup> was whether the age of the sibling altered the coping ability. She investigated two groups, one of teenage siblings of a person with autism, and one of adult siblings of

individuals with ASD. There was no comparison with siblings of normally developed people, as this was part of a different longitudinal study. She found that adolescent siblings of a person with ASD engaged in more shared activities with their autistic brother or sister, than the adult siblings did. Teenage siblings used more emotion-focused strategies and less problem-focused strategies than the adult siblings, but both groups had positive feelings towards their disabled siblings. There was a relationship between gender and how positive siblings were about their ASD affected sibling. Sisters of girls with ASD were the most positive about their siblings, while the brothers of females with ASD were the least positive. The siblings were less positive about their affected siblings when behavioural problems were a significant factor. It was not possible to analyse whether these effects were due to any differences in the developmental profile of the autistic individual, as the level of severity of the autism was not clear, and this may have been an important factor. Also, the sample may have been atypical as it was largely Caucasian.

Pilowsky<sup>136</sup> studied age and adjustment in siblings of individuals with autism as a factor in coping, and found that these siblings were well adjusted. This was a very comprehensive study of siblings of people with autism, intellectual disability, or those with a language disorder. The study took place in Israel. There was no comparison group of the siblings of typically developing children which was a shortcoming. She used a mainly quantitative methodology but compared these results with a short five minute interview with the siblings about what they thought about their affected family member.

The group with siblings with autism, described their affected sibling more positively the older they were. Pilowsky also found that the larger the family, the greater the delay in sibling's socialisation skills.

Other studies which have assessed the use of different methodologies which are relevant to the current study, are firstly, that of Mascha.<sup>137</sup> In a qualitative study of how typically developing teenagers view their sibling with autism, he investigated whether semi-structured interviews were successful in obtaining truthful reports from teenagers and concluded that they were. Most teenagers were found to have positive feelings about their sibling with autism, but there were some negative feelings related to behavioural problems. Secondly, that of Verte,<sup>138</sup> who studied the non disabled siblings, and looked at whether the parental view of the non-disabled child's coping ability was similar to the young person's own view, and concluded that in general the parental thoughts on adjustment matched those of the siblings.

In summary, there have been several studies on the adjustment and well-being of siblings of children with autism, of different ages. Earlier reports suggested that they did worse than siblings of non-disabled children but these studies may have reached these conclusions as they tended to measure stress and negative mental health factors. However, increasingly, the more recent results have suggested a positive outcome especially if beneficial demographic factors, such as higher socio-economic status, and more than one sibling, are present. These studies may have reported more positive results by asking more positively slanted questions, suggesting a

degree of bias. One of the areas explored within this study was whether siblings felt positively or negatively about their affected brothers and sisters and whether they felt they would, or could, look after them in the future when the parents were no longer able to do so.

### 1.7 The views of people with autism.

Personal stories have been published on what it feels like to live with autism from the point of view of people with autism. Donna Williams,<sup>139, 140</sup> had a major impact on the understanding of autism, as she had autism herself, and was one of the first adults to write about her experiences. She gave a remarkable description of the desperation of being autistic in the non autistic world and showed how, with courage and persistence, someone can emerge from a terrible start to be able to achieve, educationally, sufficiently well to write an international best seller.

There are very few investigations which have specifically looked at what people with autism think about having the diagnosis of autism. This is important because without this knowledge, professionals and parents do not know how to address some of the problems, which inevitably arise, in discussions about why life might be difficult for young people with autism. Studies about stress, coping and siblings have generally not included the views of the individuals with autism, who are verbal. This study will try to address this issue.

## 1.8 Summary of Introduction and research aims

.As a result of the preceding review of the literature on stress, coping, resilience, well-being and quality of life the following research aims were explored within the current study.

1. What impact does the presence of more than one child with autism in the family have on coping and what aspects of autism and its management are important to these families? These might include : the severity of autism, changes in coping over time, practical strategies of use to future parents, the use of religion, 'my time', and the use of provided services.
2. Do families feel they have a good or bad quality of life? As part of this question, is marital status a crucial factor? What are the feelings of the siblings towards their autistic brothers and sisters?
3. What do the autistic children themselves think about their autism and well-being?

The extensive literature on stress and coping in families with autism is mainly quantitative in methodology and the exact relationship between stress and coping is not as clear cut as some authors have indicated. By taking a qualitative approach, some of these difficulties could hopefully be overcome by allowing the parents to have a completely free voice. Grounded Theory, as a methodology, is capable of drawing out new information from this complex family situation. The fact that the families in this study have more

than one child with autism helps to magnify or diminish the coping and resilience issues that have been found in earlier studies.

It is hoped that the fact that the researcher was previously known to some of the participating families would mean that the data is richer and more detailed than it would have been if an unknown researcher were to have undertaken the same project. However, this also introduces the possibility of bias. In order to reduce bias, the sampling as described in chapter two deliberately included some families previously unknown to the researcher.

The choice of qualitative methodology was made after studying various authors. The introduction to qualitative researching by Jennifer Mason<sup>141</sup> was a very clear guide to the practicalities of different methods. Grounded Theory, as developed by Glaser and Strauss,<sup>142</sup> who wrote the definitive text on the use of this method, was selected for this study. This methodology uses the principle of gathering information by whatever source is most appropriate for the research questions. In the current study, semi-structured interviews were chosen. Once the material was gathered, analysis occurred using a series of codes; from initial line by line codes, to more focused codes, then themed codes, eventually arriving at a few significant categories. Analysis and further information gathering was applied until no new information was obtained about the research questions. This was following the saturation of sampling criteria described by Glaser and Strauss.<sup>142</sup> Once saturation had occurred, further analysis led on to the formation of a theory, which explained the evolving categories from the analysis grounded in the data - hence the term

'Grounded Theory'. Subsequently, Strauss and Corbin<sup>143</sup> demonstrated how the practicalities of developing Grounded Theory could be applied, and a later edition<sup>144</sup> of their work appeared more recently, with additional helpful guidance. Kathy Charmaz<sup>145</sup> also added helpful, clear information, particularly on the subject of the analysis of data.

Having completed the analysis and triangulated the information by sharing it back with the participating families, it led the researcher to the conclusion of these very fascinating and inspiring families.

## CHAPTER TWO METHOD

### 2.1 Introduction

This chapter will deal with the justification for the choice of methodology, inclusion and exclusion criteria, sampling, study design, ethical considerations the participants and reflexivity. The study proposes to examine the factors which lead to coping in families with more than one autistic child. As previously discussed, the chosen methodology for this study was qualitative, as this was thought to be the best way of eliciting rich information from families in the unusual situation of having two or more autistic children.

### 2.2 Justification of choice of methodology

The initial choice between a quantitative and qualitative methodology was made because the nature of this study was to explore families' ideas on coping in an open ended way. There has been criticism of the use of quantitative methodology in research relating to human relationships because it tends to neglect the complexity of family, kinship and experience through the inevitable reliance on over simplified numerical devices for measuring quantity. This risks being reductionist and might miss some of the importance of the holistic approach which is taken in this study<sup>145</sup>.

As discussed in Chapter 1 the two main types of coping, emotional focused and practical coping<sup>62</sup> would seem suitable subjects for a qualitative study. This allowed the participants the freedom of explaining their circumstances, and expressing their views and experiences fully. The nature of the open

ended questions used in the interviews was such as to encourage a rich, non prescriptive exploration of feelings and emotions, from which the analysis could be structured to produce an emergent theory as suggested by Glaser and Strauss<sup>142</sup> and Strauss and Corbin<sup>143</sup> and Charmaz<sup>145</sup>.

Grounded Theory was chosen as the particular qualitative methodology for this study, as it is rigorous and structured in its approach to sampling, data collection and analysis and the production of a theory through this process. During the period of collection of data and analysis, it was necessary to use processes of induction, deduction and verification in order to develop a coherent theory. If the correct procedures for Grounded Theory are followed, then the resulting theory can have claims to be valid in more than just the local context, and to have some generalisable messages.

Other forms of qualitative methodology such as ethnography, interpretive phenomenological analysis, and discourse analysis were considered but were not thought to be as appropriate for this particular study. Ethnography, which entails sustained observation and participation was considered but dismissed, partly because this study had to take place over a relatively short time interval, but also because even though some of the participants had been known and looked after clinically over a long period, they had not been observed specifically for the purposes of a research study. Interpretive phenomenological analysis, an approach that emphasises a focus on people's subjective experiences, could have been considered but was rejected as involving too much participation of the researcher with the

subjects which would have been very difficult given the nature of the previous Doctor patient relationship in some cases. Discourse analysis, which involves the detailed break-down of every pause and nuance of speech as a way of arriving at the meaning of the typescripts was dismissed as being less appropriate for a study involving children. Grounded Theory was preferred for the reasons given by Charmaz<sup>145</sup>. She explained that Grounded Theory methods preserve an open ended approach to studying the empirical world, yet add rigor to ethnographic research by building systematic checks into both data collection and analysis.

The benefits of Grounded Theory are that there is simultaneous involvement in data collection and analysis; there are no preconceived ideas and the data and analytic codes lead on to deductions and hypotheses; note taking and reflexive reactions to the data can be used to define relationships between categories in the analysis; sampling is aimed at constructing a theory rather than population representativeness; and the literature review takes place largely after the data collection. All these aspects help to control the research process and increase the analytic power of the study.

The disadvantage of Grounded Theory is that there is inevitably an element of subjectivity in the selection of the codes and categories. Some would argue that the deductions are therefore not as valid as with quantitative methodology. However all research methodologies are influenced by the researcher and it is possible that by acknowledging the part played by the

researcher in a Grounded Theory study, the reader is in a better position to criticise the findings.

It is not possible in a brief interview to know all of the answers about coping.

By using Grounded Theory on a population, many of whom were already well known to the researcher, the quality of the answers were likely to be enhanced, and the true situation about coping was more likely to be drawn out. The researcher's assumptions were challenged during the data gathering process and this led to different conclusions being drawn, to those that the researcher had at the outset. The various qualitative studies mentioned in the epistemology in Chapter 1, particularly those of Altieri<sup>109</sup> and Byatt<sup>107</sup> encouraged the author to use this methodology.

### 2.3. Inclusion and exclusion criteria

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1. Families with more than one child with autism and where at least one of those children was still living at home.
2. The children with autism had an age range from two years to adulthood.
3. All the children diagnosed with autism had undergone a multidisciplinary assessment to confirm that they met the diagnostic criteria of the International Classification of Disease revision 10 (ICD10)<sup>8</sup> for at least one type of autism.
4. The children in this study did not have to have exactly the same type of autism, in any one family.
5. Selected families were included if they had one or two parents at home, and a non birth parent was also included, if they were significant carers of the affected children. In the case of one parent families the adult invited to take part in the study was the single parent of the affected children.
6. Grandparents were only included in this study if they were the main, or significant carers of the autistic children.
7. Families had to be able to speak English, but could be of any ethnicity.
8. Families who were cared for by professionals employed by the participating Primary Care trust (PCT).
9. The siblings, without a diagnosis of autism, did not have to be blood relations of the children with autism, but must have lived in the family with children with autism for at least one year.
10. The children to be interviewed must have been able to communicate verbally but they could choose to communicate through drawings if they preferred not to speak. They could also choose to do drawings and an interview. If the non verbal child was keen to participate they could make noises on the recorder.

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Table 1: Inclusion Criteria

The principal exclusion criteria are found in Table 2.

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1. Families who had only one child with autism.
2. Non English speaking families.
3. Families who were outside the PCT area.
4. Families where the diagnosis of autism in one or more children had not been confirmed by a multidisciplinary assessment.
5. Other adult family members who were not the main carer of the children were excluded.
6. Non verbal children were not formally interviewed, but were allowed to participate in some way, if the parent felt this was appropriate.
7. Families who were currently undergoing legal proceedings in the Family Courts.
8. Families where one child with autism was on a 52 week placement outside the home.
9. Families where one or more child with autism had been placed in the long term care of the Local Authority.

Note: The following were not excluded

If parents presented with disabilities that affected their ability to take part in the interview (e.g. difficulties with hearing) attempts were made to address this effectively (e.g. making use of an interpreter using sign language)

Families who were the subject of child safeguarding procedures.

Families where one or more children attended boarding school but were at home during the holidays.

Children fostered as part of a respite care scheme, provided this was not a 52 week placement.

Disabled parents and families with children with other disabilities.

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**Table 2: Exclusion Criteria**

## 2.4 Sampling

Purposive sampling was used in this study. The rationale behind this was that the families that were to be investigated were a very unusual cohort. In any one area there are not many families with two or more autistic children. The families were identified from the autism data base in the area under investigation. The potential pool of participants for this study was only twenty families. Having decided that the quality of information obtained was likely to be richer and more detailed from families previously known to the researcher,

than from families unknown to the researcher, the full cohort of potential participants was approached.

Sampling continued until saturation had been deemed to have occurred.

The invitations to potential participants, including information sheets appropriate to adults and different aged children, were sent out by a clinical contact within the Primary Care Trust, who was not the researcher, to avoid possible coercion. The initial uptake of replies from participants was slow. This may have been partly due to the protocol, which required interested families to contact a person at the University of East Anglia who was previously unknown to any family. It may also have been due to the timing; the invitations were sent just before Christmas. Recruitment to the study took place over a nine month period. Some participants were obtained through word of mouth from families who had heard that the study was taking place and wished to participate. Some of these had previously received the information sheets but had not acted on them.

Saturation of sampling was achieved when there was a representative sample of many different types of family with a mixture of married parents, single parents, both single parent mothers and single parent fathers and reconstituted families. Table 3 presents the basic characteristics of the families recruited into the study. Saturation was also deemed to have occurred when the analysis of the typescripts did not produce any new information. A total of eleven families were recruited and forty-five interviews were undertaken.

Family no	Number of autistic children	Total number of children	2 Parents married	Single parent	Parent with new partner
1	3	6	No/divorced	mostly	yes
2	3	4	Yes/married	no	no
3	2	2	Yes/married	no	no
4	2	2	Yes/married	no	no
5	3	4	Yes/married	no	no
6	3	6	Yes/married	no	no
7	2	3	Yes/married	no	no
8	2	2	No/divorced	Yes	no
9	3	4	No/separated	Yes	no
10	2	2	No/divorced	Yes	no
11	3	4	No/divorced	Yes	yes

**Table 3: Family Characteristics**

## 2.5 Protocols used in this study

### 2.5.1 Selection and invitations

The cohort was selected from families in a specific area in the East of England, having been identified from the autism database for this area. This was compiled locally at the time of each new diagnosis and updated at regular intervals. Most of the families were known to the researcher in a former clinical role. However, some families previously unknown to the researcher, and cared for by other consultant paediatricians, were invited to

take part in an attempt to reduce bias. Any families on the data base with two or more children with diagnoses on any part of the wider spectrum of autism were available for selection; provided that they fulfilled ICD-10<sup>8</sup> criteria for Pervasive Development Disorder, which included Childhood Autism, Asperger's Syndrome, Atypical Autism and Pervasive Development Disorder (not otherwise specified),

Once a possible participant family had been identified, the details were checked by the clinical contact in the PCT using the Child Health computer. The Community Child Health records were also checked at a later date, once consent had been obtained, to ensure that the children in the selected families met the inclusion criteria.

A letter of invitation was sent to potential participants, by the clinical contact within the PCT (Appendix 1), enclosing information sheets for parents and two types of information sheet for children, one for very young children and one for older children (Appendix 2-4). Interested families were invited to telephone a number at the University of East Anglia, if they wished to participate or wanted further information. The principal researcher then returned the telephone call, to the interested families, to explain more about the study and arrange a visit to gain consent.

Families were offered two possibilities for this initial visit, either the researcher would visit their family home, or the family could come to a Health

Service clinic near their home address. In all cases the families requested a home visit.

At the initial visit, further information was discussed and questions about the project answered by the researcher. If the families and children were happy to proceed, a consent form was then signed for each adult and an assent form was signed by each child who was capable of doing so. (Appendix 5+6 for consent forms)

### 2.5.2 Semi-structured Interviews

Semi-structured interviews were chosen as the most appropriate method of obtaining the richest information from this cohort, as they allowed the possibility of follow up questions, and prompting. They also enabled further information to be obtained at a later date if more than one visit was required in order to speak to the children or spouse.

If it was convenient for the family, the semi-structured interviews took place immediately following the consent form signing. The nature of the interviews was such that open questions were used at the beginning and follow up questions were used as prompts. The length of each interview varied considerably between adults. Each adult interview was estimated to take 1-2 hours approximately. In fact the longest interview was just over three hours (Appendix 7- adult semi-structured interviews).

Wherever possible, both parents were interviewed, but single parents, and partners, who were also carers, were included in the study. One grandparent was included as she was a principal carer. Adult family members were given the choice of being interviewed alone or with their partner. The family was able to choose in what order the interviews took place. At the family's request, it was possible to do the interviews on one or more occasions.

For the full set of children's interview questions please see (Appendix 8). The children's interviews were of variable length depending on the age and verbal ability of the child. These lasted between 10 minutes to over an hour. Child participants were given the option of speaking to the researcher or doing a drawing about their family, or both. The drawings were used as a way of encouraging the child to talk more freely about their family.

Children were able to choose whether they did the interview in the presence of a parent, or alone with the researcher, or with another sibling, whichever way they felt most comfortable.

### 2.5.3 Ethical Considerations and approval

A favourable ethical opinion for this study was given by the Cambridge 4 NHS Research Ethics Committee. (Appendix 10) Local Research and Development (R&D) approval was obtained from Norfolk Community Health & Care Trust for using National Health Service premises and for checking the Child Health records of all the children in the study (Appendix 9).

Before the study started all the Consultant Paediatricians whose patients were to be approached gave written permission for the researcher to contact their families. Once consent had been obtained, from the parents, a letter was sent to the family's General Practitioner informing them that their patients were participating in the study.

Each family was asked about informal support networks before interviewing took place as an additional precaution. Coercion to participate was avoided by removing the researcher from the recruitment process until a family telephoned expressing an interest in participating.

The main ethical issues associated with this study were, firstly, that taking part in the interviews may have been upsetting for some participants and as a consequence could have had an effect on the mental health of one or both parents. To address this problem, parents were offered the possibility of seeing a clinical psychologist within the NHS Trust, already known to many of the families, for a debriefing session after the research at their request. This was in addition to the family's own informal support networks.

Secondly, the siblings of the children with autism might also have been at risk of experiencing negative feelings, during or after the interviews. If the parents identified this problem, additional support was available, in the form of a school nurse referral or support from the relevant mental health organisation, either the Child and Adolescent Mental Health Service (CAMH), or specialist NHS teams, in the area, who support families with children with intellectual disabilities and challenging behaviour.

Thirdly, the children with autism might be harmed if they felt they were being excluded from the interviews. They were no more likely than their siblings to be harmed by taking part and the same support services were also available for them.

Fourthly, in the unlikely event of a child developing behavioural problems as a result of the interviews, the children's schools could also have been informed that a child was participating in the research, at the request of the family. It was thought that this was probably not necessary for the majority of the participants, but was a further precaution established before the data collection.

Fifthly, the role of the researcher was explained in depth before the interviews started, so that the families were in no doubt that the researcher no longer had any clinical role in the management of the children.

Sixthly, assurance was given that the participation or otherwise, of the family in the study, would not compromise the medical care of their family in any way.

Seventhly, all data was made anonymous but it was recognised that the nature of these families is unusual, and therefore it might be possible to identify them in spite of not using any names. To protect anonymity further, copies of the quotations that were to be used in the thesis were sent to each family to confirm that they were satisfied with the precautions taken, prior to completion of the thesis.

For invitation and consent forms see (Appendix1+5+6). Formal signed consent was obtained from each adult family member prior to the data collection. Assent forms were completed by children who could write.

After the research has been completed, the interview recordings and typescripts will be destroyed at a time stipulated by the University, currently 15 years. The reason for this time interval is to allow intellectual challenge to the research.

The study data was only available to the research team. Each participant was coded numerically to preserve confidentiality and the codes were kept by the researcher alone in a separate place from the identifying data.

The researcher thought long and hard about whether to use families already known to her. On balance it was felt that the quality of the information obtained would be much better because of the previous medical relationship and that the families were more likely to be frank and open than they would with an unknown researcher. This issue was also debated and agreed at the Ethics Committee meeting. The nature of the researcher's clinical relationship with each family was thoroughly explored in the study as part of the reflexive analysis.

#### 2.5.4 Recording and typescripts

Each interview was recorded using a digital voice recorder. Two recorders and spare batteries were taken to each interview. After the interview was

completed, the digital recording was downloaded twice, once onto the typist's PC at UEA, and once onto the researcher's PC. The interviews were then transcribed by one of two typists and checked for accuracy against the audio recording. The standard conventions for typing the interviews were observed. Each family's details were made anonymous with the Mother of family 1 being recorded as 1M, the Father as 1F and the children as an identifying initial and number. Pauses were recorded as (....) and significant changes in the tone of the interviewee were also noted in brackets, but otherwise the interviews were typed as continuous text with a new line for each change of speaker. In the analysis section parts of interviews which have been quoted but which are not continuous speech are also recorded as “....” where the sense flows on from one statement to the next.

### 2.5.5 Analytic techniques

Using the approach of Charmaz,<sup>145</sup> the typescripts were read several times and then coded into initial codes of which there were over 100. These codes were then grouped into focused codes which reflected common themes arising from the initial open codes ( Appendix 11). From these various focused codes it was possible to extract relevant bits of text from each interview and then reanalyse to develop axial codes. Using the Grounded Theory paradigm of Strauss and Corbin,<sup>143, 144</sup> these axial codes were cross referenced back with the focused codes to begin to fit into the paradigm.

One main phenomenon became dominant and central and applied to every transcript. Having developed the central phenomenon, it became possible to

develop other aspects of the paradigm, and from this use of the paradigm, two significant categories emerged, which applied to all the interviews. These two categories became the main consequences to which all the former coding applied.

### 2.5.6 Triangulation and validation

In any piece of qualitative research there is inevitably an element of subjectivity, especially in this case, as some of the participants were already known to the researcher. The importance of validating the findings was therefore crucial. In this study, validation took place in many different ways.

Firstly, the typescripts were checked for accuracy against the audio files. Secondly, a reflexive diary was kept of each interview and during the analytic process this was referred to in order to make sure that any conclusions drawn were compatible with the contemporaneous thoughts of the researcher.

Thirdly, some of the interview transcripts were read and separately coded by the second supervisor who, as an experienced qualitative researcher, was an invaluable guide to the analytic process. At every point in the analysis the iterative process involved challenging conclusions and criticism of false assumptions. The process of iteration also took place with the main supervisor through very helpful regular contact and supervision.

Fourthly, the results were sent to families to check with them the accuracy of the quotations used in the final text and the researcher's interpretation. This was an important part of the triangulation process.

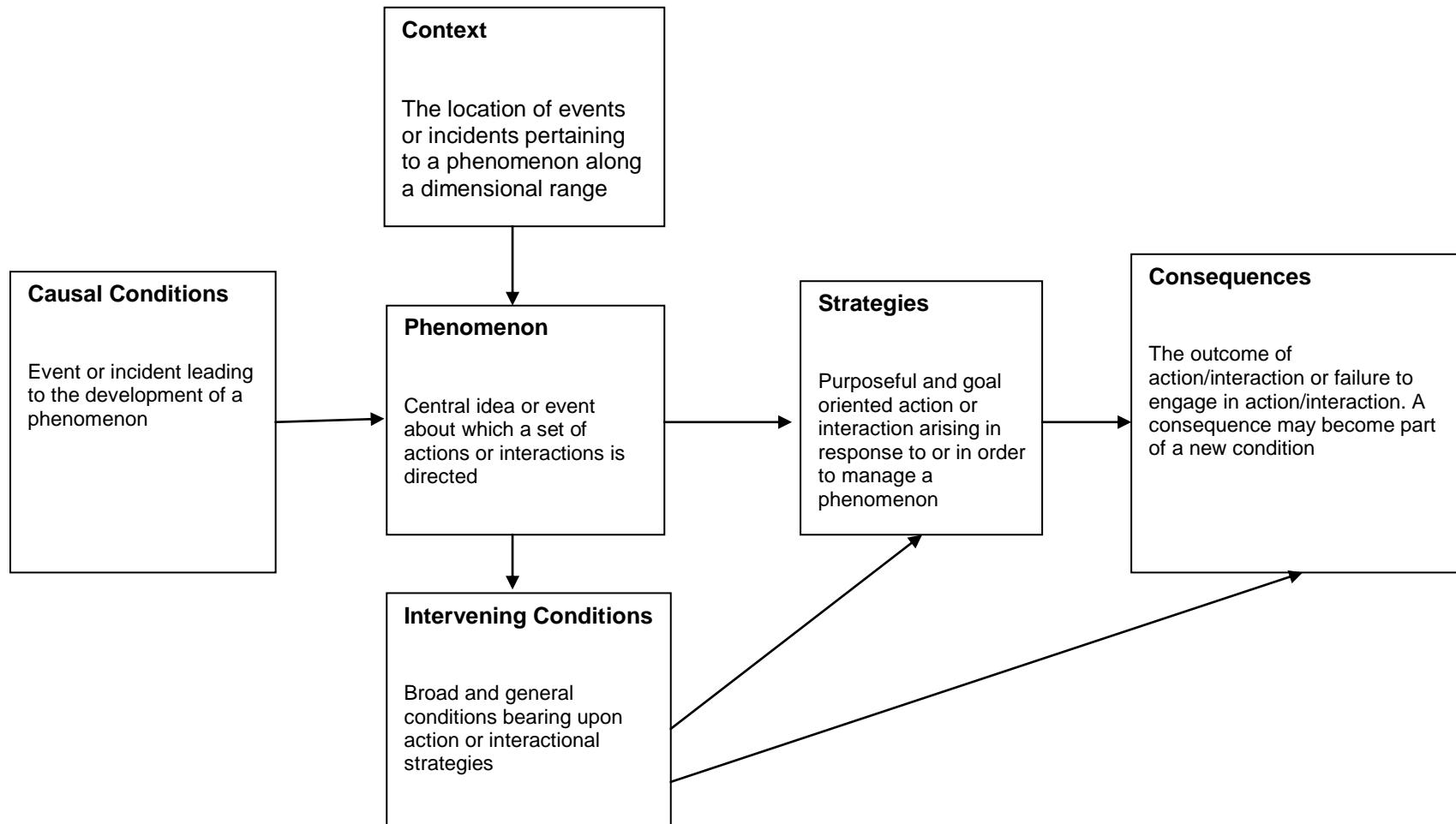
In addition to the above, the Child Health record of every young person in the participating families was analysed to make sure that the family, whose consent had been given for the study, did in fact comply with the inclusion criteria for the study. The searching of the Child Health records also had an interesting part to play in the reflexive analysis, as the researcher was surprised to find how little was recorded in the notes at the time of the initial referral assessments about the family's reaction to the diagnosis. The researcher had clear memories about these reactions but the feelings were not recorded in the child's records and did not necessarily match the family's own recollections.

The paradigm model, as suggested by Strauss and Corbin,<sup>146</sup> was used to guide the analysis. This proved to be an extremely helpful way of regulating a large amount of diverse data, into a logical flow from 'causal condition' through to 'consequences.' Each box in the diagram, shown in Figure 1, is a separate entity which influences the next stage in the analytic process.

Firstly, the causal condition needs to be clarified. In this case the diagnosis of autism. Secondly, the central phenomenon must fulfil the following criteria: It must be central which means that all other major categories must relate to it. It must appear frequently in the data applying to all or nearly all transcripts.

There should be no forcing of the data to fit with the central phenomenon, and the name of the central phenomenon should be sufficiently abstract, so that it can be used to do research in other areas leading to the eventual development of a more general theory. The phenomenon must be capable of explaining variation as well as the main arguments developed by the data. Thirdly, the 'context' is a set of properties that defines the phenomenon, Fourthly, 'strategies' are those actions that are taken in response to the phenomenon. Fifthly, intervening conditions are those factors that modified or interfered with both the phenomenon and the strategies used to improve the phenomenon. Sixthly, the final area, 'consequences' are the outcomes of the action taken in the strategies.

Figure 1: The Grounded Theory Paradigm of Strauss and Corbin



## 2.6 The Participants

Families were recruited over a nine month period between January 2010 and September 2010. Recruitment was initially rather slow, as discussed above, but eventually eleven families consented to participate and forty five interviews were undertaken. As the initial analysis was proceeding in parallel with the data collection, it was possible to realise that saturation had been achieved when the eleventh family had been interviewed.

From the demographic data shown in Table 1, it may be seen that many of the families were large, although four out of the eleven had only two children both of whom had autism. There was a good mixture of married parents, with both adults living together (six out of eleven), as opposed to single parents with no partner living at home (three families), and two families where the parent had a new partner which will be referred to as reconstituted families.

The different diagnostic categories of the children in this study were distributed throughout the sample. Only in Families 4 and Family 10 were there two classical childhood autism diagnoses and no other normal siblings. Even in these families there was a different level of severity between the two boys, with one of each pair being much more verbal than the other. In Family 3, the other family with only two children, there were two boys with an ASD diagnosis, but both were verbal and had milder symptoms than classical autism.

All the children had some experience of a mainstream educational setting but for some, this was only at the nursery school stage. Many of the more severely affected children moved to special school for High School education and beyond. Although one young man, who attended special school from ages 12 to 16, went on to normal college and then university, where he has achieved a first class degree.

Of the single parent families, one was a single father, the others were mothers. One grandparent was interviewed jointly with the mother because she was a significant carer being in the family home every day.

Of the eleven families, nine were previously known to the researcher, but two of the nine that were known in a clinical context were only seen at the point of diagnosis and had not had long term follow up by the author. Four of the families had one or more children diagnosed by a different Paediatrician. Some of these were diagnosed elsewhere and the family then moved into the area, while some were diagnosed by other Paediatricians in the same study area.

Family no	Classic childhood autism (limited speech)	Asperger's syndrome	Atypical autism	School type mainstream	School type special	School type independent
1	-	3	-	3	-	-
2	2	-	1	1*	2 **	-
3	-	2	-	2	-	-
4	2	-	-	1	1	
5	1	1	1	1	1**	1
6	-	2	1	2	1	-
7	1	-	1	2	1**	-
8	1	1	-	1	1	-
9	1	1	1	3	-	-
10	2	-	-	-	2**	-
11	-	2	1	1*	2**	-

Table 4: Types of autism and schooling

\*Predominant school type but mixed placement in mainstream and special school

\*\* Now in special school but previously in mainstream setting

Family no.	Education level of parents - degree	Educational work place qualification	Parent/s in work	Owns own house
1	0*	1	1	No
2	0	1	1	Yes
3	0	1	2	Yes
4	0	1	1	No
5	2	2	2	Yes
6	0	1	1	Yes
7	0	0	2	Yes
8	1	2	2	No
9	0	1	0	yes
10	0	1	0	Yes
11	0	1	0	No

**Table 5: Social Demography of families and parent education level**

\* Working towards degree

There follows a fuller description of each family

### Family1

This family, who live in council house accommodation, consists of a mother with her six children. She has a new partner who is a significant carer for the children. He has children of his own who do not live in the family home. The three oldest children do not live at home most of the time, but all come home at regular intervals. The youngest three were all school aged at the time of the study. The mother has undertaken higher education since having her children and has worked intermittently when family circumstances have allowed. The oldest child with an autistic spectrum diagnosis was not diagnosed until he was sixteen. The next boy was diagnosed at primary school and his younger sister was diagnosed also at primary school age. All three have a diagnosis of Asperger's syndrome. There are three children in the family who do not have a formal diagnosis, although all the family members interviewed agreed that one of the sisters should be diagnosed. All the children have attended mainstream schools throughout, but have benefitted from extra support in class. The oldest son with autism, attended university but did not complete his degree for social reasons.

### Family 2

This family is made up of married parents who jointly care for their four boys, in their own house. Father works full time and mother is a full time carer for the family. The oldest boy is developing normally, and the next three boys, two of whom are twins, all have an ASD diagnosis. Child four has additional

severe learning difficulties. All the children started in mainstream school but a mixture of placements is now operating, including special school.

### Family 3

In this family, married parents live in their own house with two boys both of whom have an ASD diagnosis, but both are fully verbal. Interestingly, the younger boy was diagnosed first and has more problems with dyspraxia. (That is a problem with coordination of both large and fine movements). Father works full time and mother part time. Both boys attend mainstream school with some support.

### Family 4

This family consists of married parents who live in accommodation provided by the father's occupation. They have two severely affected boys with classical autism, but the younger one is less severe than the older one. Both were diagnosed early at two or less. Father works full time and mother is a full time carer. Both children started in mainstream nursery but the oldest now attends special school, and the younger one is at mainstream school with support.

### Family 5

This family is composed of married parents, who live in their own accommodation with four children. All three boys have autistic spectrum diagnoses and the girl is developing normally. The boys each have different types of autism, one of them is non verbal, one has Asperger's Syndrome

and one has atypical autism (pervasive development disorder not otherwise specified). Father works full time and Mother has work which, although not full time, sometimes takes her away from home. One of the children attends a special school.

### Family 6

This large family had six children, and the married parents live in their own house with four of the children. The two oldest who neither had a diagnosis of autism, no longer live at home. Twins, a boy and a girl, have both been diagnosed with different types of autism and a younger brother also has ASD. One of the boys attended a special school; the other children have been in mainstream school. All six children had some form of disability. Father is employed and mother is a full time carer.

### Family 7

This family has three boys, two of whom have had an ASD diagnosis but one is more severely affected than the other. The parents are married and live in their own accommodation. Father works full time in the family business and mother runs her own part-time business. All three boys have been in mainstream school but the more severely affected boy did spend some time in special school.

### Family 8

This is a single parent family with the mother as the sole carer, although the children see their father regularly. They live in rented accommodation. The

boys are twins, and both of them have an ASD diagnosis, although one is more severely affected than the other. The older boy attends special school.

### Family 9

The father is the sole carer in this family of four boys. The parents are separated and at the time of the study, the children were not seeing their mother. Three of the four boys have an ASD diagnosis. The school aged children all attend mainstream school with support. They live in their own house.

### Family 10

The two boys in this single parent family both have classical autism although the older boy is able to speak well. The mother is the main carer, but the maternal grandmother is also involved on a daily basis. The children still see their father regularly although he only sees them occasionally, in their own house, during the day time. The house is owned by the mother. Both boys are now attending special school although they previously went to mainstream school with support.

### Family 11

There are three boys and one girl in this single parent family. All three of the boys have an ASD diagnosis. The elder two have Asperger's syndrome and the younger boy has a form of atypical autism. The mother was married to the father of the middle two boys, and is currently in a relationship with the father of the girl. They live in rented accommodation. The oldest boy

attended special school for a while during High School. The youngest boy has recently started at a special school. The middle boy was out of school at the time of the study.

During the study the families were contacted by telephone to arrange the initial visit. Family 1 had three home visits to complete all the interviews. Families 5,6,7,8,9 and 10 all had the interviews completed in one visit and the remaining families had two visits. When the analysis was almost complete, all families were contacted by telephone to alert them to the fact that the researcher was going to send out the quotations and opinions that were to be used in the thesis. They were invited to reply to the written communication and 9 out of the 11 replied with comments.

## CHAPTER THREE ANALYSIS AND RESULTS

### 3.1 Overview

The hypothesis used in this study is that, according to the principles of Grounded Theory, the analytical process applied to the collected qualitative data, will allow the formation of a theory about how families with more than one autistic child manage to cope, and what the quality of that coping appears to be.

The examination of the data was in accordance with the principles of Grounded Theory.<sup>142, 143, 145</sup> The data was read in three ways, initially, the literal meanings of the interviews were coded, then the data was analysed both interpretively, and reflexively, this allowed the initial codes which were very numerous ( over 100-see appendix 11 for a sample) to be developed into focused codes and categories.

The researcher's interpretation of Strauss and Corbin's paradigm<sup>146</sup> is shown below and is the basis on which all the results and analysis of this thesis are based. The results chapters will be arranged so that each results chapter describes one or more of the key points of the paradigm flowing in a logical progression from left to right. There are detailed descriptions of each of the paradigm headings and how they relate to the formation of the Grounded Theory. Examples from the recorded interviews are quoted to illustrate the reasons for the inclusion of each point.

To clarify each of the components of the Strauss and Corbin paradigm, these have been highlighted in bold in the next section.

The central **phenomenon** of 'Coping' was arrived at after the various stages of coding as described in Chapter 2 (see appendix 11-13) were completed.

The phenomenon was identified as the only central category which applied to all the focused codes and categories. The criteria for choosing a central category were as described in Chapter 2. Coping was found to be the central phenomenon in that all the major categories of the context, the intervening conditions and the strategies were related to it. All the interviews alluded to coping although the interviews of the children related to coping in a more indirect way that helped to confirm the adult's views of their own coping. The theory which was generated as a result of using the category of coping as the central phenomenon had explanatory power. This meant that the choice of using coping as the central phenomenon fulfilled the criteria of Strauss and Corbin.

**The Causal condition** in this study presented as self evident because without a diagnosis of more than one child with autism this study would not have taken place. However, the reactions to the diagnosis and the rapidity with which the adults came to accept the diagnosis had a significant effect on the family's coping ability.

**The context** of the study was arrived at following the themed analysis and axial codes which emerged (see appendix 13). A number of factors including

the total number of children in the family and the numbers with autism; the severity of the autism; the age at diagnosis; the parent's understanding of autism; the children's understanding of autism, and various school and education related matters combined to have a direct bearing on the phenomenon of coping. The ways in which each family dealt with these contextual factors influenced the strategies which each family developed to improve their coping. Some of the factors contributed to the consequence of buoyant coping and some had the opposite effect and led to perilous coping.

**The intervening conditions** that appeared which may have had a connection with the autism diagnosis, but the author considered to be external to the main context of autism, were nearly all negative factors which made coping very much more difficult. The way in which families overcame these difficulties had a direct bearing on whether they turned the adversity into a way of strengthening family cohesion or whether they were almost overwhelmed by the intervening condition and this led to perilous coping and the potential for family breakdown.

The intervening conditions that arose were: behaviours that led to child protection investigations; mental health problems in either the child or one of the parents; a partner or spouse leaving or divorcing; an unexpected death, and additional diagnoses. All of these conditions are major life events so it is not surprising that they became significant reasons for changing the course of a family's coping ability.

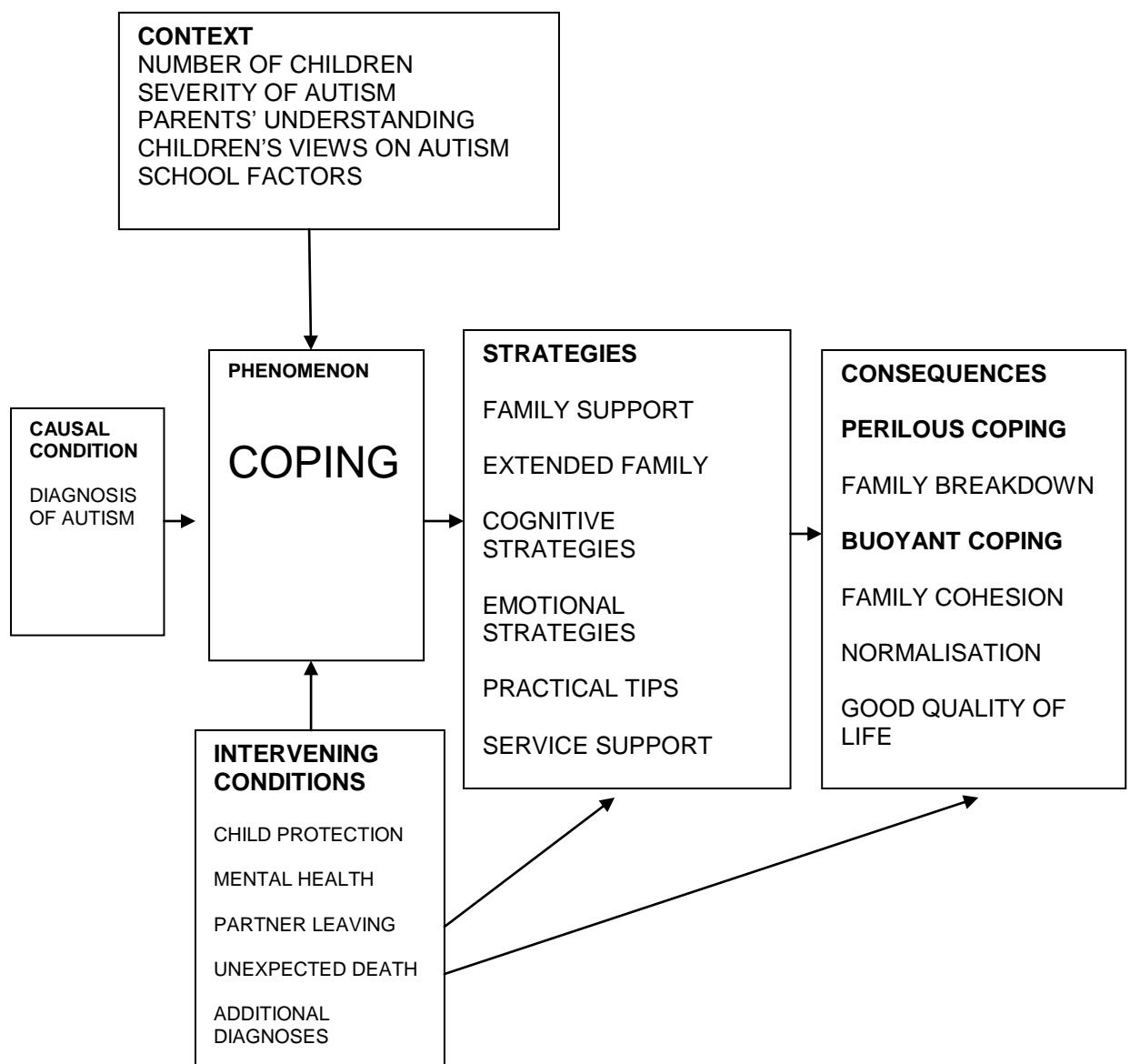
The various **strategies** employed by the families to cope with their unusual situations are outlined in Figures 2 and 8 and include the main component of family support which took many different forms and will be described in more detail in that section. The presence or absence of an extended family and how this was used to promote coping was of major importance. The various cognitive and emotional strategies that were used to enhance coping are then discussed followed by several practical solutions to daily living situations. Lastly in this section the author will explore the role of service support as perceived by the families.

The outcomes for the families are described under the heading of '**Consequences**'.

The researcher felt that the phenomenon of coping could be summarised as having two major consequences, that of 'buoyant coping' or that of 'perilous coping' and that it was quite possible for a family to move from one type to the other. The assumption made was that all families cope to a greater or lesser extent. There was a major divergence between 'buoyant coping' which was associated with good quality of life, and even an enhancement to family cohesion and intra-familial relationships, and normalisation of both the child with autism and the whole family, and 'perilous coping' which was associated with negative feelings within the family, sometimes sufficiently severe to lead to possible family breakdown. It will be argued that each family experienced both buoyant episodes and perilous episodes and that it was possible to change from one positive type of coping to the opposite negative type quite

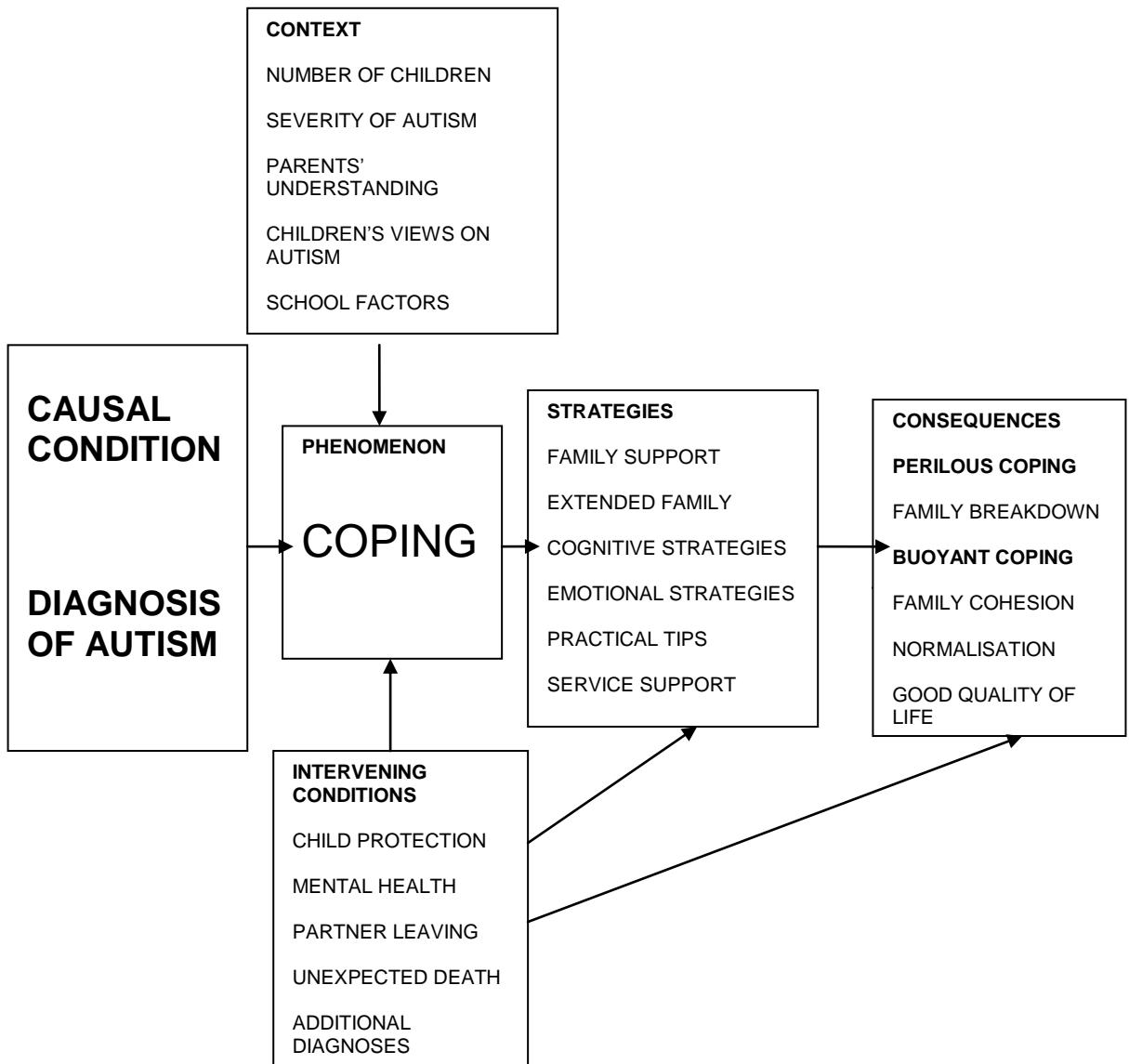
quickly. The role of the statutory services in helping to change a perilous situation into a buoyant one will be explored. In almost all the families in this study the long term outlook as stated by the family members was an optimistic one. The underlying personalities of the families in this study will be explored in order to help predictions about types of coping. The final section of conclusions and recommendations will follow in the last chapter.

**Figure 2: The Strauss and Corbin Paradigm Adapted for this Study**



## CHAPTER FOUR: RESULTS-Causal Conditions: Diagnosis of autism

Figure 3 The Strauss and Corbin Paradigm Adapted for this Study Highlighting Causal Condition



The central key departure point for this study was that all the families that were included had more than one child with a definite diagnosis of an autistic spectrum disorder. It therefore seemed logical to make this the 'Causal Condition' of Strauss and Corbin.<sup>146</sup> Although families had worries and concerns prior to the diagnosis and some of these were alluded to in the

interviews the first definite point of learning coping strategies was the point of diagnosis and this is why this moment was selected as the Causal Condition.

All the children's Community Child Health records were examined to confirm that the inclusion criteria for the study had been met. This meant that at least two children in every family had undergone a multidisciplinary assessment which concluded that the child met the ICD10<sup>8</sup> criteria for an autistic spectrum disorder.

The age at which the first child to be diagnosed in the family varied between 16 years old in Family 1 and eighteen months old in Family 4. The more severe types of classical autism tended to be diagnosed earlier and the more subtle features of Asperger's syndrome were often not recognised until the child was older. There was also a pleasing trend of earlier diagnosis in the more recently diagnosed children although this study was not specifically looking at this issue and a further quantitative study would be needed to confirm this finding.

In order to set the scene, one particular description of an episode which happened to a young man returning from university illustrates the difficulties faced by families who look after people on the autistic spectrum. It also demonstrates that the problems associated with the diagnosis are not confined to childhood.

**1M:** 'I have things where he gets on a train to come home and he ends up somewhere else if they change trains, and he has obviously left his ticket somewhere and it has been in his laptop bag so they have charged him his full ticket price which is £90.00 or something when he has already bought a ticket. And I ...., I got a sister involved with that one, because the guy, I....., I spoke to the guy on the phone and said 'look my son has Asperger's, um, he did buy the ticket, he has got the rest of the information, there is only one bit missing, I can assure you', you know, because he didn't have any money on him ;....the other people on the train had a whip round and he wouldn't let them pay the ticket guy because he said that was begging,... um, and I explained the Asperger's and he said 'to be quite honest madam if that's the case he should not even be travelling on public transport' .....So constant things go on... I am trying to help him with the money side of things at the moment. So it's, it's a constant, the impact of it, you are taking it on board all the time..... How am I going to help **1J** through this, is he going to be,...is he going to be able to get married? You know, I would hate him to hear me say this, it is horrible isn't it?"

Table 6: The Train Story

Several families described many features which are typical of autistic behaviour but the researcher felt that as these have been explored in detail elsewhere,<sup>6</sup> this study was not going to dwell on the symptoms other than as an illustration of how a family has adapted to cope with the behaviours.

The reactions to the diagnosis of autism varied enormously from relief at knowing what the condition was to complete shock and disbelief .The time

taken to adapt to the news of the diagnosis, to comprehend the full enormity of the diagnosis and to change from a bereavement reaction of disbelief, denial, anger and loss of the normal child, to positive acceptance, willingness to find out more and to help the child seems to have been important to the family's ability to cope positively.

Where a family had been struggling to defend a young person against professionals who were labelling their child as naughty and unmanageable, the reaction to the diagnosis was one of relief. Where a family had been referred to a paediatrician because the child's speech was slow to develop and were often hoping that the doctor was going to be reassuring, the news of a diagnosis of autism came as a complete shock and the family needed longer to come to terms with the situation. In spite of taking very different lengths of time to accept the diagnosis the long term acceptance was the same and positive outcomes were present in all cases.

In several families the diagnosis of the second or third child was not a surprise and indeed some families had prompted the referral themselves. As the researcher had known some of these families for as long as 20 years, reflexivity plays an important part in the nature of this study. For example, the researcher sometimes had a very clear recollection of how the family seemed to react to the diagnosis at the time, but during the study these memories were contradicted by the family's own recollection of the giving of bad news. In Family 5 for example, the family said in interview that they accepted the diagnosis of their first son quite readily, but the researcher's recollection was

the opposite. They also said that they had a greater problem accepting that their third son also had an autistic spectrum diagnosis because his symptoms were so different from his two older brothers. Whereas the researcher felt that as they were so used to autism, number three's diagnosis would not really pose a problem for them. This demonstrates that it is always unsafe to make any assumptions in clinical practice, and that each new diagnosis needs to be handled as sensitively as though it was the first one.

The reactions to the first diagnosis are illustrated in the following quotations For Family 2 who were not prepared for the diagnosis at all

**Interviewer:** ...and at the time of the diagnosis can you think about how you felt when it first came out?

**2M:** Shocked really.

**2F:** Frightened, concerned, bewildered. Not knowing what was going to happen.

**2F:** Worrying, definitely.

**2F:** Well, not really knowing what to expect or what was going to happen. It was just total and utter, you know, bewilderment.

**2F:** That's hard to put it into words how you feel in something like that, 'cause you just don't know what the future holds or what's going to happen.

Later in the same interview:-

**Interviewer:**..... could you remember how long it took you to absorb the information?

**2F:** I think, on my behalf, yes I did, because you never want to think of your children... ...as got something wrong like that, and not really understanding fully myself what it was or how it's going to affect their life or...

**2F:** ...you know. It was denial.

**2F:** But until you accept it you can't help them.

**Interviewer:** And how long was that process in your case, do you think?

**2F:** Mine was quite long...

**2M:** For you. I accepted it. I think I knew deep down there that something wasn't right.

In spite of the father taking longer than his wife they remained a very close couple and have worked out a very sustainable way of coping such that now they both say they would not change any of their children because they are so fond of the way they are. The following ideas were common to many families, especially the feeling of not knowing what to do after being told the diagnosis.

**2F:** It's the not knowing, that's the, umm, most devastating...

**Interviewer:** Yes.

**2F:** ...how the future is going to pan out.

**2M:** Yeah, how independent are they going to be able to become, cause at the moment within school and, you know they go to school and they come home and that kind of thing they're pretty well

protected, but what happens later on is quite frightening, how they're going to cope.

This is a common sentiment among all the families but later in the discussion it will be seen that the normal siblings take a more optimistic view of the future than their parents.

Another family where they were totally unprepared for the diagnosis the impact led to a period of depression in the Mother.

**Interviewer:** .....and when you were given the diagnosis; can you remember at all how you felt about it?

**4M:** Mmm...laughter.....I was shattered!!

**4M:** Yes, um...that was, that was really a bolt out of the blue for both of us

**Interviewer:** You hadn't suspected?

**4M:** No, not at all, I mean...it was the old thing...you know all we had ever heard about it was the 'Rain man' so...for Autism.

**4M** ...and I did get a bit down I have to say!

you know you never expected him to be a brain surgeon or anything like that; I just wanted him to have a normal life. You know we could go on the beach together and we would do stuff like that as you do!

A contrasting reaction to the diagnosis was shown by several families, especially Family 3 who has 2 moderately affected sons.

**Interviewer:** Okay. And how was that process for you? The process of the diagnosis?

**3M:** Umm, I was relieved, because,... when you have a child with autism it's like swimming in a sea with sharks. You don't know. We've got people telling you it's not this, it's just a naughty child, you're reacting, and a mother in law that says you shouldn't put labels on, and spouting on about labels and stuff like that....

**3M:** So it was relief in a way, because I felt like I'm just being a petulant mother otherwise.

She went on to say that she accepted the diagnosis quickly, it only took her a couple of hours to accept it. She immediately looked it up on the internet.

Even with a family whose first son was under two years old and quite severely affected the parents had done a lot more questioning and fact finding before the referral to the paediatrician. Family 10 is an example of this. In this extract the Interviewer is talking to both the mother (M10) and the maternal grandmother (GM10)

**10M:** He was..just before his second birthday...

**Interviewer:** Nearly 2...and how did that process go for you?

**10M:** Pauses...no I shall say the truth-it was brilliant!

**Interviewer:** Were you expecting something like that?

**10M:** Yeah-it was um-a lot of people go through a grief process, I didn't...I went through a relief process. That I knew there was something, and to get someone to say-yes you're right was a huge relief for me.

These different ways of receiving the news about the diagnosis of autism demonstrate that where a family is prepared for the diagnosis they can move more swiftly into a positive coping frame of mind. They can also start to find out more about the condition and learn ways of managing the behaviours which led to a calmer family environment. Where the diagnosis was not predicted at all and the parents accepted the diagnosis at different times this in turn led to tensions within the marriage. Family 1 was very honest about this. The Mother was relating how she accepted the diagnosis quickly, whereas her ex-husband had much more difficulty.

**1M:** I think that it was right for me, even though now he accepts the diagnosis, I think it is very hard for him to accept it, and he sees it in himself as well and also because he really clashed with 1J and he will call 1J lazy and he will call him this and he will call him that, and I find it quite difficult because it is things that he was like himself ....

**Interviewer:** So, the tensions between the 2 of you which you described, were they worse at the time of the diagnosis?

**1M:** (*Slight pause.....*) It did seem to kind of come to a head I suppose. I think, I did not blame him, but I think he felt that it was his fault.

**Interviewer:** This must be an awful feeling

**1M:** Yes, because he has actually apologised for it, when 1E was diagnosed, because she was diagnosed after we had separated and he actually said... and ..when I told him he sent me an apology and said 'well tell her I am sorry'....

The diagnosis of the second or subsequent child was mainly received much more easily than the first although many families were initially saddened that they had double trouble. In Family 1 where the mother had had an enormous struggle to get her older son diagnosed the process of the assessment for the next son was seen as much more positive:

**1M:** .....'got him referred to see (Dr Z) , and (her) team and everybody was fantastic, got his diagnosis, they said come to the parents thing, you will meet other parents and we will explain it to you, um, there is an Asperger's group, this is this, there is that! It was a totally different experience, you know, this time it is going to be ok as there is people there that you can talk to, people that understands. I got in touch with N (specialist autism nurse) and it was like 'wow'; there is all this support suddenly!

Other experiences of the second child's diagnosis were less positive but there was still a sense of relief:

**Interviewer:** And was it harder or easier to accept the second child had the same diagnosis?

**1M:** Easier..It was easier as much in the sort of accepting what it was, um, harder as it was like oh no, I don't want him to go through what 1J, the knowledge that I have, I don't want him to go through what 1J went through, um, guilt that had I known would I have gone on and had so many children...was it fair because of what had happened to 1J....

In Family 3 the younger child was the first to be diagnosed as is often the way if that child was the more severe. The mother recognised that the first child also had similar traits.

On a reflexive note it never ceases to amaze the researcher how much power is invested in the role of the specialist.

This same mother then gave a very frank appraisal of the second diagnosis

**Interviewer:** And then what was your reaction when you heard that actually both boys had it to a certain extent?

**3M:** Umm, It's a little bit disappointing because I think if I'd known I had autism it would have given me a little bit of back knowledge about it and in a sad way it might have actually made me stop having children. It has my brother.

This Mother has never been diagnosed herself, here she is referring to the fact that both she and her brother feel they may have some autistic traits. In this same family the Father's reaction was different to the Mother's. He had not been part of the assessment process as he was working and had a dislike of meetings. Both he and his wife acknowledged that it took him much longer to come to an acceptance of the diagnosis in 3D but the researcher was surprised that he had more difficulty accepting the second child's problem, but it may well be because the older boy 3T had had a difficult start in life as his Mother had pre-eclampsia, a complication of pregnancy which was severe in this case.

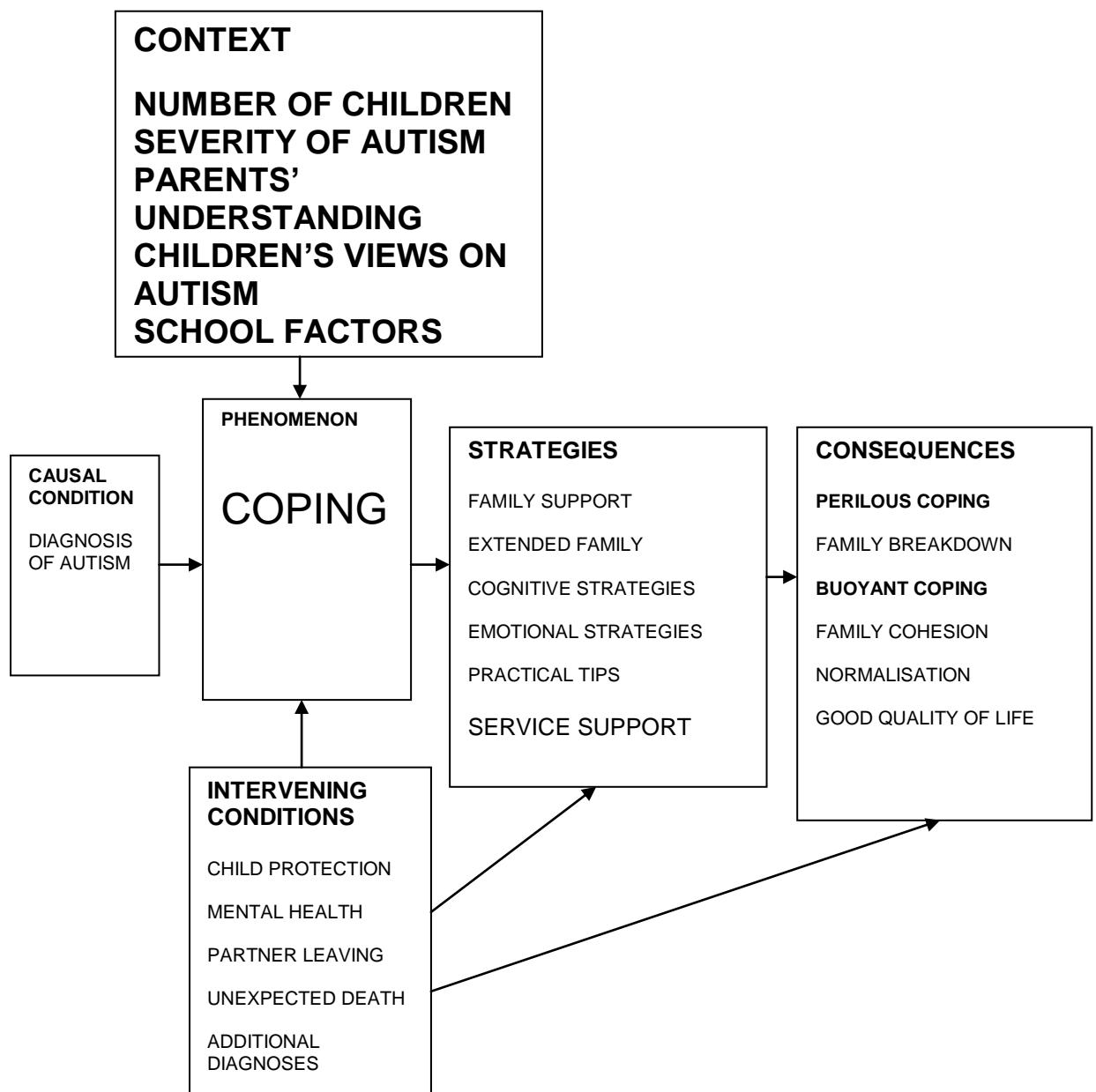
In Family 4 the mother had recognised symptoms in her younger son and she had requested an assessment so the diagnosis was no surprise. She knew more about the process and was less devastated, but at the same time not happy to receive the diagnosis, and as a result became tearful at some of the feedback meetings.

**4M:** Well...yes and I hope that even if he was Autistic, maybe he was not so severe...um and that would be a bit of hope for him, bless him....

The consensus from all the families was that the second and subsequent diagnoses were very much easier to cope with and that as most families had made great strides in adapting their lives to modify the behaviours of the first autistic child it was not nearly so difficult to cope with a second or third autistic child. As will be seen in a subsequent section some families even felt that having several autistic children was much easier than having just one as the process of normalisation is achieved more readily if the parents treat all the children as normal.

## CHAPTER FIVE: RESULTS –Context

Figure 4: The Strauss and Corbin Paradigm Adapted for this Study highlighting ‘Context’



## 5.1 Number of children

There are two ways in which the number of children in the family affected the coping strategies of the family. Firstly, if the severely affected autistic child was the first born member of the family in this cohort, the subsequent number of children was less. In Family 4, for example, the child with the most severe form of autism was the oldest son. The next child was also quite severely affected but he has some language and verbal communication. The family just have the two boys. As each child really needs an adult's supervision most of the time, the family have used child care provided by the Local Authority to help with the period between school and bed. The times when the father has to be away because of work commitments are inevitably more stressful for the mother but she is given extra support during these periods. The nature of the care she has to give to the two boys perhaps precludes the possibility of contemplating expanding the family.

The same situation exists in Family 10 where the first born son is severely autistic and his mother was pregnant with the second son by the time the first son was being diagnosed. The second son is also severely affected and the family admits that their way of managing them is to have two adults around as much as possible and for the two boys to lead pretty separate lives. This means sleeping in separate rooms and even eating at different times. Although the presence of two children with autism leads to an enhanced level of burden, both families would feel that sharing the worry between two children in some ways helps the coping rather than just worrying about a single autistic only child.

**4F:** If one of them had been autistic and one had sort of been a conventional child, they would need handling in two very different ways. But to be honest the same routine with slight adjustment to it is enough for both of them.

**Interviewer:** Right so in a sense, it works. Would you say in some ways it is easier having two autistic children than having 1?

**4F:** Um...day to day stuff, some of it, I don't know really because it's never really been any different for us. So um, it's um...we probably try and tell ourselves it's easier maybe...laughs!

On the negative side, the same father confessed that having two disabled children had had a negative impact on his career.

**Interviewer:** So, to summarise that a little bit, having the two children has prevented your promotion, a little bit before now?

**4F:** Yes it has made things difficult career wise...

In Family 3, they expressed the opinion that if they had known about the autism earlier it might have had the effect of limiting subsequent pregnancies and that would have been to their long term detriment. In Family 6 the parents tried to get ante-natal screening to consider aborting a child if it was known to have a disability. At the moment there is no screening test available for ante-natal diagnosis of autism but this family requested screening for Down's syndrome and spina bifida. The mother is now profoundly relieved

there was no test for autism as she is delighted with her fourth child who has an autistic spectrum diagnosis.

If there was a genetic marker test available for autism there would be significant ethical difficulties because of the broad nature of the autistic spectrum which would make the possibility of termination of pregnancy even more problematic than it is at the moment for other disabilities.

In Family 8 the two autistic children are twins, and there are no additional children, but one is more severely affected than the other and they were not both diagnosed at the same time. In many ways this family is the exceptional case which helps to prove the emerging Grounded Theory. The family struggles to cope with the two boys not only because they are both autistic, but rather because there are additional 'intervening conditions' which will be discussed in another section. This study did not specifically address the issue of which factors might have led to an increase in family size so it will not be possible to draw conclusions on this topic.

The second way in which the number of children in the family affects the phenomenon of coping is the total number of children in the family and the percentage of them which have a diagnosis of autistic spectrum disorder.

It appears that in families with a large number of children the autistic children fit into the family particularly well and are treated just the same as the other children. In this study this is particularly so in the two largest families, both of

which had six children, three of whom had diagnoses of Autistic spectrum disorders, in each family. There is clearly an advantage from the dilution effect of having several children with problems in the family as all the large families said that they had to treat all the children the same way as though they were all normal. In Family 6 they put particular emphasis on this point and they considered the fact that the most severely affected youngster fitted in so well was due to the fact that they had never allowed him to develop his obsessive behaviours.

In addition, the larger families had a feeling that the non autistic siblings would be able to cope with their disabled brothers and sisters later in life and that having more siblings was like a long term insurance policy.

In Family 1 the older normal siblings have already taken over some of the coping and care responsibilities when one of the affected siblings moved away from home. In Family 6 the two oldest children are no longer able to take on this role and the parents have placed a greater expectation on the younger non autistic child.

Family	Total number of children in family	Number of autistic children	Severity of autism	Oldest child most severe
1	6	3	3 Asperger's	
2	4	3	2 severe but verbal 1 atypical + LD	
3	2	2	1 Asperger's 1 atypical	
4	2	2	2 severe	yes
5	4	3	1 Asperger's 1 severe 1 atypical	
6	6	3	1 moderate+ LD 1 Asperger's 1 moderate	
7	3	2	1 severe 1 Atypical	
8	2	2	1 severe 1 Asperger's	Twins- yes
9	4	3	2 moderate 1 mild	
10	2	2	2 severe	yes
11	4	3	2 Asperger's 1 Moderate +LD	

Table 7: Number of Affected Children and Severity

\*LD = Learning Disability

Family's 1, 2, 5, 6, 7, 9 and 11 all had three or more children and the autistic children were well integrated into family life. In fact in Family 9 where there were four boys, three of whom had autism, it was the non autistic boy, who

had ADHD, who caused the parent the most problems. This sentiment was echoed in other families, for example Family 7, where the mother had more worries about their normal son and the more mildly affected boy than she did for their severely affected youngster. Also in Family 5, although the most severely affected boy has brought about a lot of anxiety, especially when he appeared to be regressing, the two other affected boys have, in the past, caused more worries about educational placement in particular. This is because the Education Authority often does not perceive the need to support Asperger's children even though they can be at least as disruptive as classical autistic children in school if they are not supported appropriately. It does appear that when there are several autistic children in one family, the adaptations made to family routine seem to suit everyone and there is less emphasis on children being different. This seems to lead to family cohesion and well-being and enhances resilience.

In all the larger families the advice they wished to impart to future families in their situation was 'keep everything normal'. They really did not wish to be pitied by the non autistic population because they love and admire their ASD children and feel there is absolutely no reason to be pitied.

In summary, if there is a small family with just two autistic boys there is less dilution of the disability effect than in the large families in this cohort where even the presence of three autistic children does not upset the coping strategies.

## 5.2 Severity of the autism

To many clinicians, social workers, and lay people the notion that the greater the severity of the autism, the more difficult the task of coping is, seems as obvious as to be not worth further discussion. Several authors also bear this out.<sup>81</sup> In this study this assumption was not found to be correct.

In this sample of families some of the children were amongst the most severe in terms of symptoms and behaviour of any that the author has dealt with over a period of twenty five years in clinical practice and yet severity of symptoms was not the major reason for difficulties in coping.

In both Family 4 and Family 10 there are boys who are non verbal and display aggressive behaviour and have severe learning difficulties and yet although there have been times in both families where the ability to keep the family together has been extremely precarious it has been other additional intervening factors which have been the cause of the crisis rather than purely the autism. The fact that the severity of the autism is recognised more readily by the statutory services leads to external support in the form of respite care and direct payments for child minding. In families where the children have classical Kanner's Autism,<sup>8</sup> all the families who benefitted from this help rated it very highly. However as resources are very limited for support for families with disabled children at the moment in the geographical area examined in this study, children with Asperger's syndrome were not entitled to the same type of external support, as those with classical autism and sometimes the

difficulties encountered by the families with Asperger's syndrome appeared to be worse than those other forms of ASD.

An example of this was Family 1 with three children with Asperger's syndrome and severe difficulties with several school placements as well as problems with neighbours. The Children's Services social care department had not offered any support in terms of respite or child minding and at a crisis point where the parents were separating; family breakdown was only averted by sheer strength of mind on the part of the mother and some support from the specialist autism nurse.

In Family 6 the oldest autistic young man, who has attended special school and now attends a special course in Further Education, does not even have a social worker in spite of the parents requesting one. In the opinion of the researcher if the parents were less able to manage their complex family he would undoubtedly be in receipt of additional social care support.

It appears that the way social care support is assessed for young people with learning difficulties and challenging behaviour is not uniform. Some parents commented in this study that they wished they had made more of a fuss at an earlier stage because when they did so the amount of respite care and direct payments was suddenly increased. This was particularly so in Family 4

**4M:** So, that's been upped, ...I used to have 8 hours direct payments a month which is just used for babysitting for me and 4F to go out...  
...maybe a year ago my direct payments have been changed, um, not

because 4F is away, they have been changed because it is standard. Um, I get actually...now let me think...in total 32 hours a month direct payments term time—that goes up to 48 hours a month in the school holidays, so yeah that has been a massive help (laughs). Um so that's brilliant because I have a total of 3 people that take up ...those hours and um, the boys love them..."

The fact that the milder cases often look and behave normally leads the outside world to presume that there are no disabilities and that parents are exaggerating their problems. This can make the role of the family caring for several ASD children even harder. Some grandparents even felt that the parents were labelling their ASD children unnecessarily and this often led to tensions within the family.

In summary, the severity of the autism does give the family added problems particularly for managing very challenging behaviours, but if the Social Care team has supported the family with appropriate respite care, the coping ability of the family with severely autistic children can sometimes be better than in those families with little or no support and children with more subtle difficulties which, however, can be equally demanding of care, ingenuity, time and patience.

### 5.3 Parental understanding of Autism

Parental understanding of autism at the time of diagnosis was very variable. At one extreme was a parent with a limited understanding of autism, as in the film 'Rain man' with Dustin Hoffman, (Family 4), and at the other extreme, a

parent who had researched about autism prior to the first diagnosis. (Family 1). The effect on subsequent coping depended on the ability of the family to accept the diagnosis, adapt the family life style and absorb new information about the condition. In this section it will be shown that the level of understanding of the condition evolved over the whole period of caring. Families told the researcher that they all went through a steep learning curve initially, and that they were hungry for appropriate information and that professionals often did not give them enough information at the appropriate times.

Some families thought that autism was only present as a severe communication disorder, and were taken aback to discover that the subtler forms of the condition might apply to their child. This father was discussing the process of the diagnosis of his eldest son:-

**5F:** We didn't really know what was being considered, .. and then when they did say it, I remember asking them, ... when they said, you know, he might have autism,... is that something you're thinking it might be, or is that something you're sure about, and they said no they were quite sure.

**Interviewer:** Did that come as a shock to you?

**5F:** Well, yes, .... 'cause I think my only knowledge of, ... Autism... was more like 5T (*the son who is mainly non verbal and more classically autistic*)

**5M:** Yes, and mine was of people who aren't affectionate, umm, having tantrums and being quite disruptive and all the things you sort of hear about...

**5M:** ...but, not the Autistic child that we had.

**Interviewer:** That wasn't 5A though, was it?

**5M:** No. We had this lovely placid little boy...

Families also acknowledged that they continued to develop their understanding over several years. Family 5 felt that the evolution of understanding takes place over many years. And they are still in unchartered waters, finding the diagnostic label unhelpful as it is so broad.

There were also misconceptions about the causes of autism. Some parents still felt that the MMR (measles, mumps and rubella) inoculation might have been the cause of their son's autism. In spite of all the evidence<sup>147-151</sup> produced to counter the Andrew Wakefield<sup>152</sup> paper in the Lancet; as there has not been a definitive gene or genes identified which have been shown unequivocally to cause autism, the lay population clearly goes on believing that the MMR might be responsible.

**6F:**... the trouble was it's a big debate over whether 6D was born with it or whether he, he contracted it. 'Cause you remember the issue with this guy who was struck off and he said he believed...

**Interviewer:** Oh, Andrew Wakefield, are you talking about?

**6F:** Yes. He believed the MMR may well have affected him.

**6F:** Well, with 6D he was first child of the two twins. He was walking and talking and he was doing all things at the age of, just before 2 and then he had the injection and he regressed...

**6F:**..and seemed to go into a shell, which we thought was strange at the time. We never actually, (*knew*).... this case of whether it was MMR.

There then followed a debate about whether the twins should have been immunised or not and it transpired that the mother had had them done without the approval of her husband because she believed it would be beneficial for the children to be protected.

Reflexivity:- the researcher feels that it is often impossible for parents to detect the early signs of autism especially if it is the first affected child in the family. They therefore feel in retrospect that the child was normal until he failed to develop speech or developed more obsessive behaviour which children do not do until they reach that developmental stage. This same family did not have a problem accepting that 6P had autism and the question of whether it was caused by MMR was never raised. The legacy of the Wakefield paper has been to leave parents with a long lasting sense of guilt which certainly does not help their ability to cope.

Another family who still has lingering doubts about the possibility that the autism was caused by the MMR is Family 7. This mother also described a normal child until the age of two, confirmed on family videos, who then

regressed. They blamed MMR even although the timing was not compatible with their theory.

In some of the children who were at the mild end of the spectrum there was some debate about whether the child fitted the criteria for an ASD diagnosis.

In Family 7 their third child 7L was assessed both in Norfolk and at the Wolfson centre and initially he was given a diagnosis of dyspraxia (coordination difficulties) with semantic pragmatic language problems. Over time it has become clearer that his symptoms are enough to fulfil criteria for a diagnosis of Pervasive development disorder (not otherwise specified). His mother acknowledged this in the following extract:-

Having had a second opinion about the diagnosis for the first child, the clinician felt it was appropriate to go down the same route for the second. Unfortunately the diagnostic centre felt that a diagnosis of semantic-pragmatic disorder with dyspraxia was more appropriate than PPD (NOS). In the long term this has proved to be incorrect.

**7M:** Um; I could never get my head around what the differences are. I mean what's the other one-Asperger's; you can tell the difference, you can see Asperger's, you can tell the difference between 7N and Asperger's. ... I think it has come out more as 7L has got older; I then kind of realised he has got more ... autistic traits.

Reflexivity The nature of the different diagnostic categories for ASD often leads to more confusion than clarity as is demonstrated in this case.

The nature of the Autistic spectrum is such that comparisons between two children in the same family do not lead to clarity of understanding.

**7F:** So all the time you are comparing him to 7N.

**7M:** And I couldn't see the comparison, but I knew something was wrong. You couldn't quite put your finger on it and then little things would develop, he could not chew-he dribbled the whole time.

This family has a very advanced knowledge of autism, but in spite of that they still feel guilty that they have sons who are affected.

**Interviewer:** Fine, can you think back to your reactions; when I told you that I thought that 7N was autistic, what did you feel at that time?

**7M:** I think part of it is relief, because you kind of think you know that something is not right and you are kind of relieved to think that, now you know what is wrong you can always work on it. I mean I have always been a big believer of that, if I ever had a problem find a solution and it will sort itself out, ...after the initial shock and after the initial guilt and disappointment.

**Interviewer:** You felt guilt did you?

**7M:** Oh I still do to this day.

Later in the same interview this mother was very honest about her own learning about autism and this seemed to apply to many of the families.

**7M:** I don't think either of us grasped what it entailed initially. Because there is no way I could have perceived how much it would have changed our lives. I never dreamed it would all be consuming.

She went on to say that one cannot take in too much information at any one time, and it is helpful to be drip-fed.

In summary, all families agreed that the giving of the right amount of information about autism at the right time helped them understand the condition and how to cope with it. Most families started at a low level of understanding and this improved over time with their own research and experience. This did not prevent some of them retaining a feeling of guilt and others being very pragmatic about how they dealt with the situation as in this extract from Family 11

**11M:** To me, I'm the only person who thinks my kids are perfectly normal...

**11M:** I mean obviously you worry, because you worry about their future and later on, but actually for day to day it's just the same.

**11M:** You know, you get up, you feed them, you clothe them. You love them.

#### 5.4 Children and young people's views of autism

All the children interviewed in this study were happy to talk about what their understanding of autism was. For the very young and learning disabled children it was obvious that the very concept of autism had not yet become part of their vocabulary. With slightly older children, although they were

familiar with the word autism they either had very little idea of what this meant or had only a hazy understanding of the implications for them. However the more mature Asperger's syndrome children were very clear about the nature of their problems and held both positive and negative views on how the diagnosis affected their lives.

This section will be set out as an evolution from lack of understanding through to the mature autistic person's opinions about themselves and ending up with the non autistic children's attitudes towards their disabled siblings. It was heartening to hear mainly very positive opinions about the autistic siblings but the fact that in a few cases the feelings were entirely negative helped to develop the theory that where there is a good understanding of autism amongst the siblings and young people themselves this enhances family functioning and coping and where the opposite is the case then the coping of the entire family becomes perilous.

#### 5.4.1 Young and immature views on autism

Obviously there were some families where it was not possible to interview the children as they were non verbal. This was the case in both children in Family 4, one child in Family 5, one child in Family 8, and two children in Family 10. The verbal child in family 10 unfortunately could not be interviewed as one of his phobias was having strangers in his house and so this was not thought to be ethically wise. Some of the older siblings had left

home and were therefore not available to take part in the study. This applied to three children in family 1, and one child in family 11.

A total of twenty six children and young person interviews were conducted.

Children were encouraged to draw their families as a way of improving communication about the family with the researcher.

A ten year old autistic boy described his more severely affected younger sibling as having a problem with speech. He himself was late speaking but verbalised earlier than his twin brother who is also autistic. In this extract he was describing his autistic younger brother who does not have verbal communication but can use Makaton signs. 2M is the Mother of Family 2, 2T is one of twins:-

**2T:** But...Mum, 2S...talk?

**2M:** He can't talk at the moment, but he will one day.

**2T:** But how old, how he get the noise in him?

**Interviewer:** Yes. Are you sad that 2S can't talk?

**2T:** Yes.

**Interviewer:** But he lets you know what he wants, doesn't he?

**2T:** Yes.

**2T:** Hector and Alvin can't talk. Alvin do like (meow noise) and the dog talks like (barking noise).

**Interviewer:** Okay. So dogs and cat can't talk, and 2S can't talk, so they're all a bit the same really, aren't they?

**2F:** (Dad) They're all animals. (laughs)

(all laugh)

During this part of the interview 2T was struggling with the concept that even the pets in his house and Scooby Doo on the TV can talk in their own way but his younger brother still cannot talk in spite of being now nine years old. This is perhaps the most obvious symptom of autism to a brother with autism himself and is demonstrating an understanding at a very concrete level.

A much older autistic young man really did not have much idea what the researcher was asking him about but demonstrated some understanding by gasping, perhaps indicating that he thought it was something bad but then went on to demonstrate that he really had no idea what it was other than something to do with his lunch box.

**Interviewer:** Now 7N, you know when you were very little and I saw you, we said you had something called autism.

**7N:** Gasps...

**Interviewer:** Do you know about autism?

**7N:** Yeah...

**Interviewer:** What is it? What is autism?

**7N:** Box?

**7M:** (*Mum*) Pardon? Your lunch box?! Laughs..

At this point there was no further insight into the condition forthcoming.

In the next extract a child aged 9 talks of his older Asperger's brother

**Interviewer:**..... Can you tell me what's really good about living with him?

**3D:** ....Umm, umm, he, he can help me with stuff that I need help with.

**Interviewer:** Yeah.

**3D:** Cause he's got a really good brain.

**Interviewer:** Oh right, okay. Now then could you tell me are there any problems about living with 3T? Is anything difficult?

**3D:** Umm, yeah, when he argues and shouts and tells me what to do.

This appears to demonstrate a fairly normal sibling relationship with a rather touching belief in his older brother's abilities and no real comprehension of difficulties particularly relating to autism. In Family 11, one of the children described his autism as a trouble thing, and when I asked him to explain he became embarrassed because he did not really know. His mother explained that they do not talk about the label but that her son understands he does have something which is the reason he attends special school.

Another intelligent child, aged 12 with Asperger's found it difficult to describe what the diagnosis meant to him although he was clearer about his younger more severely affected brother.

**5A:** 5T suffers from a form of Autism, and makes noises like this and 5O is the youngest; and he....(stutters for a bit) and he seems to like Mickey Mouse quite a bit, playing with the old pirates and things like that.

**5A:** To be honest, we are just used to 5T watching his videos and stuff and the toilet, I do occasionally wonder what it would be like if he did not have it.

*(meaning his brother's severe autism)*

**Interviewer:** Ok, what about you though, you have a little bit of some difficulties like that do you?

**5A:** Yes, something to do with socially I cannot remember.

It was interesting that he did not go into any more detail about his own condition, perhaps indicating either embarrassment or lack of true understanding.

A much older autistic young man who was able to talk but attends a bridging course post school to learn more skills for daily living had this to say about his autism

**Interviewer:** You know that some people say that you have got a diagnosis of autism? What do you think that means?

**6D:** Um...it's about when you talk too much it might be that difficult to understand.

**6D:**... And never explained too much about it, is very difficult to talk and sometimes when you are quiet, you never get your mouth closed.

**Interviewer:** I see, ok; so the difficulty around talking, is there a difficulty around making new friends or is that not a problem?

**6D:** Not a problem with making friends. I am chatty and make nice friends.

Two teenage twins who demonstrate symptoms on different parts of the autistic spectrum had this to say about their diagnoses:-

**Interviewer:** Now you know that he has got a diagnosis called of autism and somebody said that you're also on the autistic spectrum, what do you think that means for you?

**8J:** Erm; slightly learning difficulties kind of things and concentration problems, really bad social skills sort of thing.

**Interviewer:** Is that something you have been working on to try and make it better?

**8J:** Mmm...it's not really working.

**Interviewer:** Oh ok; so does that mean that you get a tough time at school?

**8J:** Mmm.

**8J:** It doesn't bother me, it is just the verbal stuff and the physical stuff that gets on me nerves.

**Interviewer:** The physical stuff? Do they go for you then?

**8J:** Constantly.

His brother who is more severely affected had a rather more bizarre understanding of autism: His brother felt that having autism meant that he could not control his body or his brain.

**8P:** And also I can't control my brain because it thinks about baby stuff, girls stuff and stuff I have not time for.

**Interviewer:** So what do you mean about girl stuff and baby stuff and all that sort of thing because I am not quite sure what you mean?

**8P:** Well baby stuff which I am too old for, and girls stuff which is only for girls and not boys.....

**8P:** I do like it, (Easter) I do like that stuff but I fear the reason why I can't control my brain is that there is not time for it yet.

**Interviewer:** Oh I see so your brain tells you, you would like to be having it now but you have got to wait several months before it happens. Right; does it help you to write down how many days until the next exciting thing is and then tick them off?

**8P:** I try and look at my calendar but...

**Interviewer:** So does having autism, is it a problem to you or not a problem?

**8P:** Not really.

Many autistic children have a difficulty with the abstract concept of time passing, and the extract above demonstrates this. One way of helping an autistic child to comprehend time is to give them the visual clue of a calendar with all the days marked on it and to get the child to cross out each day before some significant event. This is what 8P was describing here.

All the above quotations suggest a very incomplete understanding of the problems associated with autism and suggest that family and professionals do not spend enough time explaining the nature of autism to the children and young people who are affected. Of course this is very difficult in younger children who are compromised both verbally and in their comprehension, but

perhaps professionals should consider some teaching for older autistic children who might do better if they had a more profound understanding of the nature of their difficulty.

#### 5.4.2 Children with a higher level of understanding of autism.

The next few extracts demonstrate a more mature understanding in very bright, older children with Asperger's syndrome. This interview was with two young people in Family 1

**Interviewer:** Yeah, tell me what you call it.

**1Ja:** I just call it Asperger's, that's all.

**Interviewer:** You call it Asperger's and 1E do you call it Asperger's as well?

**1Ja:** Sometimes I call it Arseberger's.

**Interviewer:** Arseberger's, that's a good name. Oh, I think that's wonderful. Do you call it that too?

**1E:** No, my dad says it's a pain in the Arsebergers.

**Interviewer:** It's a pain in the Arsebergers. (laughs) And why is it a pain in the Arsebergers?

**1E:** Cause it makes you a pain. Well, it's annoying to the person who's got it.

**1Ja:** And it's annoying to the siblings.

**1Ja:** Very much so.

**Interviewer:** Is it? Is that anything you can help or do anything about?

**1Ja:** No.

**1E:** No.

**1Ja:** Cause I just retaliate the same way.

**1E:** Me too.

**1M: (Mother)** They find each other annoying.

They went on to say that they felt several other members of the family were similarly affected including their Mother and younger sister and only the oldest brother was really normal.

There followed a discussion about things that had helped to improve both the young people's understanding of Asperger's, and 1E described how she wished to help disabled people as she felt that by having Asperger's she had more insight into disability in general.

There was then a discussion about the novel by Mark Haddon called 'The Curious Incident of the Dog in the Night-Time'<sup>153</sup> and 1Ja had read it, and found that he had some things in common with the main character who has Asperger's. Both these two children had found it useful to read books about autism.

The children in family 1 who called their condition Arseberger's also demonstrated considerable insight into their own difficulties. 1Ja realised that he liked to be in control of his environment so chooses not to go and stay with other people outside his home. 1Ja felt he would have liked to have got rid of his Asperger's when he was at primary school, and his Mother confirmed that all her affected children had a very difficult time between age

7 and 11, but later they had enough insight to realise that the Asperger's was a part of their character and they did not want to be separated from it.

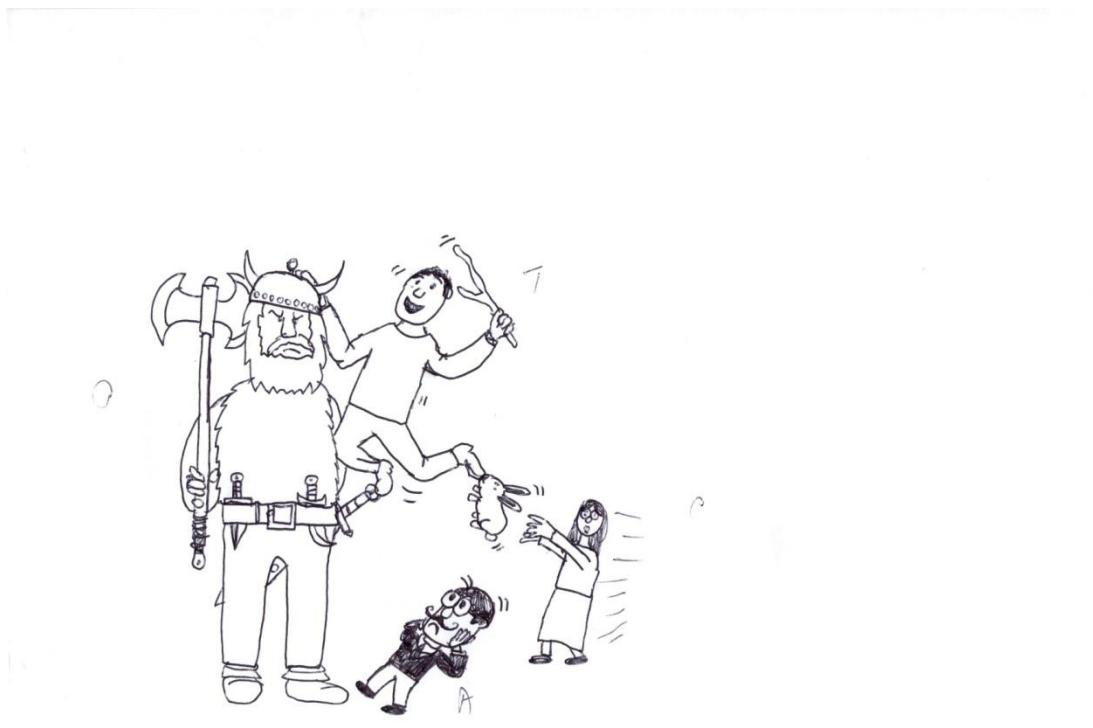
1E has some insight into the fact that her sense of humour was different to others when she related this rather sad little incident:-

**1E:** There was obvious things like there was this other girl called C and she was in the same class as me and she would say something funny and when answering questions she would just put her hand up and say something funny instead and the entire class would laugh at her and the teacher would be all like that. And I did it once and like answered a question with a silly answer and the teacher said stop being so silly 1E and get on with your work.

**Table 8: The Humour Incident**

One of the questions asked at interview was whether the child would like to change anything about himself or herself. Only in Family 1 did the children wish to lose their autism and even then, on balance, they felt that if they lost their autism they would not be themselves. When 5A in Family 5 was asked if he would like to change anything about himself he replied that the only thing he would like to change would be to be less lazy. (The author knows that he is a most conscientious child about his school work and is always drawing so does not appear to be lazy)

Figure 5: Drawing of Family 5 by 5A



Others had learnt strategies to deal with being teased by ignoring the tormentor.

One of the most able Asperger's boys was describing leaving home and the interviewer felt that he may have had problems with catering for himself or managing his laundry etc and his reply amused the researcher but also showed that he had come a long way in coping with everyday life.

**Interviewer:** Did you have the same fears when you went to university?

**11A:** No, because with university I had already spent 3 years in college so that was like-it's really not that big of a difference really.

**Interviewer:** ...and what about the business of having to look after yourself? ...because you weren't living at home...

**11A:** The hardest part was convincing my mother that I could do that.

Other questions that elicited responses which illuminated children's understanding of their autism were how does the autism/Asperger's affect you and also questions about what will happen in the future when their parents are no longer around to support the most disabled members of the family. This mother was trying to reassure her Asperger's son:-

**1M:** Try to look on the positive side of the things it's done (*the autism*) that make you different in a good way.

**1Ja** Yeah, it makes me who I am.

Later with another family, the girl who has the mildest degree of autism in the family shared considerable insight with the researcher but although she could see it was obvious in her siblings she did not acknowledge the problem in herself.

**6B:** Um well, you can tell that 6P has got autism....and so has 6D.

But if you looked at them, you wouldn't notice, you wouldn't know that they are autistic unless you talk to them.

**Interviewer:** And some people have said that you yourself have a little bit, what do you reckon about that?

**6B:** Um well mum said...well thing with me is that I can control my...because I have ADHD and but I can control that now

**Interviewer:** What about the Asperger's bits?

**6B:** No it don't really affect me...because that is quite bad and mum said that I had a trait of it. But um...I don't think I have.

**Interviewer:** And what's really good about living with all the members of your family?

**6B:** You don't get lonely and there is always something to do. There is always...they are such happy little kids and they've always got something...when I come home from uni they are always like 'come play with me, come play with me, do this, do this!' And it is great...I don't mind but sometimes I get a bit annoyed.

**Interviewer:** Ok; do you ever wish you could change anything at home?

**6B:** No because I reckon, if you change 6P and 6S, it won't be 6P and 6S anymore. So I,... they are fine how they are.

**Interviewer:** And you have never had a problem about bringing friends home?

**6B:** No. no. Everyone just accepts it!

**Interviewer:** Everyone just accepts your brothers for who they are do they?

**6B:** Yeah, yeah

**Interviewer:** And are you proud to have a brother or 2 brothers like you have?

**6B:** I am. If you asked me this when I was at school, I would have said no, no; but actually I am.

**Interviewer:** Oh what's changed to make you more proud of them now?

**6B:** Yeah I was so immature; I used to find 6D really annoying! And I used not to get along with 6D at all and he used to wind me up but now I think I have grown up a lot really and I respect 6D and 6P and I care about them a lot. I would stick up for them now if there was any problems at school and stuff.

The normal siblings of the autistic children mainly had a very caring attitude towards their autistic brothers and sisters. There were a variety of views from problems playing with the autistic children, to a realisation that any siblings fight sometimes, to sticking up for their disabled sibling. Many of them were strongly of the opinion that they would like their friends to meet their disabled siblings and that anyone who did not want to meet them was not a friend of theirs.

**Interviewer:** Okay. So do you reckon it's any different living with three autistic brothers than it would be if they weren't autistic?

**2J:** No, 'cause I suppose brothers would still fight.

**Interviewer:** They would, wouldn't they?

**2J:** But, see, you'd be able to play football whereas 2E he runs off with the ball.

**Interviewer:** Oh, I see. He hasn't got an idea where to kick it properly?

**2J:** Nah.

**Interviewer:** Are we going to magic away any of your brothers?

**2J:** (laughs). I wish I could sometimes.

This was perhaps a true version of what he thought but he still managed to find some positives about his brothers as well and it is quite possible that if one asked a random sample of children if they would like to get rid of their brothers they might well say yes.

**Interviewer:** Okay. Are you very proud to have lovely brothers like you've got?

**2J:** Sometimes...we went to this, umm, saloon bar in France at Disney...

**Interviewer:** Yeah.

**2J:** ... and 2S got pushed down, and 2T and 2E don't really like 2S much, but they still came in and stuck up for him and started on the person.

**Interviewer:** So they do stick up for each other?

**2J:** It's like they're saying no one else can bully him, except me.

In response to the question about what is good about having brothers like yours there were a variety of positive comments. Several siblings commented on how funny their autistic brothers were, and that they had a lot of laughter in them. They were also described as very nice and kind and one described his brother as cute.

**Interviewer:** Yes. And, is there a single best thing about having 7N around?

**7Ma:** Just having 7N around.

**Interviewer:** Because he is a lovely person?

**7Ma:** Well yeah and he is also my brother so, so sometimes it will happen in some situations that with disabled people they go to live away in a special home but I am just glad that he is actually at home and not somewhere else.

These sentiments were emphasised by the fact that all the normal siblings said that they would take a part in caring for their autistic sibling later in life when their parents were no longer able to do so, although several of them said they do worry about what will happen in the future.

**7L:** Well yeah, I am thinking about 50 years in the future when mum and dad are not around.

**Interviewer:** Exactly.

**7L:** I mean, either me or 7Ma will have to be a carer and at the present moment, I am unable to care for myself!

**Interviewer:** Laughs...that is very honest!

**7L:** So um...

**Interviewer:** So that could be a bit tricky?

**7L:** Yeah it would be tricky but I think we could do it when it come down to it.

**Interviewer:** Good. Ok; so would you say on the whole, yours is a very coping family?

**7L:** Yeah we are coping, doing what we can do.

**Interviewer:** Yeah. And you really wouldn't want to change it much?

**7L:** Not really.

All of these sentiments led to a conclusion that there is a huge sense of support and caring on behalf of the normal and less severely affected siblings which must lead to greater family cohesion and enhance the coping capacity of the whole family.

Not all the comments about the autistic members of the family were positive.

In one family a brother said he would quite like to lose his brothers on occasions. There were also negative comments about the things that annoyed them such as messy eating, throwing food around and getting in a strop. Some commented on the autistic sibling being very noisy and shouting a lot. They also commented that a brother sometimes blurts out inappropriate comments which can be embarrassing and some even commented that it would be better if their brother was not autistic. However it was only in one family that the feelings were universally negative and this exceptional case helps to prove that the main emphasis of all the other children was that they loved their autistic siblings and did not want them to change much.

The negative exceptional case emotions were expressed best in the following:-

**Interviewer:** to 8J: Right, what's he like on a day like today?

**8J:** It varies; it can start as quick as that.

**Interviewer:** And when that happens, what happens because I don't know exactly what might happen.

**8J:** Usually violence and gets annoyed about everything if he thinks I am spying on him or something.

**Interviewer:** Oh does he?

**8J:** Yeah spying on him or killing innocent people or something.

**Interviewer:** And what do you do when that happens?

**8J:** Well at first I just tell him to bugger off but after a while just leave him...

**Interviewer:** Ok; right. But are there some happy times as well or not many?

**8J:** Every now and again, so much no more.

The interview continued with the thoughts becoming even more negative:-

**Interviewer:** Ok, so what do you think it is that makes mum cross?

**8J:** I think everything.

**Interviewer:** Right...ok. If you could change something about living here what is it you would change? I mean if you could magic 8P away, magic mum away, live on your own; any of those things-might you do any of those-or do you want to keep it how it is?

**8J:** I would rather 8P didn't have no autism; it would be a lot easier.

**Interviewer:** Right.

**8J:** That is not going to happen though.

**Interviewer:** And what about your own autism?

**8J:** It would help if I didn't have that.

**Interviewer:** Ok. So are you optimistic things can get a bit better or not really?

**8J:** I doubt it.

**Interviewer:** You doubt it? Ok.

**8J:** Well the last couple of days it has just been getting worse, it is like it is going to keep on getting worse.

**Interviewer:** Is it? Oh right, well it seems from your point of view, things are quite bad at the moment aren't they?

**8J:** Mmm.

On interviewing the other brother, the researcher found that the feelings were no better:-

**Interviewer:** Oh, I see; right. Could you tell me what's really good about living with 8J?

**8P:** Nothing's good.

**Interviewer:** Nothing's good! Ok...

**8P:** And I am embarrassed to be related to him.

**Interviewer:** Ok; ...what would you say are the worst problems about living with 8J?

**8P:** That, that he makes me say that he is evil.

**Interviewer:** Does he? Ok; so is it 8J that sends you into a real rage more than anybody else?

**8P:** Yeah and he says that I am fat and says that I am a gay and I fall in love with men, when I don't!

The interviewer was sufficiently concerned about this family to contact the relevant health professional after the interview to confirm that the family were receiving extra support. It transpired that there had been a recent worsening

of the situation at this home due to the additional mental health problems of one of the family members.

In all the families where the coping had become 'perilous' there had often been an added mental health problem which had significantly complicated the family's stability, and was a major reason why a family which had previously been coping in a buoyant way had changed rapidly into a much more chaotic situation and the coping had become 'perilous' even to the point of potential family breakdown. It is at these points that the relationship with supporting services becomes even more vital. In the case of Family 8 quoted above the Mother's solution to the problem was to try and obtain a residential school placement for the child with the added mental health difficulties.

The discussion about factors, which included mental health problems in either a parent or a child, child protection issues and partnership breakdown will be explored in greater depth in the section on intervening factors which have a direct effect on the central phenomenon of coping and the strategies which are employed to deal with them which have a direct effect on the final outcomes for the families.

#### 5.4.4 Conclusions about children's views on autism

Interviewing the verbal children who had had a diagnosis of autism gave the researcher a completely new understanding about what the children thought about their condition. Generally it was very pleasing to hear that most normal

siblings were very affectionate towards their disabled sibling and wanted to involve them in family activity and to care for them in later life. Some siblings did express a degree of embarrassment about their disabled brother or sister especially in a school context and this was mainly so that they were not themselves subject to bullying about having a non normal member of the family. The level of understanding of the nature of autism in the young people themselves was often very limited except in the older Asperger's children. It is possible that if young people with an autistic spectrum disorder could be given greater insight into their condition they might be able to cope better within the family. The author's experience suggests that most of the information giving by professionals is directed at the parents, and perhaps more input should be towards the siblings and more able autistic youngsters.

## 5.5 Perceptions about the educational experience

In the course of the semi-structured interviews several questions were asked specifically about attitudes to professionals in all the statutory areas which led to replies about teachers and schools and further and higher education. But in addition to these, perhaps the most revealing comments were those that arose spontaneously from the interviewees at various points in their descriptions about their families because they felt so strongly about their educational experience. Several of the semi-structured interviews were in the form of open questions so that participants could enlarge on answers and move into any areas of life they felt passionately about. For the relevant interview questions please see appendix 7 and 8.

As this analysis proceeded there were two distinct groups of comments that emerged. These were the negative views about school and education. Three main themes emerged in this category which included bullying, lack of understanding and behaviour problems, which contrasted starkly with the positive comments that arose from both parents and pupils. These could be grouped into three themes also which included 'people who helped and understood', friends, and increasing confidence in the school which was also associated with the ability to make plans for the future.

By further examining these two major contrasting sets of views, it will be shown that the positive aspects of the educational experience led to family cohesion and buoyant coping whereas the negative experiences pushed the balance at home towards perilous coping.

The following figures give an outline of the main conclusions about educational experiences.

Figure 6: Educational Experiences – Positive

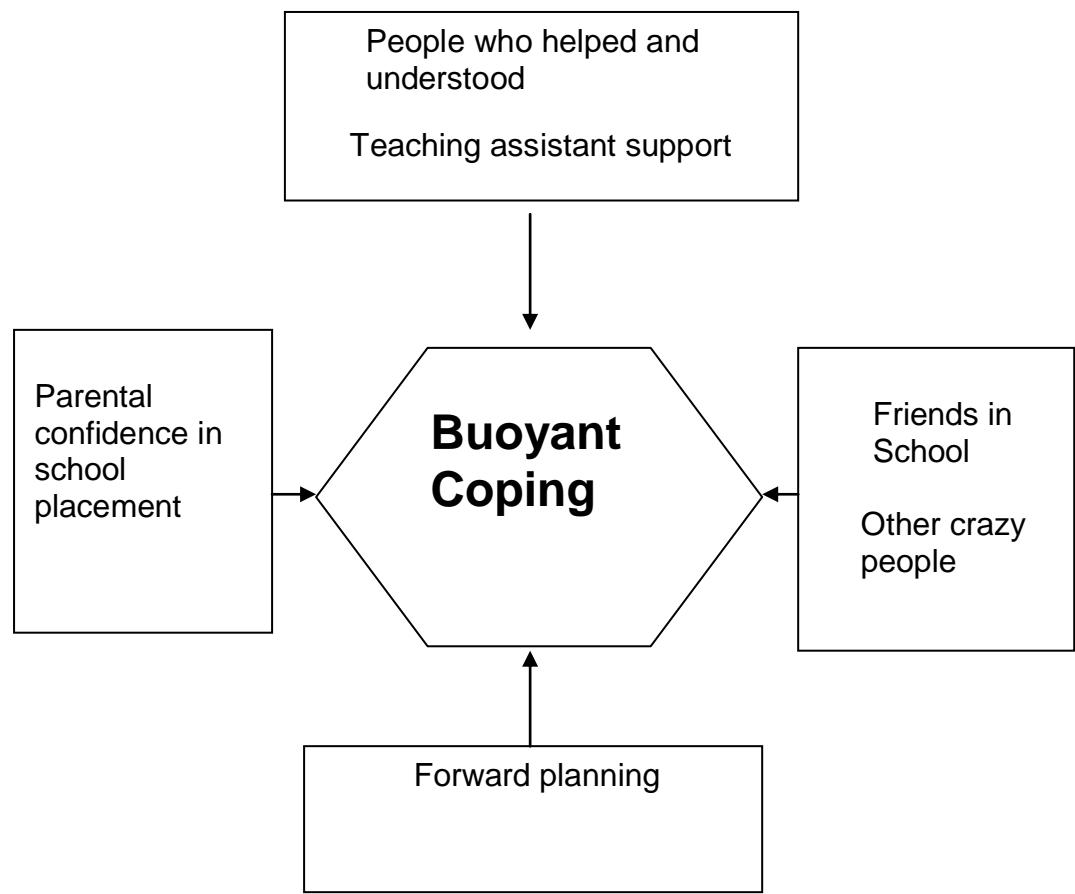
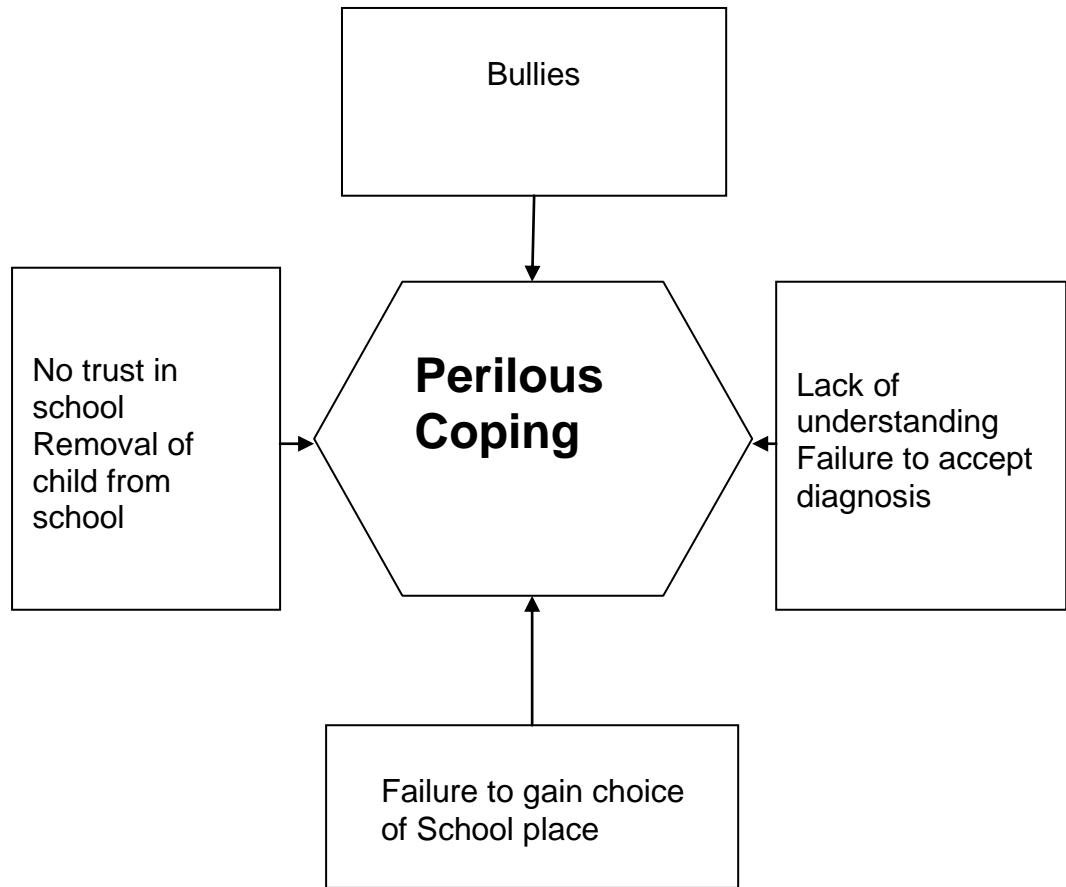


Figure 7: Education Experiences - Negative



### 5.5.1 Bullying

This was mainly described by the autistic children themselves who had suffered severe verbal abuse and sometimes physical beating as well. Parents were aware that this was happening but felt powerless to do anything about it.

**11M:** Watching him walk up to school, you know, forcing your child to do something he doesn't want to do and you can see that he just used to walk away from the car, just defeated before he'd even gone

through the day and he would know something horrible was going to happen to me today.

**11M:** And it did. It usually did.

This was the view of Mother 11M who eventually withdrew 11A from that school but went through a turbulent period while trying to work out a unique form of placement.

The following extract is from the boy described by 11M in the first quotation.

**Interviewer:** So what was it particularly about (*school S*) that you found so difficult?

**11A:** Generally just surviving.

**Interviewer:** Because other people bullied you or...?

**11A:** Yeah. Because there were times you would think 'Jesus Christ I might not come out of here with my leg attached!'

**Interviewer:** Really it was as bad as that was it?

**11A:** I would say so because I would go in there fearing that somebody was going to jump out and pick me up again because there were times, if we were in the hall...this is an example I am going to give you-I would walk through a hall and there would be two people either side and suddenly they would you push you wall to wall and then drag you outside along all the way out for the door and outside.

This tends to confirm 11M's description and leads not surprisingly to tensions at home. More time would be used up trying to get meetings to sort out the problems and this was time that was not available for normal family life.

The bullying was not just confined to school it also continued in the workplace after school.

**7M:** They can be worse than... he thought it was bad when he was at (M) School, you know boys bullying and all that, that was always a problem and he thought it would all stop. When he finished school he just assumed he would never be bullied again, he would never have to deal with these kind of problems. When you get into the real world on a construction site, they are ten times worse.

The non autistic sibling also had to put up with bullying on the subject of his disabled brother.

**7Ma:** That happened in E (*Primary*) because me and 7N were at the same school and everybody assumed that, it was like they knew that something was wrong with 7N but they would automatically come to me about it. And of course it like, you know what kids are like they are b\*\*\*\*\*s really aren't they?

**7Ma:** So yeah, and there was a couple of kids who really got on to me about that but that was sorted out in the end.

The one normal boy -7Ma and the less severely affected sibling-7L in Family 7 both spoke about bullying in school. 7L felt he had had a worse time at secondary school and that he had been teased because he had dyspraxia with messy hand writing.

Perhaps the most poignant description of bullying came from child 3T when the subject came up spontaneously.

**3T:** I would, ummm, once before when I was being picked on, on the bus, they called me a chemical retard, I told my mum and she rang up the high school and told my substitute head of year because my proper head of year was off ill...

**3T:** I'm still being called gay and all that kind of stuff.

His Mum went on to describe how he had not got a normal grasp about sexuality and was suffering because he felt that sex education was inappropriate and his friends laughed at his responses in those lessons.

**3T:** Yeah. I just, umm, at the minute, I mean well all of my friends are calling me, they say I'm a poof cause they say I'm a girl and most of the time they just say 'no, they're doing it for a joke'. And yet (raises his voice) I have told them time after time I do not have a good sense of humour, I take everything possible mostly seriously.

This latter comment also shows that child 3T had some insight into his problems but although he could tell people that he did not have a sense of humour he did it in such a way that his peers teased him further about it and that is why when he was telling the researcher about it he raised his voice and became quite upset.

Another theme that emerged from the students was that of being misunderstood largely because they displayed typical autistic behavioural traits. Sometimes the pragmatic way of dealing with this is to keep the child out of school when the parent knows there is going to be a problematic lesson.

**8M:** We are having a very OCD, (*Obsessive Compulsive Disorder*) at school...he has to wash his chair and his desk and his clothes sometimes during the day because somebody else might have touched them or something like that...

**8M:**... And very agitated and very anxious, gets very anxious about things like...we have just had a conversation with the head-teacher, the deputy head-teacher tonight who is wonderful bless her because um; he has sex ed(*education*) at school and because he has decided you are not allowed to have sex at his age and it is against the law to learn about it. And he has got very agitated about the whole thing and every sex lesson, well we missed it this week, but we did laugh because everyone at work said oh you will be glad you weren't here today...because we were actually with Dr. J; um-I said why-she said because we done STD's (*sexually transmitted diseases*). I thought oh god!! Laughs...I am so glad he weren't there!! He would not have coped with that at all; because even the condom lesson he blew his head off.

The very nature of Asperger's syndrome is that children are very concrete. This can lead them into difficulties as the next extract shows. This incident ended up by the mother withdrawing her son from school. This incident was one of the reasons the Mother felt that her son had something wrong with him .She felt that the school was not understanding him and eventually this led to an assessment and 1T being diagnosed with Asperger's syndrome.

While a child remains undiagnosed the stress for the family can become acute and inevitably leads to a situation of 'Perilous Coping'

**1M** So, um there was an incidence at his school, where they had a child and every time they took their reading book home, would be tearing just a tiny piece of the book, every page and um they had a big thing about this and then wanted to find the culprit and they spoke to all the children about it and the very next day, 1J had a book and he did that to the book, so they immediately assumed it was 1J

**1M** I was certain it wasn't, but he did like books and was very respectful of books and it would be something; if he took it on his own back to do, he would be quite upset about it-he was quite particular about things. I spoke to the teacher about this and I found out that he was hauled up in front of the whole class, marched through the school—"this is the boy that's been doing it" and I was really upset by this and he was upset by it and I said you know I am sure he didn't and that there is some other reason for it, and I spoke to him and he said 'because they said that somebody had been doing it, I thought I would try and do it to see what kind of happened and why they done it'. I do not know what was going on in his head at the time, I really did not understand what he thought he was going to achieve by doing this. But I believed that was the first book he had done, the school were then brought up by saying that they thought his other behaviour was bizarre and that he was naughty and he was this...and all this other stuff came out and I sort of you know, never had this experience before and um was quite upset and on the defensive, so moved schools and subsequently it went on happening and they found out it was another child that had got emotional problems and it wasn't 1J in the first place.

**Table 9: Tearing the Book Story**

### 5.5.2 Negative views due to lack of understanding

The parents also had negative views on school which were to do with the school's lack of understanding about their child's problem, and sometimes

negative feelings about professionals who were there to advise about their child's education. In Family 7 there was a perception that the school cared more about their Ofsted report than finding extra help for a child with special needs.

**7M:** Mr A was definitely not going to get-win any prizes because he was going to put an awful lot of funding into this one child that wasn't going to show anything back.

Another family removed their son from primary because his daily anxiety had led to vomiting. The school had not understood the cause. Following the diagnosis the parents felt strong enough to take radical action.

**5M:** Well, it did empower us to make certain decisions, because I remember that day we drove back, we decided then to take him out of school in W school didn't we? Do you remember?

**5F:** Yes.

These negative comments from both adults and students contributed to frustration and time wasting and often involved a period of time when a child was out of school altogether while the parents searched for a more appropriate placement. One parent (1M) even did a few years of home education for one of her children because she was so upset at the way the girl was being treated. Most families do not experience changes in school placement because of bullying or failure to understand their child and yet out of the 11 families in this study, Families 1,2,5,7, 10 and 11 all moved at least one child because of these problems. It is not hard to deduce from this that negative experiences at school contribute in a major way to perilous coping.

### 5.5.3 Positive educational experiences

In contrast to the above there were even more positive comments about schools and how they contributed to the happiness at home. Firstly, there were a series of reports from parents about how helpful both teachers and support staff had been. Family 11 M commented that after she had removed 11A from High school the approach taken at his special school was altogether different

**11M:** ... there's a man called G up at (E School) who would do art with them just as an extra thing....and he just got on so well within the school...that they said look, why not, why can't he just be here as a full time student.

**11M:** So they found a place for him and he just sailed, I mean, he just changed.

**11M:** ....Forget about his education as such and let him concentrate on being happy..... And I just said 11A, I'm just going to take the pressure off, just, ...do what you've got to do and concentrate on having fun...

**11M:** ...and he did have a really fantastic two years.

The result of this change was that 11A went on to college and got some A levels and then got a place at University to read Art and animation and has continued to thrive better than his mother would ever have predicted. This helped to prove that an unusual placement, that of putting a very intelligent boy into a school for children with learning difficulties, can be the right solution if the social milieu was sympathetic, and he was happy.

Other parents were very appreciative about the 1.1 support they were offered. Family 10 were very pleased that both their sons had gone through mainstream nursery and primary school before moving to a special school at the high school stage.

**10M:** They have got different teachers and 10A is in the special autistic unit now. Erm, because there was really no classroom that could deal with his educational levels-which are quite high and his social behaviour levels which are quite low. Laughs...so he is sort of in the topsy-turvy class of...

**Interviewer:** How many autistic children are there in that class?

**10M:** 5

Another father was full of praise for his son's primary school, especially for the fact that his oldest had two part time helpers, at mainstream school.

Different solutions are tried at different stages of education. The Mother of family 8 described how her son benefited from a 'Pathfinder mentor' at his high school.

**8M:** No, he gets a 100 hours a year path-finder hours which there is a young man at school S.D that does those hours with 8J, S is kind of early 20's and just a big teenager, just a big kid himself you know at that age and they go off and do boy stuff together.

**Interviewer:** Does he like that?

**8M:** He loves it, he loves it and because S lets him do more grown-up stuff I suppose; he will say 'oh I will let you do that but don't tell your mum!' but he will tell me anyway and 8J will tell me anyway!! ...

It is often a relief when a young person moves out of mainstream school if he cannot cope, and the immediate benefit is the emotional improvement in the child. Family 5 felt this when their son 5T moved to special school.

**5F:** Umm, and I mean, I think looking back, umm, what was nice about it was the fact that, umm, there was, unlike kind of before, there was such a confident manner of having a child like 5T within that environment, umm. They were extraordinarily positive, .. about everything that was happening, .... and the particular class teacher, ... was very very dedicated and then worked extremely hard.

For some families the school environment was never quite right but the young man really benefitted from his post-school placement. 7M felt that the time was not right for her son to be taught literacy and numeracy while he was of school age as he simply did not engage with it and did not understand the point of it.

**7F:** He has done more since he was 16 than he did at any of the other schools.

**7M:** I think 7N would only learn things on his terms, when he was willing, when he was interested. You had to put the input, is no good, you would be hitting your head against a brick wall. When 7N all of a sudden twigged what was interesting. All of a sudden he liked books

and they were interesting and you couldn't get enough of them, but you couldn't get them on his level. So we ended up making books.

Many of the children with autism spoke of the importance of friends in school and this clearly influenced their attitudes to their school experience. With 11A he described how his fellow peers at university who were also doing art were all a bit crazy. He said that he had had no problems making friends at university as everyone else was also eccentric.

**Interviewer:** Do you think some of them have got autism too?

**11A:** I don't know-there probably are one or two-in fact there's one I'm am positive have it and sometimes I pity the guy because he is very low functioning if you will. It's like none of us can stand the guy but we are like 'oh-we shouldn't be this way with him, but when you are sitting in a lecture room and someone mentions the name 'L' and he jumps up and says 'that's my name' and says the same thing every time and you think 'oh no!'. You were being so good until you started embarrassing yourself.

This again demonstrates a sophisticated level of insight into the symptoms in others who may also have problems on the autistic spectrum and may account for the amazing success that this young man has achieved' Some of which must be due to his change of fortunes when he moved out of mainstream school and into special school as a teenager.

11A's younger brother spoke somewhat sadly about the number of friends he had in his previous school which was a mainstream school. He said he had 33 friends then but only a few in his new school, and that his memories of his old primary school were the best memories he would ever have.

From the parents view point, the right type of school placement was a reason for rejoicing as is shown by the following extract from Family 4 M

**4M:** Yes, yeah, he is fine; he goes off on the bus in the morning and I mean most days the school diary says 'happy, happy, happy'...

In this family there are two very severely affected boys one of whom is completely non verbal at the age of 8. This young man has spent many days and even years being far from happy so it was with considerable delight that I heard this very positive report from school and this fact along with others has changed the focus of this family from being one of considerable stress, unhappiness and even Child Protection enquiries into one of buoyant coping.

Further positive comments about the education system were in the form of being able to plan ahead thanks to the fact that the autistic children had Statements of Special Educational Need. These were not only used to help procure appropriate placements at the next stage of education but also led to a boosting of self esteem and empowerment in the parent.

Family 2 who have autistic twins were already completely sure about High School placements six months before the twins were due to transfer which

led parents to be quite relaxed about a transition which usually causes considerable anxiety in parents of normal children. A discussion took place after the interviewer had asked about the twins visiting their new school and their mother was completely relaxed about the future in spite of a move from mainstream to a special high school. The twins had changed primary schools at one point because the parents did not feel the first one was meeting their needs, the second one was a great success.

The father of family 2 went on to talk about the youngest child 2S who attends two schools

**2F:** I think that's probably the best thing that we've ever done, was giving, was getting 2S that dual placement.

He explained that he was delighted that in the special school he could charge about quite a lot and was one of the more able bodied children, but that he benefitted from the normal school because he had the ability to socialise with normal children.

The author was impressed that during the time when she was in clinical practice there was a marked shift in the education department philosophy about the placement of autistic children. More imaginative placements were developed and many autistic children appeared to enjoy their schooling more as a result, which in turn led to greater happiness within the family.

Another source of support for parents was the professional advice given about possible placements. One nurse came in for particular praise. The

mother in Family 1 compared the difference between her first autistic child who was only diagnosed when he was fifteen and had had no support to the second boy who was diagnosed in primary school.

**1M:** ( referring to 1Ja) It was a totally different experience, you know, this time it is going to be ok as there is people there that you can talk to, people that understands. I got in touch with N (*specialist autism nurse*) and it was like 'wow'; there is all this support suddenly! Um, got him an IEP (*Individual education plan*) at school, he was put on to action plus, got him away from Primary school because that particular school are not special needs friendly at all, I have realised that now and started him off at high school.

She went on to describe all the support that was put in place at the high school.

The difference that one teacher can make is well known to any parent but it was particularly good to hear of one teacher who revolutionised the attitudes of this little girl, 1E

**1M:** Yes, and her teacher was a guy called P and he... the confidence he gave her, he told her she was a fantastic writer, you know all the things she was good at, you know he would use her as an example for the other kids she had never had that happen before ...'look what 1E has written, let me read this out to you'. And then she would come home with a huge smile, before she went there, terrible trouble getting her up in the mornings.

The mother also described what huge problems she had had getting the family ready for school each morning because 1E had been so slow that the whole family were often late getting to school and the mum would be told off by the staff for being late.

#### 5.5.4 Summary of findings on the educational experience

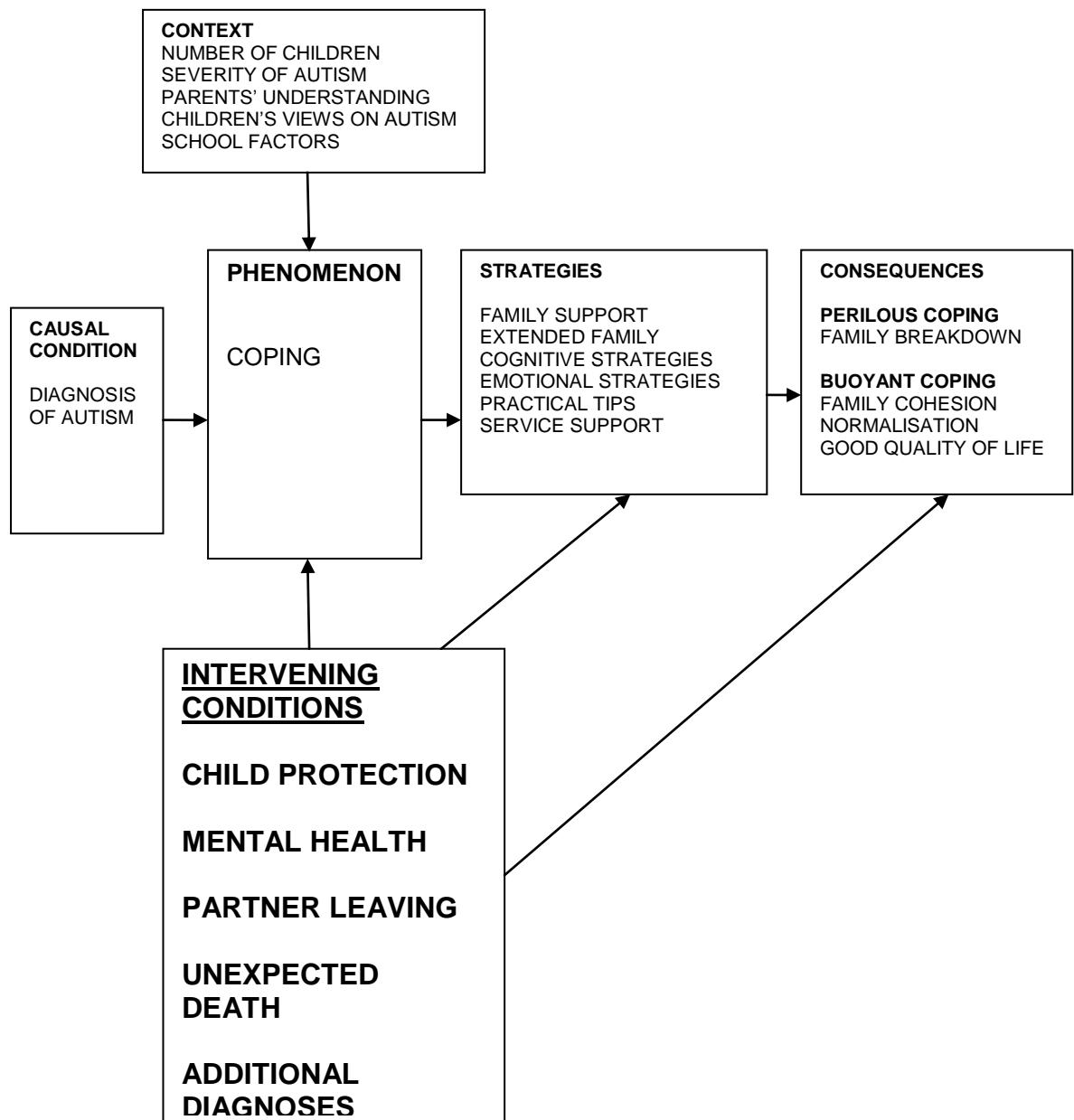
Two distinct themes arose from the analysis of all the quotations relating to schools and the educational experience. The first were several long and harassed discussions about disasters which had befallen children with autism in the school system. These difficult and painful experiences were undoubtedly associated with periods of stress and difficulty coping in all the families that experienced them. It is to be hoped that as schools become more familiar with children on the autistic spectrum these experiences will become increasingly rare; and also that more professionals will be better at assessing children with ASD and giving appropriate advice about the types of placement. More work is required to educate school aged children about the idiosyncrasies of their peers on the autistic spectrum so that the problem of bullying diminishes.

The opposite theme, that of the very positive school experience, had dramatic effects on the young people and families leading to a very happy atmosphere at home and buoyant coping. Often a change of school was necessary to allow this change to occur to child and family but sometimes the very fact that the school understood the nature of the problem was enough to completely change the child's outlook. The relief that parents felt when the right placement had been secured and the child would return home happy

everyday was a joy to hear about. It became obvious that each child required a different solution for their education and there was no magic package which would work for all children with autism. Sometimes very special packages had to be devised as is the case in Family 5 where two of the autistic children are at different independent schools of very differing types. When I asked the Father of Family 5 whether he felt that independent schools were the answer he said he felt fortunate that he had placed two of his children in an exceptionally caring independent school and that not many other schools of any type would be able to care for them as well. This convinced the researcher that time spent working out the right solution for each child is time spent well. It was also important that the different caring professionals worked together as a multi-disciplinary team to find the right solutions for each autistic child.

## CHAPTER SIX-RESULTS-Intervening Conditions

Figure 8 Strauss and Corbin paradigm adapted for this study highlighting intervening conditions



## 6.1 Child protection incidents

In this cohort of 11 families, five had been involved in Child Protection investigations at some time. This was a very high percentage and warrants further explanation and analysis. These types of intervention from the Children's Services department are extremely stressful for everyone concerned and tend to lead to a perilous coping situation, in the short term, and may have long term consequences which are damaging to family unity.

The researcher was only aware of the problem in one of the families at the time she was a clinician, and although one incident occurred after the time when the researcher had ended her clinical responsibility it is surprising that she was not contacted by the Social Services department as being a clinician who knew the family well. The five families where there were child protection concerns were:

Family 1, where the Father of the six children started to become violent towards the oldest autistic child;

Family 4, where the oldest autistic child was failing to thrive and this led to a full Child Protection Case conference;

Family 7 where the non autistic son made allegations against his Father;

Family 8 where the less severely autistic son made allegations against his Mother; and Family 11 where the Mother referred her teenage son to Social Services for his own safety but they misinterpreted this as a potential danger to the younger sister. In no cases did the child have to leave the family home, as a result of the investigations. There were no care proceedings in any of these cases.

There were no specific questions in the semi-structured interviews that asked about Child Safeguarding. All these incidents came up during the interviews as examples of very stressful periods in the long term happiness of the families concerned.

The two cases which are very significant for the development of this Grounded Theory are the two that concerned the less affected child making allegations against one or other parent as a way of drawing attention to themselves. In both cases it appeared that the boys felt that the more severely affected sibling was getting too much of the parent's attention and that the balance needed to be shifted towards themselves. Both boys ended up withdrawing the allegations and both sets of parents made adjustments to their parenting as a result of these incidents.

A brief description of each case will follow as the author believed that all these cases are important as examples of how an intervening condition could suddenly throw a stable family off balance. While it is obviously important that the welfare of the child is paramount and that such cases should be thoroughly investigated this study sheds light on an area which is not often discussed that of the high prevalence of Child safeguarding in families with disabled children.

In Family 4, the oldest son, 4G, was born very small for dates. He did not grow along the predicted lines on the growth chart even for a small child and one of the main reasons for this was his extraordinary diet. When the

researcher first investigated this, as a clinician, 4G had a diet which consisted solely of beef hula-hoops which are like circular crisps. He would also drink one brand of fruit drinks, and had the occasional dried cheese biscuit. It is quite surprising that this was compatible with any growth. There was a concern that as he was Learning Disabled he was not promoting brain growth and could be further damaging his brain function. He was extremely rigid about his eating and all attempts to increase his diet had failed. There was such a high level of concern from the dieticians and the clinical team that it was felt that a Child Protection investigation was necessary. As a result of this there were extra resources put in to try and improve his eating at home and at school. The result has been that his diet has increased a bit and he is no longer quite such a worry from this point of view. However although this intervention was done purely for the good of the child, the parents found the whole experience very difficult, and at the time made their coping even more perilous. It does suggest that the somewhat bureaucratic way that these issues are dealt with is not the most beneficial way of helping a family facing very challenging circumstances.

In Family 11 the second son 11T, who has Asperger's syndrome, has caused his Mother an enormous amount of worry as he had refused to go into school in his final year of compulsory schooling and had run away from home and spent some of the time living rough. This Mother contacted the Social Care department because he was still technically a child to ask for their help protecting him. When the social worker came to do the assessment she appeared to have misunderstood the Mother's concerns as she started a

Child Protection investigation on behalf of the baby sister. This had the result of causing even more hassle to a parent who was going through a very difficult spell. It also had the effect of reducing the mother's trust in the social care department which might be detrimental in the long term for the family.

The two cases referred to earlier in this section as contributing to the development of the Grounded Theory most were Family 7 and Family 8. In Family 7 the mother described how she had told the older brother 7Ma that his younger sibling had autism when she started telling me of a horrendous incident which had nearly torn the family apart. 7M had had a session with her oldest son explaining that 7N, the autistic brother would be at the same school as him but that he need not worry as would have his carer with him.

**7M:** 7Ma accused 7F (*Dad*) of hitting him; we had all kinds of trouble. He...kicked him and god knows what else what, we had health officers down and we had investigations. It was either 7Ma or 7F leaving the house and to make a decision of who was going to go where, because they couldn't have the two of them in the same house, so I actually ended up with 7Ma going to live with my mother in law who is just down the village for a week to give a bit of space, and it kind of sorted itself out. Then he admitted that 7F had never hit him, and they put it down to the fact that he was just crying for the attention.

**Interviewer:** Yes perhaps he felt 7N was getting all the attention.

**7M:** Yeah with 7N and 7L, then we went for a few sessions as a family to counselling and in the end it fizzled out and everything calmed down and it sort of went away, but I think we had about 6 months of that.

Table 10: 7M Description of Child Protection Incident

A very similar situation occurred in Family 8 where the less affected son accused the Mother of hitting him. She described the incident while saying that she had not yet had 8J diagnosed but this incident was one of the reasons she asked for an assessment from the Paediatrician:-

**8M:** I mean 8J got to the point where he was...telling people at school that at home he was neglected, you know and beaten and all these sorts of things...And when 8P got everything you know, I suppose because so many people came to see 8P and came to the house about 8P, and appointments for 8P and everything was 8P and nothing was 8J...I don't know; if that kind of made it worse for him maybe. But yeah, he did and then one occasion he told his new teacher on a move up day that he never wanted to come home, he never wanted to be near me again...um; blah, blah, blah...They called social services....it was horrible because it was P(*school*) and I used to work there. And the headmaster from there rang me at M (*school, where she was at work*) and said 'oh you need to come in' because I have had to ring social services...‘What!...what’s happened??’ And he said oh this is what 8J has written and it was awful, awful and social services were involved and um; then in the end 8J admitted to the social worker that he had said it, he had said that particular thing because I had told him off in the morning and he was really cross with me. But then when he done it, he...that was there...but then in the year 6 he transferred up to U School because we moved here; and he said something along the lines of that to the U School, and the U School rang social services, who rang the police who...and I am going 'he is saying this stuff again...he is lying!'

**Table 11: Child Protection Incident – 2**

It is apparent from the tumbling phrases used in this quotation that this Mother was still agitated about these incidents several years later. The effect on the family was to concentrate more on the child 8J and get a diagnosis

which may have gone some of the way to addressing the imbalance that this boy felt at the time which led to a perilous coping situation.

Throughout the interviews with the less affected and normal siblings these feelings of missing out on parental attention were not voiced at all. It could be postulated that most of the time these 'normal' siblings do have loving feelings towards their more disabled brothers and sisters but do not get the possibility of discussing the aggravations that must occur quite frequently and the negative feelings which are bottled up sometimes explode in unpredictable ways and the nearest person to blame is a parent. In both of these cases a pragmatic approach was taken by the investigating Child Care team as neither case progressed to a Child Protection Case conference. The message that arises from these cases is that child protection situations arise commonly in these families and that particular attention needs to be paid to the less affected or unaffected siblings, whose cries for help sometimes take a strident and upsetting turn.

## 6.2 Mental Health Factors

The second of the intervening factors that had a major impact on the families' coping abilities was added mental health problems in either the child or one of the parents. These were present in Family 1, where the father of the six children had some mental health problems which were never adequately diagnosed that led to one of the causes of the marriage breaking down.

In Family 4, the mother was diagnosed with depression, on more than one occasion, and although she was prescribed anti-depressants she never actually took them. One occasion was at a time when she was trying to come to terms with the diagnosis of autism. It is not clear whether the depression was the cause of the difficulties with coping or whether she was just struggling to cope with a very challenging son and this led to the depression. Either way there was a long period when the coping strategies in this family were extremely perilous.

In Family 8 it was one of the children who had added psychotic illness which led to severe strains on family functioning. The mother said that while she just had two autistic sons she could cope, but when one of them started becoming aggressive, unpredictably, as a teenager then the whole family framework became unstable. The other son also found that he disliked his brother because of the unpredictability of the abnormal behaviours occasioned by the psychotic episode. (This quotation is used again to emphasise the nature of the mental health of the sibling)

**8J:** It varies; it can start as quick as that.

**Interviewer:** And when that happens, what happens because I don't know exactly what might happen.

**8J:** Usually violence and gets annoyed about everything if he thinks I am spying on him or something.

**Interviewer:** Oh does he?

The same type of situation occurred in Family 10 where one of the autistic children developed some additional aggressive features which were thought

to be due to a new superadded mental health problem. This was the cause of a very perilous situation when the mother was so fraught that she did not look after herself for several days and ended up being admitted to hospital because she was dehydrated. In this situation it was vital that the Grandmother could move in after the Mother had come home from hospital. Without that support the boys probably could not have stayed at home.

**10M:** I have had a couple of break-downs...

**10M:** Yeah...I have been hospital just through exhaustion...I collapsed didn't I and was sent to hospital sort of thing... I think it was a combination of physically, mentally and emotionally drained and I wasn't eating and so-you know...

**10M:** I was going through a bad spell with 10L, the extent that I actually took the door off, erm 10A and 10L were constantly fighting-not physically fighting but...

**10GM:** I was going to say rephrase that...

**10M:** It's not physically fighting each other-they would be banging doors, making noises, screaming-the screaming was constant and I had a partner at the time as well...and of course we had been through a trauma as well of having a house fire...

It is hard to imagine just how difficult it must be for two very rigid and obsessive boys to have to move out of their home for several months, and this period was very perilous for this family. The story of the fire is told in table 12

**10M:** It was partially my fault, erm-there was a storm brewing and I put a candle at the top of the stairs-made sure it was safe and couldn't be knocked over which it was safe-I will say that to my dying day.

**GM10:** That was the thing though weren't it?

**M10:** It was safe as houses if you know what I mean-it was safe, knew it couldn't fall over because it was on a table and wasn't near curtains or near any furnishings...you know...

**M10:** Yes. Unfortunately I fell asleep and 10L was awake and he was at the stage of throwing things and I think 6+6 made 12 and...I woke up to a fire at the top of the stairs...

**M10:** Luckily my partner was here at the time that night-because he hadn't planned to stay that night and for some reason he said 'oh I will stay tonight' and I said ok-and um; lucky he did because we managed to...for some reason I woke up and I shouted-yelled at him and said 'house is on fire!'...so he grabbed 10L and I grabbed 10A and out we got. And then called the fire brigade and we had to move out of the house for 6 months because it was uninhabitable.

**Interviewer:** Goodness it was that bad was it?

**M10:** Yes because there was smoke and fire damage upstairs and water damage downstairs because it had burst all the heating system-so there was water all over the house.

**Interviewer:** But you're all safe...

**M10:** We're all safe but the house had to be pretty much refurbished.

Table 12: The Fire Story

The second son of Family 11 needed referral to a Child and Adolescent psychiatrist for mental health problems which caused him to opt out of school in his final year and leave home. A precise diagnosis has not been arrived at but his symptoms were somewhat bizarre with a craving to pierce himself as a form of self harming. The effect on the family was very serious as the

mother was so worried about child 2 that she had less energy left to cope with a new born premature baby and two other sons. From being a very positive individual, the mother had become anxious herself to the point where she was requiring medication for herself.

**11M:** ....he's quite self damaging, if that makes...

**11M:**.... I mean I miss him and I worry and I wake up in the night still worried where he is, what he's doing, but I've had to take such a step back because self preservation.

**11M:** Because I was in, I was constantly panicking. Where is he, it's raining, has he got a coat, is he warm, is he sitting outside in the rain, is he sleeping on the street, is he umm, not that he had to, because he had everything here.

**11M:** They tried at T (CAMH) but it got to the point where 11T refused to go.

**11M:** He probably had about four or five sessions. They put him on a medication.

**11M:** But all 11T wanted was a diagnosis.

**11M:** It wasn't like he, what's the name of it, what's wrong with me, why have I got this, why, you know.

**11M:** He wanted a reason for his behaviour and I kept trying to explain to him, your behaviour is you.....

**11M:** He just says oh, there's something wrong with me. He says I think I've got psychosis.

**11M:**.... she said he had depression.

This mother felt that the cause was a combination of taking cannabis and other substances and not really understanding his Asperger's syndrome.

Out of all the eleven families, five have had significant mental health difficulties which have led to periods of instability in the family and 'perilous coping'. It is perhaps not surprising to find such a high prevalence of depression in the parents as other authors have commented on this on several occasions<sup>2, 69, 72</sup> .What is more surprising is the prevalence of mental health problems among the young people with autism and the devastating effect this has on family coping. Searching the literature for the prevalence of mental health disorders in children with autism did not reveal many studies, but Emerson<sup>154</sup> studied children with an Intellectual disability and found that 14% of all children with a psychiatric disorder had an intellectual disability and there was a high prevalence amongst those with autism. He also noted that amongst children with intellectual disabilities there was a prevalence of 36% that had some form of psychiatric disorder.

### 6.3 Partner Leaving

Out of the eleven families in this cohort five had experienced partners leaving, leading on to divorce. In all cases the parents said that the autism was a part of the reason for the separation but not the crucial or only reason for the relationship breakdown. Various authors have studied the marital

quality in families with an autistic child. Kersh<sup>155</sup> showed that greater marital quality led to lower parenting stress. Ridal,<sup>156</sup> with a meta-analysis of marital adjustment in parents with children with disabilities found a much smaller effect on the marital relationship than earlier authors had predicted. Stoneman,<sup>157</sup> found that the females reported better marital adjustment if the fathers employed more problem-focused coping strategies. There is therefore perhaps some evidence that the divorce rates in families with autistic children are not quite as high as other authors had found.<sup>158</sup>

Although the problems caused by the separation were severe at the time and some parents commented that these times were particularly hard for them to cope with, the surprising finding was that in the longer term the fact that the parent was a single carer did not lead to difficulties coping. In fact, where the absent parent was able to have regular contact with the children, this led to the main carer having a period of respite or even being able to take a holiday without the children which could not have occurred if the two parents had remained together.

The following families all had experienced a partner split up. Family1 where the father of all six children left after the sixth child was born. The mother was clear that she found it easier to cope after he had left because the threat of violence was no longer present. She remains convinced that the father has many autistic traits and that his own difficulties made it harder for him to understand the needs of the children. Some contact is maintained with the children and relationships between the father and his children had improved

over the past year. The mother has a new partner now, who is a major source of support. He became involved in full knowledge of the autism diagnoses within the family.

The father in Family 8 had regular contact with the boys, which allowed the mother to have weekends by herself, without the children.

In Family 9 the mother was the parent to leave and this was because of mental health problems. The father is still in close touch with one of the maternal grandparents who acts as an additional safety net. Although the marriage breakdown has led to difficulties with the father having to give up work, he now has a very calm and organised approach to coping. His main concern about his ex- partner is that she can cause a lot of upset to the children by not keeping her word on visiting or contact times.

In Family 10 the father of the two boys left several years after the diagnoses and the mother feels that the autism was to blame to a certain extent. Various relatives in her family had had different disabilities and no one in his family had had anything like that, so the mother feels that the father blamed her for giving him less than perfect children. However the father still has regular contact with the boys in spite of living a long way away. When he visits it allows the mother to leave the boys with him in their own home for several hours and so she is able to have some time to herself. Later in the interview she admitted that the autism led to her spending too much time with the boys and not enough on her partner. She also

acknowledged that she did not feel that the relationship would have worked in the long term even if the boys had not had autism.

**10M:** I mean we split up on an amicable basis, it was a joint decision and we just felt that we had grown apart and you know; we just didn't want to live that life together anymore. As I say it's been amicable the whole way through erm; you know-as I say I have the house because I had the children, I was to keep the children and he would visit and it's always been.....(*amicable*)

The mother in Family 11 has had three partners during the life time of her children. Autism was certainly not the cause of the original relationship breakdown as it was before the first child was diagnosed, when her oldest was still a small baby. The second split up was also unrelated to autism and the current partner knows well what he has taken on as he has known the family for more than ten years. The mother admitted that she herself had a few autistic traits and this may have been a factor. She did not agree that her partner's leaving made coping worse in the medium or long term.

It appears that although there is a relatively high prevalence of marriage breakdowns in this study, the autism, in each case, was only an additional factor in the cause and not the main reason. The effect of the partner leaving led to short term perilous coping but had not affected coping in the longer term and in some families had actually led to enhanced coping.

In several of these families and in those families where the parents have remained married there were tensions in the relationships due to the fact that one partner came to a level of understanding and acceptance of the diagnosis much later than the other and in some case not at all. A failure to accept the diagnosis was therefore a significant reason for a period of perilous coping rather than the fact that the relationship was not working.

The percentage of marriages ending in divorce according to the Office of National statistics is 45%. This figure is an interpretation of the national statistics which are expressed as the number of divorces in each age group as opposed to the number of married people in each age group,<sup>159 160</sup> these figures show that the number of divorces is declining from a peak in 2002.

The percentage in this study is 45.45% or almost exactly the national average. Although some authors have argued that the rates of marital breakdown are higher in families with children with disabilities<sup>158</sup> in this study the families were not showing a higher rate of family breakdown than families without autistic children.

## 6.4 Unexpected deaths

The association between death and bereavement has been long established.<sup>160, 161</sup> It is therefore not surprising that when the families in this study experienced death, it had a significant effect on the family's coping ability.

Several of the families had experienced the death of a grandparent and in one family this had sadly occurred just before one of the interviews took place. In Family 4, this loss was perceived as quite a major blow to the family's coping strategies as this particular grandparent had been very supportive to the family. Although, as the grandparents did not live close by, the daily coping strategies were not altered, the pattern of visiting when on holiday had suddenly changed. In this case a novel solution was being worked on so that both grandfathers could together help support the family so that visits could continue.

In some families the death of a grandparent had taken place several years before the study and was acknowledged as a sadness that that particular area of support was no longer available, but the family had long since adapted to the loss.

The loss of a child is fortunately a rare event. The loss of two children in a road traffic accident could have been catastrophic for family cohesion especially as in one family in this study the two who died were the most normal of all the children. The parents had been relying on these two to provide support for the more disabled ones when the parents were older and less able to cope themselves. In this particular family's case they felt that they were able to go on coping because the mother had learnt survival strategies at a young age when her own Mother committed suicide. She told the researcher that you learn to take whatever life throws at you and you continue to manage for the sake of the children.

A conclusion that could be drawn from these experiences was that although the bereavement that follows a death in the family leads to a period of perilous coping while the family adjusts to their loss, in the longer term if the family is one who tends to rise above adversity, and possibly have an optimistic outlook on life, they do adapt to the new situation and some stronger bonds are developed which in the longer term can lead to greater family cohesion.

The role of grandparents in supporting families will be explored in more detail in the section on strategies.

#### 6.4 Additional diagnoses and co-morbidities

There were three main additional diagnoses that affected coping in this cohort. The first was epilepsy which affected three children in the eleven families. The prevalence of epilepsy in the general population is between 4 and 7 per 1000<sup>162</sup> but it is more common in childhood at about 1 in 100 children,<sup>163</sup> although the figures vary according to the methods of ascertainment of each study<sup>162</sup>. The estimated prevalence of epilepsy in children with autism is about 10%.<sup>56</sup> Out of this cohort of 27 autistic children, 3 had the additional diagnosis of epilepsy. The approximate prevalence of epilepsy in this study was therefore 11% or very close to the expected national prevalence in an autistic cohort. Obviously the very small sample size did not allow any true estimate of prevalence but the calculation was

made to show that this sample was not significantly different from any other group of children with autism.

It is worth commenting on the presentations of epilepsy in these three children as they did affect the family's coping to a significant extent.

In Family 9 the child had a seizure which led to the referral of the child (9S) to the paediatrician. That was the first symptom which had given the father any cause for concern as he felt that 9S was developing normally. In this case the seizure led to the diagnosis of ASD which then allowed the parent to start making preparations with the school for appropriate support which in turn led to improved coping.

In Family 7 the epilepsy presented when 7N was 8 years old. He had been diagnosed with autism when he was three and had been doing well, with support, at his local mainstream school and at home. One summer his behaviour changed just after the family returned from staying in a caravan for their summer holiday. 7N started to bite himself and become uncharacteristically difficult. The paediatrician wondered whether this change of behaviour was related to an upset in his normal routine staying away from home. His mother thought that that was unlikely as he had been to a caravan before. Repeated electro-encephalograms (EEGs) were normal and a sleep EEG was also normal but the clinician felt that epilepsy was the most likely diagnosis and decided to treat him as though he had a diagnosis of complex partial seizures with a drug called carbamazepine. Immediately his symptoms

improved and he returned to the happy compliant boy he had been before. Over time his EEG became more abnormal and the diagnosis of epilepsy was confirmed. He has been treated with a variety of different medications over the years and from time to time his epilepsy worsens .He has also had a trial of steroids suggested by the neurologists at Great Ormond Street Hospital who were doing a trial of steroids to see if possible cases of Landau-Kleffner Syndrome( a problem with language acquisition and epilepsy) responded by improving their ability to communicate. In 7 N's case it did not appear to have any benefit and in fact it increased his appetite enormously, with the result that he became obese and developed borderline diabetes. The steroids were therefore discontinued. The whole saga of his initial epilepsy diagnosis and the subsequent management added to the family's difficulties in coping and led to a period of perilous coping which has now been reversed with good symptom control.

In Family 10 one of the children developed epilepsy which compounded the difficulties of coping as it caused 10L to become more aggressive, this in turn meant there was a period of perilous coping.

The second added diagnosis which the author feels is more a co-morbidity as it occurs so commonly with both Asperger's syndrome, atypical autism, and pervasive development disorder (not otherwise specified) is dyspraxia (a problem with co-ordination of fine and large movements). In six families in this study dyspraxia was such a dominant feature of the symptoms displayed by the child that the difficulties that arose as a result of the dyspraxia were at

least as marked as the autistic features. In Family 3 both boys were dyspraxic with one more severely affected than the other. In Family 5 the child with atypical autism had dyspraxic problems which impeded school progress. In Family 7 the first diagnosis of the youngest sibling was dyspraxia and children in Families 10 and 11 had at least one child whose learning was compromised by difficulties with writing and coordination.

The motor symptoms associated with autism are often overlooked as the social and communication difficulties typically predominate but the bullying in school is often in part related to the clumsiness. By addressing some of the motor problems, the demeanour of the child can improve significantly which in turn helps the family to cope better. (Researcher's own observations when in practice)

A particularly distressing medical problem which occurs in a significant minority of children with autism is chronic constipation which is often associated with a level of faecal incontinence. This particular problem was not specifically enquired about in this study and therefore conclusions about its prevalence cannot be made. However the subject came up in at least three interviews as being a cause of major hassle to the parents. The relief which the families felt when the child had conquered the problem was very evident and made life easier for the whole family.

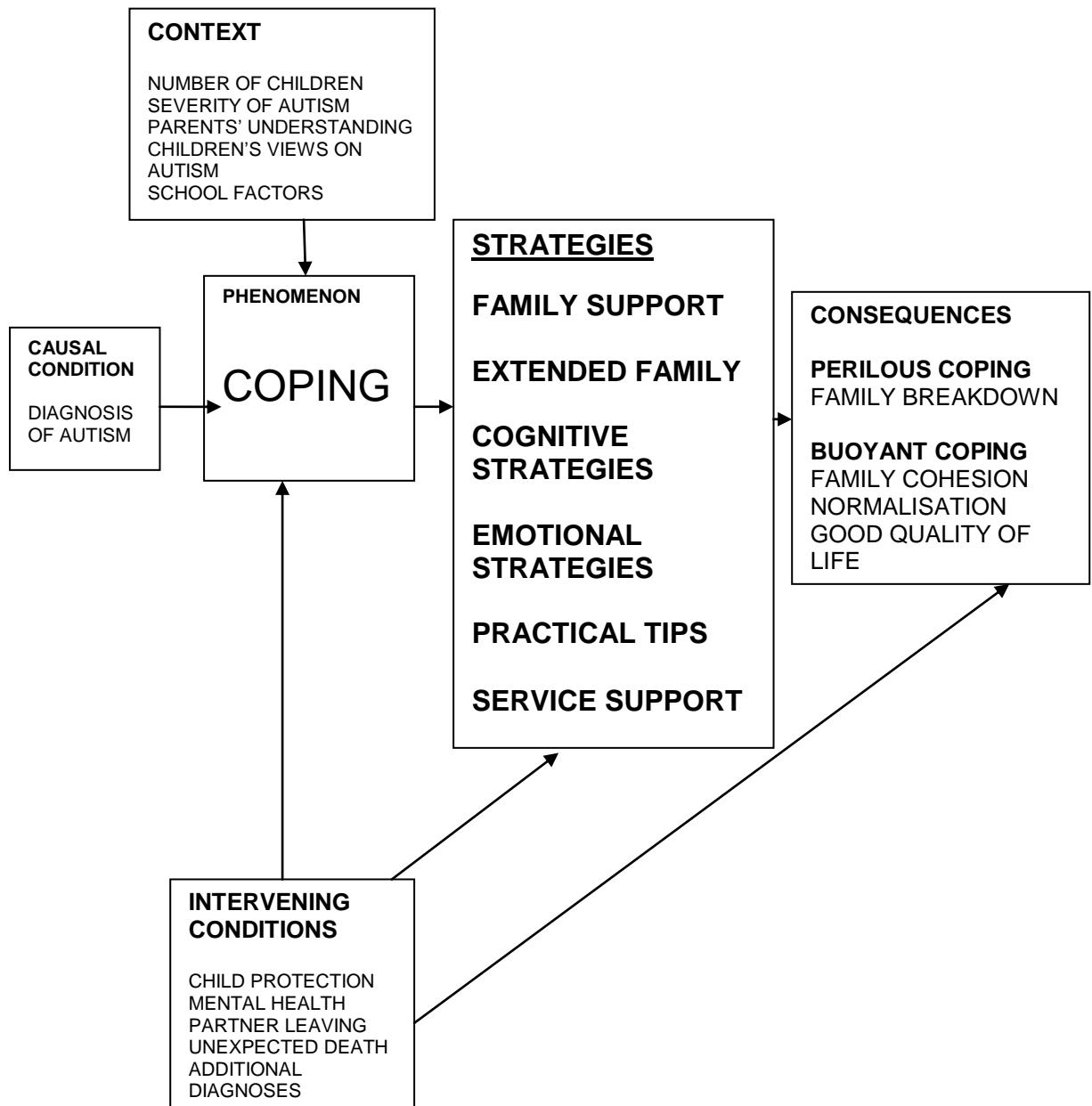
The other diagnosis which parents commented about was obsessive compulsive disorder (OCD). As part of the triad of impairment,<sup>6</sup> obsessive

behaviours are a component of the behavioural phenotype. The researcher felt that it was difficult to keep this as a separate diagnosis although sometimes an interviewee would refer to it as such.

Epilepsy, dyspraxia, chronic constipation and OCD all occur commonly in children with autism. It is important for the coping abilities of the families that paediatricians are alert to these problems so that by dealing with them early, they can prevent spells of perilous coping.

## CHAPTER SEVEN-RESULTS- Strategies to improve coping

Figure 9: Straus and Corbin paradigm adapted for this study highlighting Strategies



This section deals with the various strategies employed by the families to assist and improve coping. It is divided into the following subsections.

7.1 Family and extended family support, which particularly highlights the role of grandparents.

7.2 Emotional coping strategies

7.3 Cognitive coping strategies

7.4 Practical coping strategies

7.5 Service support and how it is viewed by families

7.6 The role of religion

## 7.1 Family and extended family Support

In this study the families were almost evenly divided between those who found the grandparents the most helpful form of support of all, and those who rarely saw the grandparents and did not find them of any help. It is useful to look at the reasons for these opposing views. This finding is in common with several authors who have examined the role of grandparents in families with a child with disability.<sup>164 165, 166</sup> This literature suggests that the reasons that grandparents do not engage in helping the parents are more to do with the emotional involvement of the grandparent with the mother, than the proximity of living close to the family with a child who is disabled.

There are many fewer papers specifically looking at the role of grandparents in families with a child with autism but at least one paper does address this issue.<sup>167</sup> These authors used a qualitative methodology to explore the

feelings of grandparents and found that the parental bond (protective bonding towards grandchild and adult child) was important. However it was sometimes difficult to support that role without undermining the role of the parent towards the autistic child, but grandparents were also an important source of information.

In six of the families in this study the grandparents were very involved, both giving practical support, in the form of child minding, overnight stays etc., and emotional support, particularly on the phone for those who lived far away. The types of support will be examined and later the reasons why some grandparents were not helpful will be discussed.

In Family 3, the maternal grandparents were particularly emotionally supportive in spite of living abroad because the diagnosis of 3D led the maternal grandfather to look at his own problems and realise that he also was on the autistic spectrum and so was his son (3M's brother) . This promoted family unity emotionally and although these grandparents could not be helpful in a practical way, the mother viewed them as being extremely important. In the case of 3F's parents, who live in Yorkshire, the family sees them every 3 months but only once has one of the children been to stay overnight.

For Family 4 the paternal grandmother had been a great support but had recently died and this was causing the family not only grief at her death, but also the loss of someone they could rely on to have the children when they

went to stay there. However the support from the 4M's point of view was mixed as paternal grandmother had never developed a deep understanding of autism and kept asking her daughter in law when 4G was going to speak.

**4M:** I can always remember her saying to me, you know, it is like I will try and help you as much with the kids....I mean it didn't always...she always used to ask me 'is 4G saying anything yet?' and it was like no! I think I would have told you...laughter. That would be a real event!

The two remaining grandfathers happen to live in the same town and a new way of helping the family was evolving while the interviews took place. Both grandfathers were going to team up and see if they could manage the children together.

**4F:** Oh yes, we have just been to stay with him for about 10 days. And in fact on, my sister was there as well; so one evening myself, my wife and my sister went out for a meal and we left the 2 boys with my dad and their other granddad 4M's dad...so the two Granddads' had the boys and there was no problem!! So um, yeah they are quite happy there and they keep doing their usual thing, and they went through their usual bedtime routine and there was no problem.

The paternal grandparents were the more supportive in Family 7. The family also had support in the early days from the maternal great grandparents although the maternal grandparents were not thought to be very helpful because they worked and did not have much time for the grandchildren.

The paternal grandmother in Family 9 was a regular support to her son.

**9F:** Yeah I mean .....every other weekend my mum comes and watches them for a couple of nights so I normally get a Friday or Saturday depending if she is going to Bridge classes...or goes to bingo!

**Interviewer:** So they get on quite well with their Grandma?

**9F:** Oh they love her yeah. That's my mum.

In some ways Family 10 was the exceptional family in terms of grandparent support as the maternal grandmother was completely part of the household and daily routine, coming in at least twice a day and doing a significant part of the daily caring such as feeding, dressing and other activities. This had even been recognised by the authorities, by having her as an official carer paid for with direct payments from social services. She was also the back up if ever there was a crisis such as when the mother had to go in to hospital; the grandmother came and lived at the house for a week. The interviewer asked if this was ever too much for both parties and they both said that they had grown emotionally much closer to each other through the joint caring. If they ever had a disagreement it was always aired and soon mended.

Other members of the extended family all support 10M which shows what a very close knit family this is and helps to prove the findings of Findler.<sup>164</sup>

10M summed up her dependence on 10GM in this way

**10M:** I could not have more support if I tried.

**10M:** Mother has been there, I wouldn't know, I would not still have the boys if it wasn't for Mum.

**Interviewer:** What do you think would have happened to them?

**10M:** I wouldn't have been able to cope, because although the boys..we live in the same house-they do integrate sometimes, but they almost live separate lives. Um; they don't like doing the same thing-they won't compromise on what the other wants to do...

**Interviewer:** ..... So you would say that the most important thing really is to have a really good Nan?

**10M:** It is! It's an essential! ...

**10M:** ...it's an essential and to make the best of everything, enjoy every moment.

**10GM:** Yes, we laugh a lot you know....

**Interviewer:** Good; and the boys laugh too?

**10GM:** Yes they do.

**10M:** I can honestly say with my hand on my heart that my boys have a wonderful quality of life.

Continuing the theme of helpful grandparents, in Family 11 the Mother lived with maternal grandmother when her first son was born and that has meant that maternal grandmother has a very close bond with that particular child. She also provided financial help to the family throughout the years and although 11M feels she is not much support in other ways she will always provide support if it is requested.11M felt that she disappointed her own mother and that is possibly the reason why there is not a closer emotional bond between mother and grandmother.

A novel solution to the lack of grandparent support was devised by Family 5. They live in a large house and have filled it with lodgers. The lodgers not only help the family financially but are also expected to help with the caring. This even extends to looking after the most severely affected child when the family go abroad. Although both sets of grandparents are alive neither lives very near the family and none of them are close to their children emotionally. Family 5 admits that there are times that they would like to have the house to themselves but the benefits outweigh the disadvantages.

Several reasons were given by the remaining five families who did not have any helpful grandparent support. Many of them said they would have benefitted from such support and when compared to the six families discussed above it is easy to conclude that they are at a significant disadvantage. In many cases the grandparents had died. In Family 6 this was so for all the grandparents. The more usual reason given was that the mother did not really get on with the maternal grandmother, or that they were not close emotionally, and this concurs with the literature on grandparent support.<sup>164</sup> Geography was given as the reason for not seeing more of the grandparents but as has been shown in Family 3, even if the grandparents live on the far side of the world, they can still provide emotional support if the relationship with the parent is a strong one.

Some parents felt that the reason they did not engage with their grandchildren was due to fear and lack of knowledge about the condition. In Family 2 the parents would have liked more engagement as was enjoyed by

mother's sister but the grandparents were too frightened of the boys to have them on their own. Another reason was that some parents felt that the grandparents felt threatened by their grandchildren. In the case of Family 8 there was a real risk of violence but in most families it was their lack of understanding about why behaviours arose that seems to have been a barrier. Embarrassment of the children's behaviour in public was a reason given by several parents. In Family 8, the mother gave an example of her son planning to buy a toy at a shop and when the item was not available he ran off leaving the grandparent very frightened.

Another reason was that some grandparents were concerned about their good genetic material not having found its way into the grandchildren. Although it was not expressed in those words it was clear that some parents felt they had let their own parents down by producing disabled children and this had led to a rift in the family.

Where there was a lack of support from grandparents, the family itself was the main support. Parents would view older siblings as being supportive to them and in the case of Family 6 the parents felt that without their two oldest children they might not have been able to keep the most severely affected child within the family. In the two largest families where each had six children, the siblings were definitely viewed as a significant support for the autistic children but also for the parents.

## Conclusion

Grandparents were perceived by a majority of families as being the single most helpful form of support to enable them to cope better. A lack of emotional bonding, particularly with the maternal grandparents was the main reason why this did not happen, but a significant factor was that there was a lack of information for the grandparents about autism and this led to fear, anxiety, embarrassment and agitation which prevented a closer and more supportive bond forming. This message is extremely important as it is an area which Health or Social Care could address to the benefit of all families and their coping strategies.

In larger families the siblings of the autistic children were a source of support not only to their disabled siblings but also to the parents.

### **7.2 Emotional coping strategies**

Although there were no specific questions about how families used their emotions to help them cope, a number of positive and negative emotions were discussed which contributed to the strategies employed in families to promote better coping.

At the time of the diagnosis, the overwhelming emotion that was expressed was that of relief. This has been referred to in an earlier section about reactions to the diagnosis. The fact that there was a definite reason for the child's behaviour and delayed development enabled the parents to grieve for

the child they thought they had but found they did not have. This finding resonates with Boushey's study.<sup>100</sup> This process of grieving took different forms in different families. For example in Family 10 there was such a sense of relief that there was no initial grieving but the Mother described how she is now grieving when the boys are adolescent for the lives that they will never enjoy. Others who had little warning of what the diagnosis might be went through the typical stages of grief ,as first described by Kubler-Ross,<sup>168</sup> shortly after the diagnosis was given. These consisted of feeling numb then anger and denial and disbelief through to a gradual acceptance and finally a rejoicing in the delight of the children as they are. This was particularly marked in Family 2, who demonstrated that they had completely reached the acceptance stage.

**2F:** ....I think now if someone was to be able to flick the switch and make 2T and 2E normal...

**2F:** ...I think that would take a lot away from the house to be quite fair with you.

**2F:** You know we've learnt to live and enjoy their personalities as they are.

**2F:** Like I say, touching, going back on the personalities of 2T and 2E, you know, their personalities have grown on us and, you know, they're in our hearts now, you know. We wouldn't...

**Interviewer:** You wouldn't want to change them, would you?

**2M:** No.

This section will examine emotions that emerged in a more reflexive way by families who discussed the feelings they now had about having a family with at least two autistic children.

Several families said that having children with autism made them more tolerant as a family. In families 1, 3 and 7 they each said that the family had been strengthened by the experience. Family 8 and Family 9 talked about increasing closeness developing as a family the longer they lived with autism. Several of them said that the extended family had become very supporting. As the relatives became more accepting of the diagnosis and the behaviours, they felt that the feelings of love had increased and that extended family members had become less judgemental. Many mentioned that the positive emotions outweighed the negative as time progressed. Many of the non autistic children mentioned how happy their autistic siblings were and that they were proud of the achievements of their disabled siblings. An increasing sense of warmth within the family was described in Family 6 and several others. The impression gained by the answers to the question "Do you think your family has been strengthened by the experience of having autistic children" was almost universally positive although in one family ( Family 8) the two boys felt very negative about each other and did not have many positive emotions at all. This was the exceptional case where very few positive emotions were expressed by the boys although the parent generally had evolved a more positive outlook through various cognitive strategies which perhaps the boys were not yet capable of.

An almost equal number of negative emotions were discussed at different parts of the interviews. It is important to look at these as they had to be dealt with in order to improve coping.

In Family 1 there was a discussion about the resentment that the children felt towards their father for leaving the family. The mother had to respond to this through her own inner strength but she admits that at times this crumbled which led to a perilous coping situation. When help was requested from Social Services the dominant feeling was that of being stigmatised for having asked for help. This mother described 'self reliance overload'. Worry and anxiety about the future were mentioned by several parents although to cope with this several adopted a pragmatic approach of staying in the present.

Frustration was a common emotion particularly applied to the dealings with Educational Authorities when they appeared not to understand about autism. The main way of reducing this was thought, by the parents, to be better information for schools about the autistic spectrum.

Many of the siblings found their autistic brothers very annoying at times, but this was tempered with positive comments about their achievements. It is hardly surprising that a twelve year old boy gets annoyed that he has to help his ten year old brother with toileting. The parents on the other hand are thrilled that the ten year old has at last shown some awareness of the need to use the toilet so they viewed this as a positive step forwards.

Some of the siblings were very diffident about discussing their sibling's autism with their peers in school. One said that he did not mention it as he was shy about it. Some said that they were embarrassed by their siblings but this was countered in one family by a brother saying in a very forthright way that anyone who did not like his brother's autism would not be a friend of his. In Family 8 both brothers discussed feeling agitated and anxious and having to deal with outbreaks of rage.

Some parents admitted that they expended so much emotional energy on the autistic children that they neglected the emotional needs of the normal offspring. As has been discussed in the section on child protection issues this problem manifested itself in attention seeking behaviours on the part of the non autistic child by contacting Social Services and claiming that they had been abused. In two families the young people themselves developed the coping strategy of denying that they had an autistic spectrum disorder as a way of appearing to be more normal. In one case this had led to problems in the workplace which the father had had to sort out. Both sets of parents in these families felt it would be more helpful to the young person to acknowledge their disability but this was not the message from the interviews of the teenagers.

In common with several authors who have written about emotional coping <sup>74</sup>, <sup>88, 169</sup> the positive emotions that arose from caring for autistic children outweighed the negative ones. Finding ways of dealing with the negative emotions in itself led to a strengthening of the family cohesion and more

buoyant coping. However at the time of coping with violence, depression, anger, non acceptance and fear the situation in some families was clearly quite perilous.

### 7.3 Cognitive Coping Strategies.

The emotional coping discussed in the previous section was often the trigger for families to develop cognitive approaches to coping. In Family 1 the mother had been through some periods of depression and she had evolved a philosophy of 'if you can't change it leave it'. She had been helped to arrive at this position by her partner who was much more laid back than she was. He had also advised her to keep a sense of humour. At times when she was very low she had raised herself up by saying "what are the choices? The kids have only got me." The challenges of having two severely autistic children had made Family 4 more capable of coping with general aspects of life and they felt stronger emotionally as a result.

Other families had learnt to live with uncertainty. Family 5 admitted that the learning that is needed about autism goes on indefinitely. New problems arise at each stage and you never know enough at be certain about what is going to happen or how best to deal with it.

**5F:** And I think there can be a sort of panic maybe with the beginning bits until you realise that this sort of thing does happen and in other ways sort of you can still have a reasonable life.

**5M:** So, in a way, it's the unknown. We don't know. We have a sort of vague idea, don't we? I mean we're thinking of getting a house with an

annex so that we can, so that 5T can be in the annex with some, you know, care.

They admitted that they never got bored because there were always new challenges. Their way of dealing with the challenges was to 'talk loads' as a couple and with the children. They were always on the look out to improve coping through using opportunities as they presented, such as finding a child minder who then became a lodger leading to mutual support.

**5F:** ... pretty much everything that's happened, umm, has happened for a significant reason and I think there's a sort of awareness that we're all having to kind of work pretty hard to do what we, umm, need to do for each other, and I think that, umm, that's sort of a binding thing.

The family's motto was 'Aim for the sky' for all their children. This had caused them to pursue educational opportunities which were extremely unusual.

In Family 8 the mother had made a conscious decision to use her work to divert the more painful emotions she was confronting at home. She used this in two ways. Firstly, as a diversion from home and, secondly, she used her colleagues as her main source of support and advice.

Over time parents had used their cognitive approaches to become more realistic. The mother in Family 10 said it had taken her several years to realise she was not 'supermum' and as a result had become more realistic

and allowed herself to ask for help and enjoy the time she had when the boys were not at home. One family said everything will be fine because we have made it fine. As part of that process another family said that they had learnt to lower their pride.

When thinking about the future most families were quite philosophical. Some had planned a long way ahead by buying property that could be converted into flats for the disabled children when the parents were no longer around. The father in Family 6 described this as 'completing the cycle'. The pragmatism of many families was a recurrent theme. Several said that there was not much point in too much navel gazing, and that the choices were limited because the 'kids have only got me.' Some had 'put up a wall' to help them cope with professionals. Several commented on the autism leading them to greater self realisation. Another parent realised that she threw herself into things as a way of avoiding confronting some of the more painful problems at home. Family 7's father took a very realistic view about problems and how they dealt with them.

**7F:** If it wasn't for him being how he is, I don't think if he was normal what we would do to be quite honest...laughs. He creates problems, and half the thing of getting the problems is getting over them, and once you do it is a relief and you just wait for the next one to pop up! You just hope there aren't too many in the line at the same time!

But the ultimate comment on pragmatism belongs to the mother in Family 11 who said it had taken her a long time to realise that it is 'OK not to cope.' In

Family 4 the mother acknowledged that it was all right to accept that things are a bit crazy a lot of the time. In the end love is the way forward. The last word on this was from Family 11.

**11M:** I mean my only thing is, you know, you get given what you're given and you just.....and you just love them and that's it.

The main strategies of a cognitive nature were therefore self realisation, pragmatism, employing a sense of humour and not being too introspective. All these led to improved coping. Erecting barriers as a way of avoiding reality was only helpful in the short term and might have led to perilous coping if it had been the only approach.

#### 7.4 Practical or problem-focused Coping Strategies

The universal practical advice given by everyone in this sample was that families need to develop their own routines and that life for the children with autism and therefore for the family as well was much happier when a routine had been established. This applied whether the family had employed a good structure prior to the diagnosis of autism or not. In fact some families commented that they had been pretty scatty before they had a child with autism, but a combination of necessity and the children themselves caused them to change and become more organised. However, routines were also deliberately altered in some families in order to prevent an obsession developing. Family 6 were very insistent that they had reduced 6D's obsessive tendencies by always changing a routine before it became a habit.

As part of this structure some families were very keen on making lists. These had several advantages. If a list was created for the order in which clothes were put on, for example, then the mother no longer had to nag the child because the list could be ticked. Similarly several families used lists to remind the older more independent young people what to do in certain situations, for example at the airport you need passport, ticket and money. Modern technology has helped with lists as reminders as these could be texted to the person with Asperger's at the crucial moment.

Another useful tool was reward charts which were used by many families to achieve a particular behavioural goal. This was used particularly in toilet training but also to break a particular obsession.

By being structured and organised families found that they could predict various pitfalls and thus reduce troublesome behaviours. An example of this was in Family 7. At one particular time 7N developed a phobia for traffic lights. If the family car had to stop at traffic lights then he would have a screaming fit. The parents got expert at devising routes which avoided traffic lights and thus prevented an unpleasant car journey.

A second group of practical suggestions was visual clues. In some families, these took the form of pictures placed on objects to get the child with autism to identify the object, and thus improve naming and comprehension. Several families had benefitted from the use of the Picture Exchange Communication System (PECS).<sup>170</sup> This is a system of getting the child to exchange the

correct picture for the object or reward that he wants. It has been shown to be an effective way, not only of improving verbalisation, but also of improving behaviour.<sup>171</sup> This was described by many as being the way that they had initiated the process of getting a non verbal child to communicate. The mother in Family 8 had been on a course to learn the 'Treatment and Education of Autistic and Communication related handicapped Children' TEACCH<sup>172, 173</sup> method of education which relies on visual clues to prompt the child about the next activity. This method has been used in schools for decades to promote concentration and enable the child to order their day using visual cues.

Other families used visual calendars as a way of conveying the meaning of time. However one autistic teenager told the researcher that even with the calendar and all the days marked on it till Easter his brain still could not wait that long. In Family 2 they always used a calendar to show how many nights were left before they went on holiday. This prevented them being asked every day how many days it was until they went away.

The use of restraints in young children was described by more than one family. Having a harness to prevent the child with autism from running into the road, long after the age when most children would no longer need one. The use of a large buggy to improve transportation and for the older children the mobility component of the disability living allowance which enabled parents to have a car, and the disability disc which enabled parents to park near to their chosen destination.

The use of certain play activities, which improved the acquisition of language, such as a dolls' house even for boys, was highly rated by some parents.

Praise was given to the services of the specialist autism nurses, the Child Development Centre nurse, an occasional educational psychologist, several teachers and one particular social worker. All these offered practical and emotional support to families.

Some families commented on their friends as being of particular practical help, others mentioned colleagues who would come in if there was a crisis.

As a way of coping on a daily basis some families discussed the need to have time out and 'time for me'. In Family 4 the mother said how much she looked forward to her bath after the children had gone to sleep. She would set up her candles and have a book and really relax. Others used a bottle of wine as their escape. Pinot Grigio was named by more than one family but this was probably a metaphoric description rather than a specific prescription.

All families were thirsty for knowledge about autism and its management and were keen to make sure that sources of information were more readily available than they had been for them at the time of diagnosis. They were critical of too much knowledge being fed to them at the wrong times and although the Internet has provided a rich source of information for parents they all felt that it was most helpful to speak to professionals about strategies

rather than depending on electronic information. But they wanted their professionals to be well informed and be able to convey just the right amount of information at the appropriate time.

Some families had benefitted from adaptations to their home which had allowed an extra room to be built on so that autistic children did not have to share a room with non autistic siblings. This made a significant difference to some families. These physical changes were only possible once a family had had a full assessment from the occupational health department of Social Services and a means test of the family's finances. Frequently this was a very long and drawn out process but when it was successful the family benefitted enormously.

The final key message that almost all the parents were keen to convey was that they see their children as normal children with a few problems and they want their children to be treated as normal as much as possible. In particular they do not want to be pitied by the non autistic world as they all believed they have wonderful children. This conveyed to the researcher that those who expressed these opinions had achieved a reframing of the view of disability in their family and had arrived at a lasting resilience.

## 7.5 Use of provided services

There were strong views expressed about the statutory services both positive and negative. The positive help obtained from various different services was

conducive to better coping and similarly if the services provoked irritation and frustration a period of perilous coping could ensue. These reactions will be summarised under four headings. The use of health services including doctors, nurses, speech therapists, occupational therapists and others; the use of the Educational Services including teachers, and educational psychologists; the use of Children's Services, particularly social care; and finally the use of services provided by the voluntary sector.

### **Health Services**

The description of doctors involved in the care of autistic children is possibly biased in view of the previous relationship of the researcher with some of the families. The comments were therefore only analysed if the families were talking about other medical professionals, and not the researcher. The access to an initial assessment had been difficult for two families (Family 1 and Family 6). In Family 1 the most helpful health professional had been an occupational therapist based in the Child and Adolescent Mental Health unit. She had recognised the nature of the young person's problems and had treated him appropriately but the mother did not get a formal diagnosis until her son was sixteen.1M described the complete contrast between the struggle she had trying to get a doctor to see her older son and the joy of having the second one assessed and the diagnosis leading to the provision of services. Other parents were universally positive about the role of the paediatricians involved in their care but less complimentary about GPs who they felt often did not have enough knowledge about the condition.

Specialist nurses were singled out for praise. In the study area there were nurses who provided follow up care and advice which was available on the phone. This was seen as extremely helpful provided the nurse responded in a timely manner. One nurse received praise for the help she had given with the application forms for Disability Living Allowance.

**5F:** The skills involved for supporting families, you know, like ours, isn't a question of someone carrying around in their head, sort of, actual information, you need, ...to be quite flexible and creative with your thinking,.... and that,... it has to be good, it has to be achievable, it has to be realistic, it has to be something that can actually happen.

Speech therapy received mixed approval. Family 7 employed their own private speech therapist and felt that much of the progress their son made with language development was due to her help and guidance. The NHS provided service was the subject of much criticism, mainly on account of the paucity of the provision, not due to the quality of the therapists. Many families were extremely frustrated that the level of therapy fell far short of that recommended in the Statement of Special Educational Need.

**10M:** That has been awful all the way through-I have fought, and fought, and fought and there has been times when there has not been a speech therapist at all and I've written to the authorities and said look, you know it's on his statement that he is meant to be getting speech therapy...it's a legal document and you're breaking the law by not providing that service for him.

Speech therapists also ran the 'Early Birds'<sup>174</sup> programme which was a parent instruction course run by therapists who had all undergone extra training with the National Autistic Society. This course was organised to run over 8-10 weeks with a group of parents who had had a child diagnosed with autism within the last six months. To be accepted on the course, one of the parents had to agree to attend all the sessions, and they had to have a recently diagnosed pre-school child. The sessions were also open to the other parent or other close relative. The majority of families had found this course helpful, particularly for the guidance on behaviour management.

This quote is typical:

**3M:** Yes, I did. I used the 'Early Birds'...

**3M:** And that was fantastic.

**3M:** Yeah. It helped a lot. It was very good...they gave me a lot of ideas and it was nice to see other parents...

The criticisms came from families who had had the diagnosis for some time before attending the course. They felt that the course was somewhat demeaning as it assumed little prior knowledge.

**Interviewer:** How did you find Early Birds?

**5M:** Umm, not, not too amazing. I found it was going over things I'd already gone over.

**Interviewer:** So you'd already read about it, all that sort of stuff?

**5M:** Yes.

**5F:** It was inflexible when you were...

**5M:** It was very patronising in a way...

A related course, Early Birds Plus<sup>174</sup> which was for children diagnosed slightly later, who were about to attend a formal educational setting, was also much praised and had the advantage that the teaching assistant for the autistic child could attend as well as the parent. The negative comments came from families who admitted that they disliked being in groups and found other parent's problems to be somewhat depressing. All the families who had attended 'Early Birds' felt that grandparents should have the opportunity to have a similar course for them, so that they could understand why the parents were using the behavioural techniques that they had been taught.

There were two other Health Service organisations that were generally helpful. Both these were new services developed by the Child and Adolescent Mental Health service (CAMH) to support children with learning disabilities and challenging behaviour. The families tended to rate these as helpful or not depending on the particular professional they were working with. Clinical psychologists and nurses were praised for their help with behaviour management. But one particular psychologist caused extreme annoyance by saying that she could not assess one boy because his behaviour was too bad on that particular day. The mother felt that this was completely out of order as that was the reason she had taken her son to see this professional. She never went back again.

In this sample there were no parents who commented on other therapists such as physiotherapists largely because in this cohort of children they rarely

saw physiotherapists after the initial assessment for autism. Health visitors were mentioned as being supportive at the beginning before a child was diagnosed but in the study area they had less contact with parents after the diagnosis when the support role was taken on by the specialist autism nurse.

## **Education**

Various teaching professionals were the cause of negative comments particularly when they did not believe parents and did not have a good understanding of the autistic spectrum. Children having a bad time at school were a major cause of parental discontent and often precipitated a period of perilous coping. Sometimes this was only resolved by the child being removed from a particular school. One parent commented that the perilous period was ended by the child being accepted by a different school.

The converse was so with teachers seen as the saviour of a child once they understood a child and could look at their strengths and not at the autism. Parents often felt that they had insufficient information on how the system worked. Some parents said that schools should give children with special needs a higher priority in terms of placement and support but that this was at odds with the school inspection system. Many felt that schools should be more adaptable.

Educational psychologists were mainly vilified with one notable exception. Their main task, as perceived by the parents, was to perform an assessment of the child's capabilities in order to advise on appropriate educational

placements. Several parents felt that their children were wrongly labelled as being learning disabled because the child was assessed on a bad day. A negative report from a specialist had the power to infuriate parents and lead to a period of perilous coping as their hopes for a placement were dashed.

There was much praise for teaching assistants who supported the child with autism in the mainstream class. Family 9 were particularly pleased that two part-time assistants had been appointed so that their son did not get too dependent on one individual.

### **Social Care**

Those families who were able to access Children's Services in the form of Social Care were universally pleased with the Respite Care scheme. This took various forms, depending on which local authority the family lived in.

The threshold for having a social worker for a disabled child was high in both counties in the study area. Once a family had a social worker there was the possibility of respite care provided either in the home, in another family's home, or children's home provided by the local authority.

The Direct Payments scheme was introduced some years ago in one of the study counties, and Family 2 were amongst the earliest of the families to benefit from the scheme. Under the scheme, a social worker would determine how many hours were appropriate for the family for respite, and a sum of money was then given to the family to purchase the child minding care, appointing their own carers.

The only criticism any families made of this scheme, which several said was a major life line, was that there was not enough of it. Some families were very diffident about accepting respite care while others did not see themselves as 'Social Service' families. In Family 4 when one particular crisis arose, they had a new social worker who quadrupled their respite care. The mother commented somewhat ruefully that she wished she had requested a higher level of help several years earlier.

The Children's Services were praised to the sky when a parent had a social worker whom they trusted. One individual had supported Family 10 for years and they described her as their rock. Other families were appreciative of the respite care arrangements which made their life more tolerable, but some wondered why the level of support seemed variable and even commented that they wished they had admitted they were not coping earlier because when they did they suddenly had an increase in their respite hours. The negative comments came from families who had been denied a service which was largely due to the fact that their child or children were not thought to be severe enough, to receive a service. This was a resource problem. A common feeling that applied to all families was the sense that they did not want to ask social care for help, at first, as they saw themselves as not coping and that was a sentiment they could not bear.

The Disability Living Allowance (DLA) was praised by all who received it. This was especially so for parents who had the mobility component and were

provided with a vehicle. For families who were struggling with daily routines it was helpful to have a car which was insured and tested regularly without the parents having to organise this.

### **The Voluntary sector**

The voluntary sector provided various types of service which the parents found extremely helpful. Firstly, the National Autistic Society was a source of helpful information and they also provided welfare officers, who visited parents following a diagnosis, to offer support.

Secondly, there was a unique resource available in the study area which parents could be referred to for foster care or help about behaviour problems in school or home. This organisation was staffed by a clinical psychologist, speech therapist and occupational therapist and also had its own specialist school. Some children in this sample had had help from this organisation and all families who had experience of this organisation were complimentary. They said that the help that they had received from these professionals was amongst the most helpful resource they were aware of. The only problem was that as the organisation was run independently it had to charge for its services and sometimes the Health Authority was reluctant to allow families to be referred.

Another source of help came from the Armed Services Welfare Organisation that provided volunteers who could come and play with children of Service personnel.

In summary, the families appreciated services that were designed to support them particularly if the professionals involved were caring, well informed, not patronising and available when needed. The attitude of the support worker appeared to be more important than the qualifications or professional training and background. The main irritants to families were bureaucracy, delay and artificial barriers caused by a lack of resources. It was salutary to note that the families did not perceive the statutory or voluntary services to be the most important source of help and support but rather their own families and extended family members.

## 7.6 Religion

The adult participants were asked a supplementary question about the role religion played in their lives and whether they used their faith as a support in difficult times. The overwhelming view was that religion played no part in their lives at all and was not part of any coping strategy. This view was in complete contrast to Gray<sup>87</sup> who suggested that in Australia, religion became an increasingly important part of the emotional coping strategies of families of older autistic children. Other authors have studied the role of emotion in religious coping<sup>175</sup> and King<sup>176</sup> found that the role of hope which was enhanced by religious belief was a strong coping factor. These authors did not suggest that religion played little or no part in the lives of those studied but the situation in the UK may be very different from other countries.

There were only two families who had significant comments about religion.

The other families said that religion was not part of their lives. In Family 6 the mother said that her religious beliefs were an important part of what sustained her from day to day. These beliefs were essentially Christian although she did not attend a church and her husband disagreed with her about religion.

In Family 7 one of the parents had been brought up as a Roman Catholic, but neither of the parents or the children were church attendees. An official from the Catholic Church had contacted the family recently to enquire why 7N had not been confirmed. This had the effect of irritating the mother enormously as she told them that he had no concept about religion and it was entirely inappropriate. She also wondered why they were so interested in the most disabled member of the family and had not asked about her other two sons neither of whom had been confirmed but both of whom could have understood about religion and had chosen not to participate. The effect of this contact was to send the family further away from religion than it had been before.

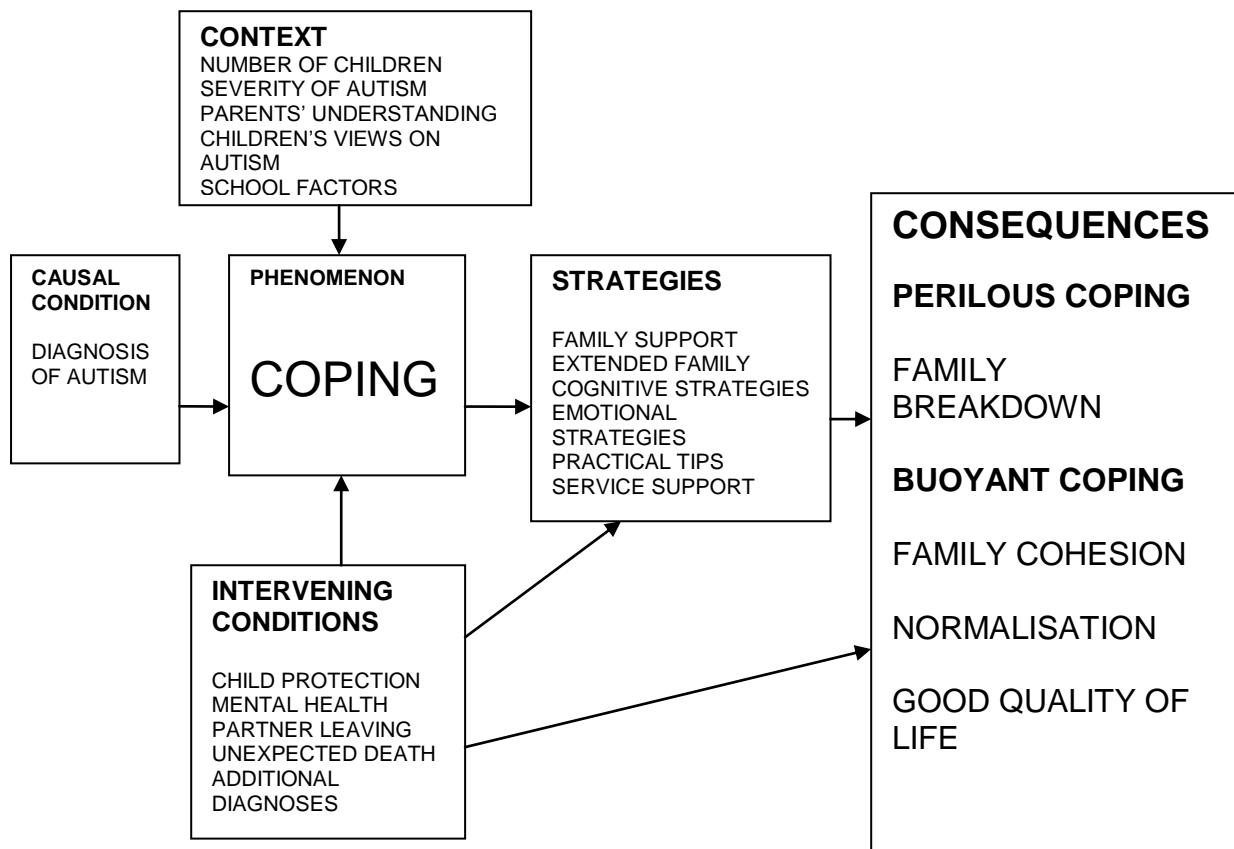
These findings probably reflect the very secular nature of our society in England in the twenty first century. Although the last National Census in 2001<sup>177</sup> showed that 72% of the population claimed to be Christian, subsequent surveys have shown a significant decline from this level. A report by the Tearfund Charity<sup>178</sup> in April 2007 showed that 58% of the 7000 people surveyed said that they had a Christian belief; but that only 15% went to

church at least once a month, and two thirds of those that said they were Christian had not been to church other than to attend a baptism, wedding or funeral in the last year. The British Social Attitudes survey 2007<sup>179</sup> also suggests that there has been a steady decline in the number of people professing to be religious. This study certainly does not support the view that religion is a significant source of support to the participant families.

## CHAPTER EIGHT-RESULTS- Consequences

As a result of the strategies and the intervening conditions the final area of the paradigm, the consequences, emerged. The consequences resolved into two opposing main types of coping, which the researcher has called 'perilous coping' and 'buoyant coping'.

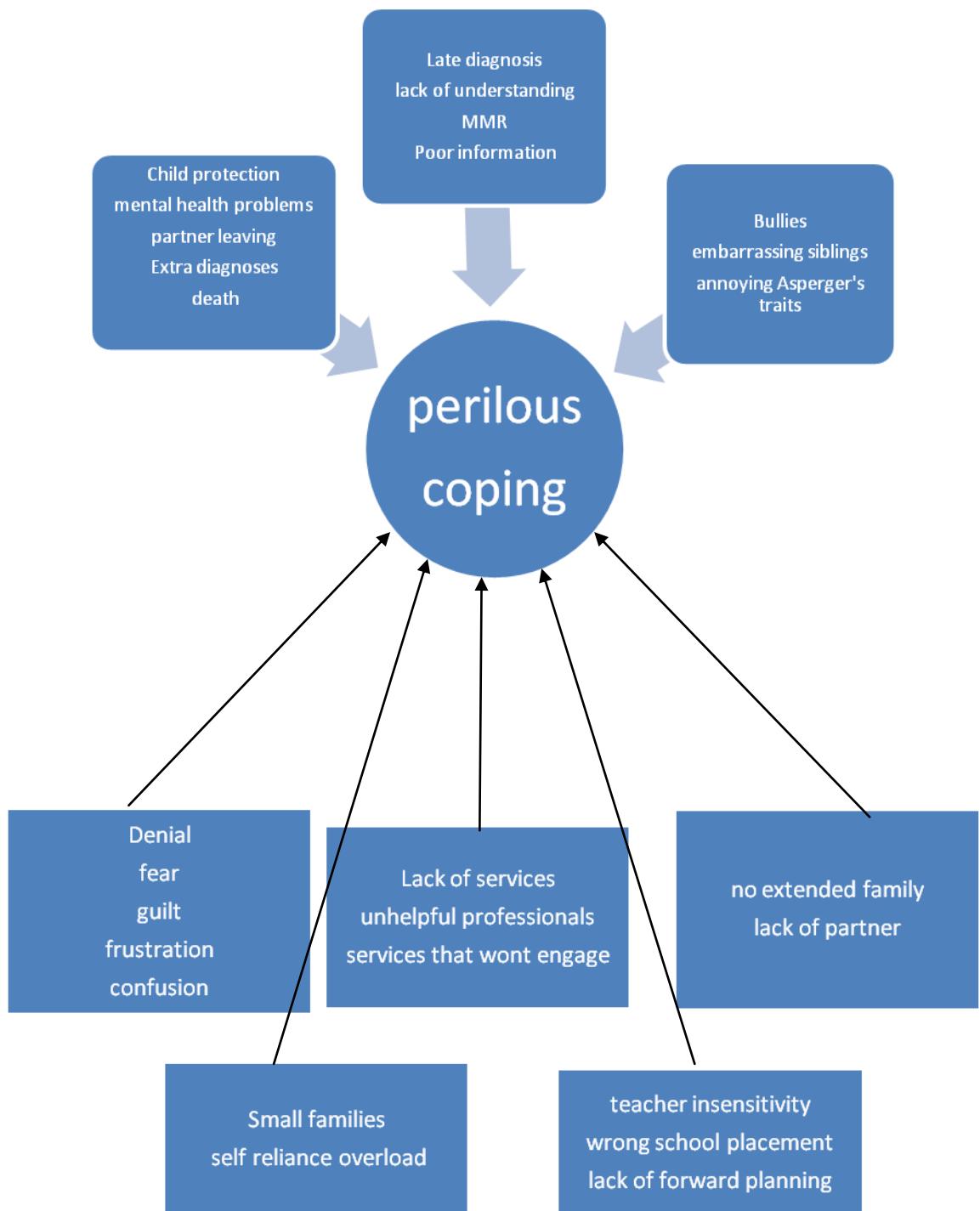
Figure 10: The Strauss and Corbin Paradigm Adapted for this Study, highlighting Consequences



The main consequences of the strategies described in the earlier section are best summarised in figures 10 and 11. These illustrate the factors which produced each of the two types of coping. Perilous coping will be described first.

## 8.1 Perilous coping

Figure 11: Perilous Coping



In the previous sections of the results chapters a number of factors were described which had a tendency to destabilise family cohesion. These have been summarised in the perilous coping chart above but will be discussed in more detail below. Following the sequence of the adapted Strauss and Corbin paradigm,<sup>144</sup> the negative factors which led to instability will be described.

### **Causal condition**

The lack of diagnosis was the first major factor which upset the family. In Family 1 this was particularly marked as their first affected son was not diagnosed until he was 16 years old. He had already suffered numerous bullying incidents at school and was the butt of his Father's aggression before his Mother understood the reasons for his behaviour. Hopefully this situation is much rarer now with the greater recognition of autism in the general population.

If the parents did not understand the nature of autism and accept the diagnosis at the same time this also led to tensions in the marriage which could have had serious consequences.

The quality of the information given to the parents both at the time of the diagnosis and subsequently was a factor in whether coping was enhanced or diminished. Some parents described information overload while others had an unquenchable thirst for more information. The internet was used increasingly over the time period 1991 - 2009, but sometimes the sheer

volume of data about autism was confusing to families. Several commented that they relied on professionals to give them the right amount of information at the right time. If the appropriate professional was not well informed this again led to a negative situation developing.

### **Context**

Parent's understanding was also a key factor especially with reference to The MMR debate. Several families continued to suffer guilt as a result of believing that they had caused their child's autism through giving them the MMR inoculation. This was in spite of strong evidence to the contrary.

A major source of discontent in families was the school situation and the educational experiences of the affected children. It is not surprising that education featured so strongly in the discussion of their children's welfare as it occupied such a large part of the child's time, and was central to their development during their formative years. The fact that several parents were experiencing daily hassles related to school or the anxieties related to it frequently led to periods of perilous coping.

The children's own views on their autism, or their lack of comprehension about why they had problems, was quite marked and is an area that professionals should be more aware of in future. The more mature individuals with Asperger's syndrome all agreed that when they were younger they found it hard to cope with but with increasing insight life had become easier for them.

The descriptions of bullying were heart rending and an obvious source of problems within the family. The normal siblings also described periods of embarrassment on account of having a disabled brother or sister. It is to be hoped that schools become ever more aware of this hazard particularly in this very vulnerable group.

Teachers who failed to understand the nature of the diagnosis or who thought that because they had had one child with autism in the past, they knew all about autism, were a significant cause of family tension. Also if the child was thought to be in the wrong school, this was a cause of perilous coping until the situation had been rectified. The lack of formal recognition of a child's special needs led to poor planning and once a child had a statement of Special educational need it was much easier to plan school transfers. Even with a statement one family had huge problems finding a new school when they moved house possibly as there is still some reluctance to take on children with extra needs.

### **Intervening conditions**

All the issues discussed in this section were associated with periods of family disharmony and potential breakdown. The less affected children who invented child protection scenarios did cause one family to split in the short term and perhaps a greater awareness of this problem in families with autistic children may arise from this study.

Mental health problems in both the parents and the children were a significant cause of family instability. The prevalence of depression in parents of children with autism is well known and not a surprising cause of family breakdown but the extra mental health issues amongst the autistic children has been less well recorded and was significant in this study.

The problem of a partner leaving the family was only a cause of poor coping in the short term although the lack of a partner was discussed by some parents as a factor which made coping more difficult.

Many parents of disabled children described how they can cope with one diagnosis but when a second or subsequent extra diagnosis is made, even if it is a relatively minor one, that throws them out disproportionately.

The death of important sources of help and support such as grandparents was not surprisingly a cause of diminished coping while the parent was grieving and before a new way of coping could be arranged. The death of a child was in some ways more catastrophic as the future plans of the family were completely disrupted. However in this study that family showed a very high degree of resilience.

### **Strategies**

Lack of extended family support was a problem for some families but these families often invented ways of coping within the family or used an artificial extended family as in Family 5. It appeared that families who did not have a

good relationship with the grandparents were at a disadvantage and by trying to support the grandparents at an early stage in the assessment and diagnosis might help to prevent the fear that some parents felt the grandparents felt. Conversely families without support from the older generation did confess to self reliance overload which could be a cause of mental ill health and perilous coping.

### **Emotions**

Several negative emotions were described which contributed to lack of family cohesion and an inability to cope. Many of these were described arising from the post-diagnostic period which is well recognised to be a stressful time. Denial, fear, guilt and frustration were all mentioned. Sometimes these persisted for several years as in the case of Family 7 where the mother said she still felt guilt twenty years on. This was partly due to her feelings about MMR but also the feeling that maybe she could have done even more for her affected children.

### **Service support**

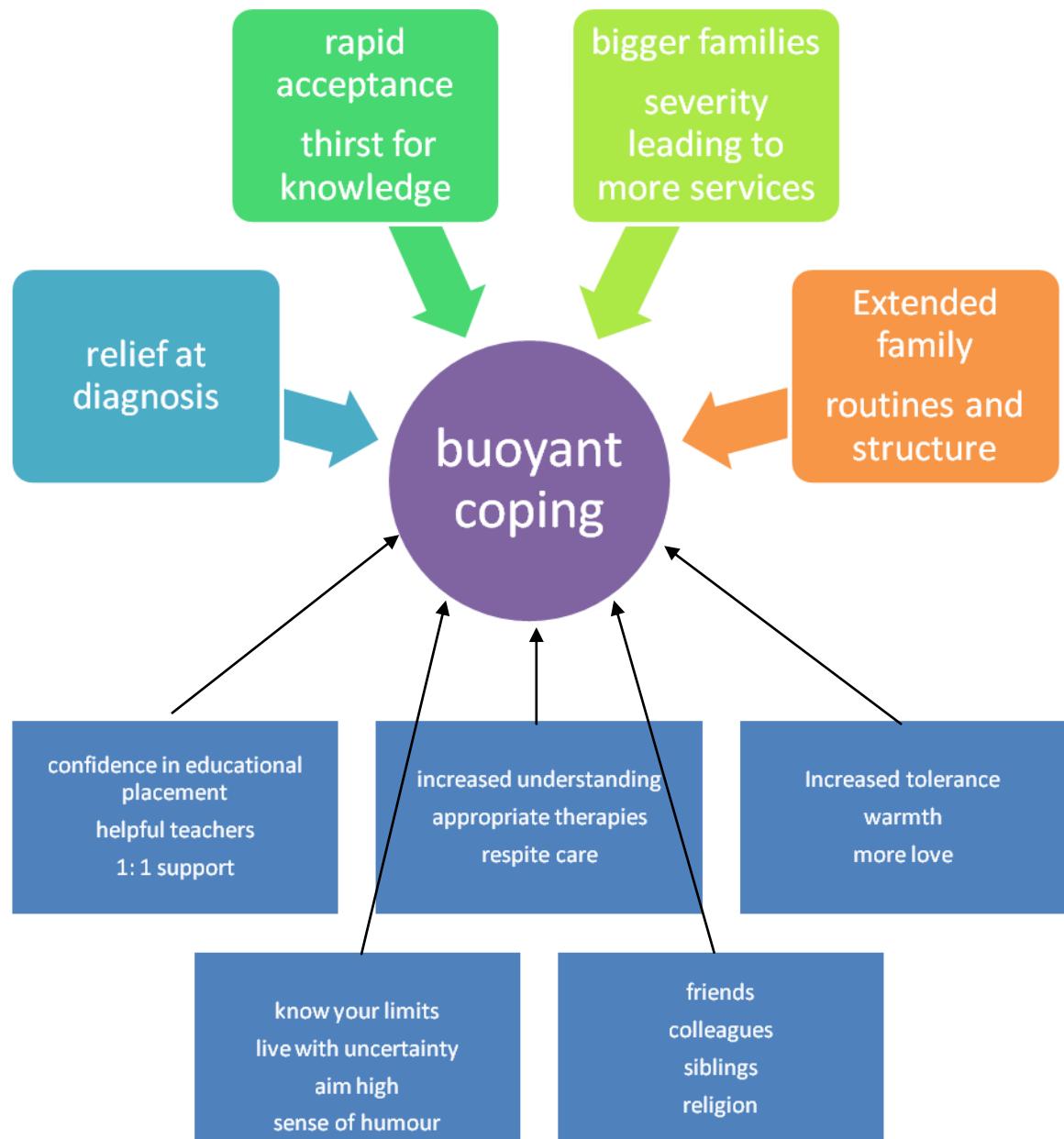
The main complaint about the services was the lack of resources, or in the case of social services, a failure to engage with the family in spite of severe disability, perhaps because the service felt that the family were coping without outside help. This compounded the coping situation and made it more perilous.

The lack of speech therapy was mentioned by several families as not only causing frustration but leaving them feeling helpless as they did not know how to help their children with communication. As in autism one of the main deficits is with communication this was a significant cause of frustration.

Unhelpful professionals were also a source of dismay as was described vividly by the parent who went for a behavioural assessment with a clinical psychologist and was told that the child's behaviour was too bad to assess. The way the professional handles the parent in those circumstances is obviously crucial. That particular parent never sought psychological support again which was not in the long term interests of family coping.

## 8.2 Buoyant Coping

Figure 12: Buoyant Coping



The order of description of factors that led to buoyant coping, family cohesion and resilience will follow in the same order as in the previous section, using the adapted paradigm of Strauss and Corbin.

### **Causal Condition**

The relief at having a proper diagnosis and understanding the reasons for the abnormal behaviour was a major source of improvement in family well-being. Even though the knowledge of a child with an incurable disability would seem to many to be a cause of dismay, living with uncertainty was worse. The start of changing family routines and structures following a diagnosis was a very positive move which immediately led to more buoyant coping.

If there was also rapid acceptance of the problem by both parents this improved family functioning rapidly. Families who were thirsty for information and acquired it through many different channels were also demonstrating positive practical coping.

### **Context**

In this study the larger families often demonstrated more buoyant coping than the smaller ones. The reasons for this are complex. In some of the smaller families they had two severely affected autistic children, which might have meant that coping was more difficult, although it also meant that the statutory services were more likely to give respite care. However, in one family who had just two children, both of whom were quite mildly affected, they demonstrated buoyant coping, although the two boys spent a lot of their time

playing separately. In the larger families there seemed to be a dilution effect so that the most severely affected child did not stand out too much from the others. It may also have been the case that the siblings supported each other well in the larger families and this improved family coherence. Inevitably there seemed to be a greater acceptance of autism and more discussion about it in the families with more than two affected children.

The educational placement, if it was good, was an important source of stability and family cohesion. If the teachers understood the child and were able to praise them for their achievements, the whole family benefitted. The right teaching assistant support came out as a very positive influence.

The grandparents and other extended family members were the major source of buoyant coping. In addition to grandparents, other sources of informal support including friends, colleagues and other family members were key factors in improving coping and were sometimes the reason for changing a perilous situation back into a buoyant one.

### **Strategies**

Various cognitive strategies were employed to promote better coping, especially the ability to understand themselves better as a result of the trauma of accepting and living with autism. Several parents commented that they knew themselves much better and were now able to live with uncertainty about the future for their children. Sometimes this was by using a strategy of living from day to day in the present but often they had made complicated

plans about their future housing and care needs. They were full of helpful advice to newly diagnosed families, such as aim high, treat your children as normally as possible, and always maintain a sense of humour. These strategies had led to a clear demonstration of resilience. Many of them had arrived at a level of acceptance which meant that they did not want to change their children at all; they loved them for who they are. Several also commented that although there had been hard times, the relationships of the parents had been strengthened by having autistic children, and many of the siblings felt that they had benefitted from having a disabled sibling or two. The older normal siblings were particularly positive about the autistic ones and several said that their parents need not worry about the future as they would somehow manage to look after the disabled ones.

In conclusion, the balance was very much in favour of resilience, and buoyant coping with families commenting on their good quality of life. Although the factors which could cause perilous coping were ever present and the situation could change fast if one of the negative intervening conditions, such as a new mental health problem, suddenly occurred.

The families were all consulted about the findings and they all agreed that this summary reflected their situations. One family said that they had just endured a period of perilous coping as they were not sure about the schooling for number three son, but when they heard that he had got a place at the same school as his oldest brother the whole family dynamic improved and they were back in buoyancy again.

## CHAPTER NINE: DISCUSSION

### 9.1 Introduction

In this chapter, following a section on reflexive analysis, the research findings will be discussed with reference to the research questions. A more detailed analysis of the strengths and limitations of the study will be presented and the overall conclusions set out. The discussion will be set out in the following way.

1. Reflexive analysis
2. The research questions
3. A further discussion of the results of the qualitative analysis.
4. A discussion about the main findings of the buoyant coping and the perilous coping theories.
5. The strengths and limitations of the study.
6. A discussion about how the study could be improved with suggestions for further study.
7. Participants' recommendations.
8. The implications and recommendations arising from the study.
9. Overall conclusion.

#### 9.1 Reflexive Analysis

Reflexivity has been defined by Charmaz<sup>145</sup> as 'The researcher's scrutiny of his or her research experience, decisions, and interpretations in ways that bring the researcher into the process and allow the reader to assess how and

to what extent the researcher's interests, positions, and assumptions influenced inquiry.'

'A reflexive stance informs how the researcher conducts his or her research, relates to the participants, and represents them in written reports.'(Page 188-189)

In the course of this thesis there have been several points when the author has added a reflexive note. In this final chapter these have been drawn together and grouped for further clarity.

The most obvious reflection was concerning the relationship between the participants and the researcher. Any scientific research is compounded by the role of the researcher in the analysis, although this role is more commonly discussed in qualitative rather than quantitative research. There is always a danger that the findings are too subjective. In this study the subjectivity was reduced by the iterative process with the supervisors and the feedback to the families for their approval of the use of quotations and findings. In spite of this, subjectivity cannot be eliminated and in this study, although attempts to be as objective as possible have been made, the author's integral role in the study must be recognised.

The former clinical role was explored in the Ethics committee as well as with each of the participating families. The consent form also made it clear that the current medical support for the family would in no way be compromised by the former role of the researcher.

The benefits of a previous clinical relationship became apparent in several interviews. The researcher was able to prompt parents about events that the researcher had been involved with. In Family 7, the distressing onset of epilepsy was vividly recalled by the interviewer which enabled the parent to go into detail about the perilous coping episode which resulted. The families did confide in the researcher in a way that they said they would not have done with an unknown person. One family even mentioned after the tape recorder was switched off that they would not have agreed to participate if the researcher was unknown to them. The author concluded from these comments that the previous clinical relationship did improve the quality of the interviews, giving richer and more detailed information. However in families where there was no previous clinical relationship, useful information was obtained which helped to confirm that the interviews were appropriate, and gave interesting data for analysis without the need for prompting using clinical memory.

One possible hazard of former clinical contact may have come from the children in the study, some of whom might have wished to please the researcher, because of the previous long term relationship, and they might have given rather more positive reflections on their siblings than would have been the case with an unknown person. In this respect bias was reduced by interviewing as many family members as possible some of whom hardly knew the researcher prior to the study.

Another difficulty which arose from previous clinical practice was that it was almost impossible in the mind of the researcher to be completely sure that a conclusion drawn from the interview material was not in some way influenced by previous clinical experience. It was not a realistic proposition to try and separate the conclusions drawn from each source as inevitably clinical experience over many years does influence the way a subject is approached and this in turn adds to the validity of the analysis. However, there were several occasions on which the information obtained was quite surprising to the researcher and therefore was not influenced by clinical observation. Although one conclusion was that this group of families are all fascinating and inspiring which was probably derived from both sources.

Clinical experience led, on one occasion, to the researcher making a clinical referral after the interviews. This did not influence the study material because no second visit was required to that family. However it might not be possible to rid oneself of a clinical approach completely after more than thirty years of practice.

Another source of possible bias was the fact that families might not feel comfortable in discussing the Doctor's role in their coping strategies. It was obviously difficult for them to give an unbiased opinion of the researcher's own role and therefore any comments about the researcher were excluded from the analysis. However families did not seem to be diffident about discussing other Doctor's faults or strengths.

Previous clinical experience had suggested that families with more than one child with autism seemed to cope at least as well, if not better than those with only one, and this was a major reason for undertaking this study. The fact that one of the conclusions of this study was that these families do in fact cope remarkably well, and show considerable resilience should not be invalid merely because of previous clinical suspicion. This conclusion arose from the testimonies of the participant families and was confirmed by the families' subsequent feedback.

Another area of reflexivity arose from the cross referencing of the contemporaneous diary with the coding of the interviews and the searching of the Child Health records. This demonstrated to the researcher that memory for events cannot always be verified by the clinical notes which tend to record actual findings rather than impressions of parent's feelings. On occasion the parent's recollection of their emotions surrounding the diagnosis was at variance with the researcher's memory. But on these occasions the interview material was used in the analysis not the researcher's memories. In the course of the study the researcher developed a new understanding of how children with autism view their condition. This was not influenced by memory.

The influence and power of the professional as a diagnostician and source of trustworthy advice should not really surprise readers. But in the age of the internet the author felt that this power had diminished considerably, and was therefore surprised to find that many participants were still of the view that

the professional advising them, in particular the Paediatricians' role was still critical and of great significance.

There was some debate about why the point of diagnosis was selected as the 'causal condition'. The child develops symptoms long before a referral is made for an assessment and diagnosis. The moment of diagnosis is a finite one and parents have a clear recollection of this, whereas their memory of the first time they noticed something was not right with their child is less clear. The researcher opted for the diagnosis of autism as the starting point of the paradigm to increase clarity while at the same time not rejecting families' emotions prior to diagnosis.

The recommendations for schools came from a combination of the interview material backed up by clinical experience. This was demonstrated in particular by the opinion that was expressed in 5.5.4, that as schools become more familiar with dealing with children with autism the negative attitudes described in this study will become increasingly rare. The role of the Paediatrician in advising about school placement is a controversial one. This study helped to confirm a clinical impression that time spent advising parents and education authorities on the needs of children with autism was time well spent.

The researcher was surprised and alarmed about the descriptions of child abuse enquiries. Although, in a former clinical role this had been an area of expertise for the author, it had not occurred to the author prior to the

interviews that questions specifically about child safeguarding should be included. As it stated in the analysis several of these enquiries had occurred without the author being informed in her clinical role.

Finally, there is the fascinating question of whether there is some factor inherent in a child with autism that promotes coping and resilience in the families who have more than one of these children. In spite of reflecting on this the researcher does not have an answer, but it would be interesting to devise a study to test this idea.

## 9.2 The research questions

The main aim of this study was to explore the coping strategies in families with more than one child with autism. The whole family was invited to give its views on the family structure and function with the ultimate goal of understanding how these complex families thrive or disintegrate. Within this broad aim there were several questions which arose from the epistemology of coping and related subjects.

- 1 Does the presence of more than one child with autism in the family make it harder to cope effectively, and what aspects of autism and its management are important to these families? Is the severity of the autism significant? Does the type of coping change over time, with a greater emphasis on emotion focused strategies and religion as the

children grow up? What are the most useful practical coping strategies?

- 2 Do families feel they have a good or bad quality of life, and which factors contribute to this? Is marital status a crucial factor?
- 3 What are the feelings towards the children with autism held by the parents and siblings? What are the children with autism's own views about autism?

There are various speculations and ideas which have arisen from the review of the literature. The first suggestion, which was a major reason for undertaking the present study, was that families with more than one autistic child might even cope better than families with one autistic child, and also be able to demonstrate resilience.

Secondly, increasing severity of autism would lead to more difficulties with coping.

Thirdly, the stress of having one autistic child would be increased by having a second or subsequent child with autism in the family.

Fourthly, that, as in Gray's study,<sup>54</sup> the emotional coping strategy of using religion became more important as the child grew up into an adult.

Fifthly, the more knowledge and information the families had the better able they would be to manage the demands of their autistic children.

Sixthly, the ability to adapt quickly to the diagnosis of autism would enhance the coping strategies of the family and also that denial of the diagnosis would have the opposite effect.

Seventhly, those families with more than one autistic child would have less well-being and a lower quality of life than 'normal' families, and would be generally pessimistic about the future.

Eighthly, siblings of autistic children would have negative feelings about their affected brothers or sisters.

### **9.3 Discussion about the results.**

How has the analysis answered the research questions?

1. The Multiplex family: (the family with several affected children), severity of autism and changes of coping over time. The main aim of the study, to try and understand how families with more than one child with autism managed to cope, was achieved within the possibilities of this methodology. It was interesting that the presence of the second child with autism in the family did not impair family cohesion and in many cases improved the quality of life.

In general the presence of a second or subsequent autistic child did not make it harder for families to cope. In fact the opposite was true. This was probably due to the fact that the burden of expectation was shared, and that skills learnt from the experience of the first autistic child, were applied to the second. This seemed to be the case even when the severity of the autism was very different amongst the affected siblings. Also, those structures that were put in place for the first affected child worked well for the second and subsequent children. It is also possible that the process of grieving for the normal child, having been experienced for the first child to be diagnosed, was less severe when the second child was diagnosed. The diagnosis of the second or subsequent child was often greeted with relief and pragmatism tinged with regret at the thought of double trouble.

The information gathering from the first diagnosis was also useful for dealing with subsequent children. Several parents felt empowered to challenge the Health and Local Authorities to deliver services they needed. In fact many of them commented that they wished the non autistic world would stop pitying them and treat them as normal families who just had some extra needs.

The particular aspects of the management of autism that most affected families were: late diagnosis, acceptance of the diagnosis, and failure of various services to acknowledge the diagnosis and put in place the relevant support to help the affected children. This applied to all three types of children's services including health, education and social care. Where the

service provision was in place families were very positive and full of praise for the support they received. But they were critical of services which did not deliver the anticipated level of contact, such as Speech and Language Therapy. The very strong reactions to educational placements were a significant factor in producing either buoyant coping or a perilous situation. The contrast between school placements which valued their children with autism and those which were usually critical was crucial to the family well-being.

As in another study,<sup>180</sup> the rapid acceptance of the diagnosis led to positive action to seek support and in some cases change the environment in the educational setting, which in turn led to greater happiness on the part of the affected child and this further promoted family harmony and buoyant coping. In contrast, denial of the diagnosis, in one parent or a grandparent, led to lack of support for the main carer and potential family crisis. If the grandparent disliked the idea of their grandchild being labelled with autism, they continued to have unrealistic expectations about behaviour and development which caused further parental distress. Grandparent's lack of understanding of autism was also a factor in them opting out of support, because of a fear about possible behavioural problems and an inability to control the children with autism.

The severity of the autism did not necessarily affect the coping in a negative way. Families who had several children, with what is considered to be less severe forms of autism, sometimes went through longer periods of perilous

coping than those with more severely affected children. The reasons for this were complicated. If the young person had not been assessed and diagnosed, schools often misinterpreted idiosyncratic behaviour as being naughty, and this led to many school based problems and difficulties for the parents, often resulting in the young person being removed from a school. The fact that someone has Asperger's syndrome is often not obvious to the non-autistic world. This can result in problems as was seen in the train story. The young person is frequently the object of bullying in both the school and the workplace. They were not readily offered support services and this can be especially difficult for a struggling parent.

On the other hand, those families with severely affected children suffered differently, often with sleep deprivation<sup>181</sup> and sometimes with physical aggression. This was lessened by access to Children's Services and specialist health service support. Overall in this study, the families who had longer periods of perilous coping, seemed to be those who had children whose autism would be categorised as less severe. This finding is similar to the work of Mori<sup>182</sup> who also found that looking after Asperger's children was very stressful.

The severity of the autism did have some negative effects on the family in terms of learning to cope with challenging behaviours, but families with children with more severe autism were more likely to obtain respite care and the enhanced level of Disability Living Allowance, which enabled them to

cope as well as, or better than, families with theoretically milder cases who were not offered any respite care or additional free child minding.

However, in this study, when the first born child was autistic and severely affected, it did seem to limit total family size. Although with such a small sample size this can only remain a supposition. The suggestion that families with more than one autistic child might even cope better than those with only one affected child seemed to be confirmed by this study, particularly in the larger families.

Stress seemed to be increased by having two affected children, when the two children had to follow separate routines as in the case of Family 10, and to a lesser extent with Family 4, which required two adults to be present to feed and dress the two children. Even in Family 10, the mother felt that having two autistic children was better than just having one and she would not change her two boys as she loved them as they were.

There was some evidence that coping styles changed over time. However, the changes were largely practical adaptations in line with the developmental progress of the children with autism. There was no evidence from the present study that the use of religion and emotional focused coping strategies became more important over time, as was suggested by Gray.<sup>87</sup>

The most widely used practical coping strategy was that of creating order and routine. In fact, families who freely admitted that they were originally rather

chaotic felt that having a child with autism had helped them become more organised. In addition to having a routine, avoiding situations which were known to produce difficult behaviours, and adopting a normal approach to holidays and socialising, all helped to improve family functioning. Appropriate use of respite care and added child minding, sometimes using the direct payments scheme, were all seen as aiding coping. Further practical strategies will be discussed in a later section.

The postulation that families with more than one autistic child might cope better than those with just one cannot be entirely proven by this study as no direct comparison with families with just one child has been made, but there was a definite suggestion that this was the case. This would require a further quantitative study, to explore the idea further. The only comparison that was made in this study was between a family with one child with autism and how that family deemed itself to be coping after the arrival of the second or subsequent autistic child. In several families they commented that by having more than one child with autism, the burden was shared and the skills learnt from coping with the first affected child were easier to apply to the second and subsequent children.

2. Quality of life. The present study did demonstrate that many families had a good quality of life most of the time. The descriptions of the use of extended family, friends, colleagues and lodgers were full and heart-warming. Families improved their cognitive coping strategies, in line with experience and increased knowledge of autism. In fact, all the families in this study

demonstrated resilience. This finding fits well with other authors.<sup>107, 183, 184</sup>

Although some families were still experiencing severe daily hassles, all were able to speak about extra warmth in family relationships, extra closeness and some positive benefits from caring for autistic children. There was one family where this was not the case between the siblings but this was the exceptional case. Many families demonstrated resilience by saying that the presence of children with autism in the family had either led to the parents, the siblings, or both becoming more tolerant to each other. In one family (Family1) one of the siblings wanted to have a career in caring as a result of her experience within her own family. It is interesting to postulate that there might be some factor about autism, which drives the family towards resilience when there is more than one affected child. This could be the subject of a future study. Given the finding that none of the families wanted to change their children and all of them said how much they loved them, it appears that all of them experienced a good quality of life at least most of the time.

However, there were times, when extra pressures, in the form of intervening conditions, added to the burden of caring, to the extent that family cohesion was threatened, and a situation of perilous coping ensued. These periods could be interpreted as a poor quality of life. However the underlying resilience appeared to allow the families to emerge from the perilous periods.

The marital status of the parent caring for autistic children did not appear to have a major impact on the ability to cope. But coping was compromised during the period of separation. In fact, once the separate lives of the two

parents had been established, there were some benefits for the single parent in terms of child minding when it was the ex-partner's time to have the children. This obviously did not apply where the ex-partner was not able to see the children. In families where both parents remained married, there were positive advantages of the partnership in terms of the ability to talk and share worries on a daily basis.

Although there was anxiety expressed about the future in most families, this did not prevent several of them making quite elaborate plans for the future and therefore further demonstrating their resilience. The normal siblings of the autistic children were more confident than their parents that they would be able to cope with their siblings in the future. All the young people who were old enough to have thought this through were convinced that their siblings would be a major part of their future lives.

The main conclusion was that families are very resilient and that they adapt by accepting the diagnosis, gaining knowledge about the condition, and actively seeking assistance from family, friends and the statutory services. This resilience leads to a good quality of life.

3. Feelings and views about autism. The feelings that the parents and normal siblings had towards the affected ones were almost entirely warm and positive, with one exception. However, there was frustration expressed by some of the younger siblings about their brother's inability to talk, or problems with toileting and behaviour, but a very positive feeling of protection

towards the vulnerable ones was also present. Whenever the future was discussed with siblings, there was initially a bit of concern expressed, but all of them felt that they would look after their brother(s) even if life was quite a problem for them already. This finding might come as a surprise to some of the parents.

The siblings expressed a variety of views about their own well-being. Many of them had suffered bullying as a result of having a disabled sibling at the same school. This had led some to wish that their sibling did not have autism. These findings tend to confirm the study of Ross.<sup>185</sup> Some siblings had invented child protection scenarios to try and draw more attention to themselves, which suggested a degree of unhappiness and low mood, but, contrasted with this, was the view that none of them wanted to get rid of their disabled siblings even if some of the daily hassles involved in their care were rather annoying. Nearly all gave very positive descriptions of their siblings and were prepared to care for them in the future if their parents were not able to do so. Only in one family were both siblings sure that life would be better if they did not live under the same roof. This view was probably very telling because of the added complication of mental health problems which frightened the whole family.

The views of the young people with autism about their own condition were amongst the most interesting findings in this study. The level of understanding in young children with autism about their own condition appeared very low, but perhaps this is to be expected in the light of delayed

and disordered communication skills. The more developmentally advanced individuals had some concept that they had problems with socialising, but did not have many ideas about how they might deal with these difficulties. The most able and most developmentally mature did have a clear idea that their Asperger's was a pain and a problem to them but also that it was the autism that gave them their personalities and therefore they would not wish for it to be taken away.

The lack of understanding amongst children with autism about their condition, perhaps points to some work which could be done with this group in the future to try and improve their knowledge about the difficulties and thus help them to be less different and perhaps avoid some of the bullying.

In summary, there was ample evidence that the families in this study showed resilience, that the stress of coping with two or more autistic children was not significantly worse than looking after the first one alone, and that given the right type of support, the more severe degrees of autism were no more difficult to cope with than those families with several Asperger's children.

#### 9.4 Discussion of the buoyant and perilous coping model

A full description of the factors that led to either perilous or buoyant coping was given in Chapter 8. The relevance of the use of the model in clinical practice will have to await a further study. But the following points need further emphasis as they could be the basis of the recommendations of this study.

Perilous coping caused by a late diagnosis could be lessened by prompter referrals and earlier sharing of diagnostic suspicion in the assessment process. The uncertainty of not knowing the diagnosis would also be diminished.

The feelings of guilt arising from the MMR immunisation which were prompted by the Wakefield paper<sup>152</sup> which has now been retracted by the Lancet<sup>149</sup>, surprised the author as so many years have elapsed since the paper was found to be flawed<sup>147, 148, 150</sup>. A possible solution to this could be a clear set of information about the discredited paper should be available at the time of diagnosis. Other appropriate information supplied at the same time might reduce the perilous factor of lack of understanding in both parents and grandparents.

The alarming prevalence of child protection investigations was a perilous factor that needs further highlighting. The national prevalence of child protection amongst all children was described by May-Chahal<sup>186</sup> and is significantly lower than in this study. Although it has been recognised that there is a higher prevalence of child protection concerns in children with disabilities<sup>187</sup>

Mental health problems as a perilous factor was not surprising but the rates of mental health difficulties in people with autism might warrant further research. Other authors have found higher rates than in the normal

population.<sup>154, 188, 189-190</sup> In the current study there were only two autistic individuals with an added mental health problem at the time of the study, both were causing very considerable problems within the family (Family 8 and 11). The mental health of the parents was also a significant factor in destabilising the family and producing perilous coping. Many authors have assessed the psychological stress of parents. Montes<sup>191</sup> found that in spite of high levels of mental health problems in mothers of autistic children there was a remarkable capacity to cope. This study would tend to confirm this finding.

Many autistic children had additional diagnoses, or co-morbidities. This finding was in line with several studies.<sup>187, 192</sup> It has been known for a long time that epilepsy has a higher prevalence in children with autism.<sup>56</sup> It is therefore not surprising that this was so in this cohort. However the presentation of complex partial seizures in a non verbal child with autism can be difficult to diagnose and this can lead to a very stressful period for the family and perilous coping. A greater awareness of this in clinicians would be helpful.

Other perilous coping factors which might assist the clinician in their understanding of these complex families are the negative emotions of denial, fear, guilt, frustration and confusion. Another factor which is less obvious was self-reliance overload which in turn could be the earliest sign of impending mental health problems.

Does the argument for greater understanding of buoyant coping situations also help the clinician? Rapid acceptance of the diagnosis is not something a clinician can necessarily influence but by providing the right way of breaking the news about the diagnosis and doing this in a timely manner this could lead to acceptance.

A surprising finding was that the larger families tended to feel more buoyant about their coping than those with only two or three children. There are a number of possible reasons for this. Firstly, it became evident that the main source of support came from within the family or the extended family. The larger the family, the more there were possible sources of support from within the family. In Stainton's<sup>193</sup> study, they showed that the presence of a child with an intellectual disability had a positive impact on the family. What is not clear is whether by having several children with an intellectual impairment the positive impact is increased. It is suggested that siblings of children with autism, derive benefits from the presence of their disabled sibling(s).<sup>130</sup>

The reliance on friends and colleagues was also a major buoyancy factor. These informal forms of support have been described elsewhere<sup>194, 195</sup>. Perhaps professionals should spend more time ascertaining whether these informal networks do exist, and helping parents to use their friends more if they appear to be isolated.

Although an investigation of the personality types of the parents was not part of this study, the fact that so many of them appeared to have a positive

outlook perhaps suggested a personality type that demonstrated positive well-being. This would confirm the findings of Glidden et al.<sup>196</sup> In the study of Heiman,<sup>194</sup> the authors suggested that families with Asperger's syndrome had fewer social support networks than families with other developmental disorders. In the current study the friendships and colleague support networks were described very positively which goes against Heiman's findings.

The theory concerning 'perilous coping' and 'buoyant coping' seems to encompass the situation that is found in families with more than one child with autism, and could stand up to various clinical situations as described above. It might well prove useful as tool in both the clinical setting and for parents. The model would have to be tested further in a future study to prove its usefulness and validity.

## 9.5 Strengths and Limitations of the study

### 9.5.1 Strengths

The recruitment to the study, although slow initially, did eventually include a wide and varied sample of families such that saturation of sampling was achieved. Out of a potential pool of twenty families in the study area, eleven opted in to participate and only one declined to participate. It is not known how many other families received the information sheets because of the unfortunate timing of sending out the paperwork in the pre-Christmas rush. However, some of the families who were recruited later said that they had a vague recollection of receiving some information earlier, but because of the increased demands of the time of year they had lost the original invitation.

Recruitment continued until the analysis indicated that no new information was coming from the interviews. There does not therefore appear to be any bias in the sampling.

For this type of qualitative study the total number of interviews was adequate to perform a staged analysis including line by line coding, focused coding, themed coding and the development of categories and a paradigm. There were in total eleven families participating and forty-five people were interviewed. This included nineteen adults and twenty six children.

The nature of the sample was varied with a good spread of two parent families, single parents, both single mothers and one single father, and reconstituted families. It appeared that the information obtained was not biased by a preponderance of one type of social class or educational status of the parents, although a majority of the families had at least one parent with a further or higher educational qualification.

There were no time constraints on the interviews and families all opted to be interviewed in their own homes, which should have improved their ability to relax and give detailed and accurate replies. The longest interview was with a single parent mother and lasted more than three hours. The shortest was with a barely verbal child who was interested in making sounds for the tape recorder but it only lasted a few minutes. Most adult interviews were about one and a half hours. Most of the children's interviews were under an hour. Some families were visited more than once in order to obtain interviews from

other family members. This occurred in families 1, 2, 3, 4 and 11. In these families the mother sometimes interjected in the children's interviews and said something slightly different to her original interview. For example that she was either feeling more positive or rather low on the second occasion. This was interpreted as a strength in this study, as it helped to develop the final conclusion about parents going through either buoyant or perilous coping phases.

All families were contacted following the completion of the analysis. This was to confirm accuracy of the quotations, allow the families to withdraw any quotations they felt embarrassed about, and to ascertain that each family was comfortable with the way their information had been made anonymous. They were also asked to comment on the accuracy of the conclusions and make suggestions. All families were spoken to on the telephone and then sent a copy of the parts of the results which included any description of their family and their quotations. All were pleased to be contacted and keen to know that the information from their particular interviews was being used. Out of the eleven families, nine have sent written replies. Triangulation of the results has therefore occurred. The families who have responded in written form have validated the conclusions.

Triangulation has also taken place during the analysis phase through the iterative process between the researcher and the two supervisors.

Bias has been reduced by the process of analysis which has produced some surprising results which the researcher did not expect from clinical practice. For example, the fact that the larger families seemed to have more buoyant coping strategies than the smaller ones.

### 9.5.2 Limitations

The study took place in one limited geographical area. This was a mainly rural area with one large market town and a second smaller market town. The results may have been different in a very urban population.

The fact that the interviewer was known to the majority of the families prior to the research may have influenced some of the interviews. The question which is most likely to have given rise to biased answers was the one about the use of NHS services, particularly the service that they had from Paediatricians. The answers to this question were entirely positive when applied to local doctors. The fact that there were negative comments about GPs and other therapists suggests that the answers about other services were probably reliable.

There was also a possibility that some of the participants were trying to please the researcher by giving a more positive outlook to their situations than was the reality. The only way of controlling for this, was to include the two families who were previously unknown to the researcher. Of these, one had a very positive outlook on coping (Family 9) and one had an exceptionally negative response from the children (Family 8). As there were a

variety of positive and negative responses from each family it suggests that this type of bias was minimal.

The families who were previously unknown to the researcher may have given less full and rich answers to the semi-structured interviews than those families who had known the researcher over several years. In fact, the interviews in Family 9 were shorter than some of the other interviews. This might have been due to the age of the children, as all were still at primary school or pre-school, but could have been because the family were unknown to the researcher. However the recordings of Family 8 were full and varied suggesting that the previous clinical relationship was not essential for the quality of the responses. In general the ability to recall earlier episodes in a child's life (on the researcher's behalf) helped with the follow up prompt questions and probably led to more comprehensive answers.

The fact that some families had been known to the researcher for twenty years ( in the longest case, Family 7) may have biased the reports from the young people as some were now in their early twenties and they may have had a very different view of autism and their siblings to that of younger children. This is partly a limitation but also a strength as it gives a longitudinal view of coping which adds to the richness of the material. Some of the young people admitted that they had changed their views about their autistic siblings as they had got older (Family 7 and Family 1)

For the majority of participants there was only one interview. This may have resulted in a snap shot approach, which may have elicited different responses to those that would have arisen if repeated interviews had been used.

There were some families where the researcher returned to the family on a subsequent occasion. (Families 1, 2, 3, 4, 11) The view of how they were coping on the second visit was sometimes different to the view given on the previous recording. This fact lent support to the theory that both buoyancy and perilous coping live side by side at different times.

The families were given choices about how they were interviewed. In some cases parents chose to be interviewed in the presence of their partner and sometimes separately. If interviewed together, there may have been a degree of collusion about the answers they gave. This was a risk, deliberately taken, in order to make the families feel more comfortable in the interviews.

Some of the research questions could not be fully answered by using qualitative methodology. The question of whether the resilient families were more likely to be optimists was not addressed in this study and would require further research.

## 9.6 Possible improvements to the study and further research.

Although the methodology was appropriate for the study questions there could have been alterations to the study design which might have improved the quality of its findings.

The semi-structured interviews were not first tested by a pilot study. It is possible that had the questions been piloted some of the questions would have been modified to give richer answers. The reason this was not done was to do with the process of ethical approval and time constraints.

It could be argued that a wider catchment area for participants, including a more densely urban environment would have increased the likelihood of more general applicability. The reason for the choice of geographical area was that it could be contained within one Primary Care Trust which improved the communication with potential participants and allowed a thorough search of the child health records to take place. It would be possible to repeat the study in an area where the participants were completely unknown to the researcher.

The use of computer programmes in the development of the results and coding might have streamlined the analytic process, and improved transparency. A decision not to use these tools was made early on to give greater flexibility to the coding levels.

Future studies might concentrate on longitudinal follow up of this cohort to find out what happens to the coping abilities of the siblings once the parents are not in a position to keep the family together as they all were in this study.

It would also be interesting to apply quantitative measurements to the coping abilities of families with one autistic child as opposed to families with more than one and see if quantitative measurements of coping also produce a similar result to this study.

It would be possible to implement the further support of grandparents, and the extended family, using the 'Early Birds' scheme and then do a study to see if the uptake of grandparent support had improved compared to this present sample.

The whole problem of co-morbidity in ASD is unclear. A prospective study into the true prevalence of co-morbid conditions and whether they are in fact part of the original diagnosis or true extra diagnoses and how they complicate coping would be a fascinating line of enquiry.

The literature on coping, starting with the work of Lazarus,<sup>62</sup> suggests that there are two main types of coping, practical coping and emotional focused coping. This study demonstrated that, in this cohort, the practical based strategies were predominant. The fact that practical solutions led to resilience and a good quality of life tends to confirm the work of the majority of researchers in the field but the finding that so few of them relied on emotional

focused strategies is unusual. A future study might pursue this thesis further to investigate whether the presence of two or more children with autism inevitably leads to practical coping and whether there is an inherent factor associated with autism that promotes optimism and a resilient outcome.

Many of the findings of Kuhaneck<sup>98</sup> were confirmed such as 'recognising the joys', planning and 'knowledge as power'. Altieri's<sup>197</sup> findings about parents agreeing on many variables were also confirmed in the present study.

Several parents demonstrated a high level of self-efficacy which might explain their psychological well-being as suggested by Bandura<sup>114</sup>.

## 9.7 Participants' Recommendations

The families were all asked what advice they would give to other families in a similar situation to their own. There were some recommendations which were common to all the families and some more specific practical tips which only applied to a few.

This section will be discussed under different headings:

Parent's advice

Participants' philosophy of coping

Practical tips

Helpful Services

Changes to the Environment

### 9.7.1 Parent's advice to newly diagnosed families

The overwhelming practical advice was to develop a routine and apply it to everyday life. All the families made this recommendation even if the families, by their own confession, were not previously very well organised. All said that children with autism are much calmer when they know what to expect, either from everyday events, such as the timing of tea, or the use of a picture of a ferry to signal the start of a holiday when it comes to going abroad on holiday. Having a routine was seen as a strong positive, but several families commented that it was important to change the routines periodically so that obsessions did not build up. Together with the use of routine, firm discipline and the use of rules was recommended.

The other universal recommendation was to keep everything as normal as possible and to treat the children with autism as though they were normal. By this, they meant that the children with autism should be involved in as many normal activities as possible, such as going out to a restaurant or going to the cinema. In order to achieve this, the family would have to develop a thick skin while the affected child was adapting to the new event, but the eventual pleasure that was gained was always worth the first few difficult times.

A further recommendation was to anticipate trouble spots so that these could be avoided or circumvented. Behavioural outbursts could be prevented by avoiding known triggers.

### 9.7.2 Participants philosophy of coping

Each participant was asked for their advice to others and they all came up with statements which will be summarised here:-

‘don’t blame yourself’; ‘negativity does nothing for you’; ‘autism is not negative’; ‘don’t think all autistics are the same’; ‘we do not need pity’; don’t treat them differently’; ‘don’t take things to heart all the time’; ‘don’t be defeated by autism’; ‘be stubborn to cope’; ‘don’t worry about doing it right all the time’.

There were several positive pieces of advice which have been grouped together:-

‘be determined to achieve change’; ‘just do it’; ‘learn to adapt’; ‘be firm and strong’; ‘getting over the problems brings relief’; ‘keep persevering and keep everything normal’; ‘learn to compromise’; ‘lower your pride and accept help’; ‘say I can and accept help’; ‘don’t always say you’re fine’; ‘asking for help feels as if you are failing’; ‘you cause problems yourself if you don’t let people in’.

A further group of responses highlighted the importance of humour which has been accepted as another coping strategy by Carver.<sup>86</sup> One parent’s advice was to laugh a lot. This was a theme in several families.

Others spoke of pragmatism, and this quote summed them up. ‘If you want to do something, just do it.’ Others said that you cannot expect things just to come to you; you have to go out and look for support. One of the larger

families advised not to limit the size of your family just because you have one child with autism. Another advised not to neglect the normal children in the family.

Time for yourself and time out, was another recommendation, including leaving the room until calm had been restored, sometimes with the aid of a bottle of 'Pinot Grigio' (white wine), sometimes by having a soothing bath by candle light. One father found his time at the gym was his way of letting off steam.

### 9.7.3 Practical Tips

Many parents said how helpful it had been to use visual clues to improve understanding and help with the concept of appreciating time passing. The visual calendar was advocated by many. Visual reward charts to bring about behavioural change such as potty training were often praised. Picture cards to help develop vocabulary, and the Picture Exchange Communication system (PECS) were all found to be useful tools. A sentence builder with words kept in a box was advised by one parent as a way of getting their child to start reading. Another parent used the Mr. Men books to teach the alphabet. One mother had started to get her teenage son interested in the concept of autism by watching TV programmes with her about people with autism.

Perhaps the most generally applicable visual aid was the use of lists. Many families used these to help with dressing in the morning but also continued to

use them for their adult autistic youngsters as an aide memoire for coping at the airport or on the train.

Another group of practical advice was around helpful devices such as a harness for a young child to stop him running off when the family were out. By the same token the supermarket trolley was used to prevent unwanted disappearance. One ingenious device was the use of a tuck box for the adult young man at training college. The mother was worried about the things her son was buying from the tuck shop each day which were mainly high in calories, so she put suitable edibles into the tuck box with the price of each object attached to it. She also gave her son some money to buy back these things from the tuck shop after he had handed them over at the beginning of the week. The tuck box therefore had two purposes, one to offer her son suitable snacks and the other to teach him about money and change. Another recommendation came from a speech therapist which was to buy a dolls house even for boys so that the parents could discuss the vocabulary of every-day objects while playing with their child.

#### 9.7.4 Useful Services

The following services were recommended, in the study area, as being of particular help: the specialist autism nurse, and the mental health team who managed children with intellectual disabilities and challenging behaviour. Other professionals from the social services and educational psychology were singled out for praise. (Although there were other individuals from these departments who came in for particular criticism also). Also some private

speech therapists, volunteers from SSAFA, and many individuals from a local private provider of advice in occupational therapy and clinical psychology were particularly lauded. Various groups were recommended including the National Autistic Society, particularly for their information, 'Asperger Norfolk', and the Portage pre-school group. Allied to this was a request for the services to develop more help specifically aimed at parents and how to manage aggressive behaviours and use safe methods of restraint.

The in-class support given by certain classroom support workers and individual teachers was a firm recommendation from several parents. The 'Pathfinder' programme for special needs support was also praised. Respite Care provided by Children's Services was a real life-line for many parents and received almost universal praise. The main criticism was that it was limited to severe cases, and that parents themselves often refused to accept it for years, on the mistaken belief that they would be seen to be failing if they accepted that sort of help.

The Early Birds programme for newly diagnosed families was recommended by most families but it does involve group participation which does not suit all individuals.

On the financial front various parents recommended the 'Family Fund', the 'Disability Living Allowance', and the 'Social Services' financial aid which had assisted families in making adaptations to their homes which had

revolutionised their way of life by improving sleep patterns and allowing the autistic youngsters to have more independence.

### 9.7.5 Changes to the environment

Many parents benefitted from home improvements such as an additional room for one or more of the autistic children. This was provided by the Social Care department following a needs assessment and means testing. Other improvements greatly enhanced family life such as a safe garden, with containing fence or additional play material such as a safe trampoline.

All these factors came as recommendations from the parents in this study to future parents. The next section will be a summary of the recommendations drawn from the entire study which hopefully will be useful to the service providers for people with autism.

## 9.8 Implications and author's recommendations arising from of the study

The main implication arising from this study was that families with more than one autistic child are a very resilient group. The diagnosis of the second or subsequent child with autism did not make coping worse. The stresses which are associated with autism do appear to promote coping, even in families which were previously rather chaotic. But various factors can derail their

coping strategies and professionals should be on the look-out for these so that an enhanced level of support can be given in order to prevent family breakdown following on from a perilous coping episode. The proposed model of perilous or buoyant coping could be used and tested in clinical practice.

The main negative situations leading to perilous coping were all the intervening conditions such as child protection incidents, mental health problems, in children and parents, parental separation, unexpected deaths, additional diagnoses, and very late diagnosis of the affected children. If these factors are better recognised by health professionals, some of the perilous situations might be avoided.

On the other hand if the factors which seem to promote buoyant coping can be encouraged then there should be enhanced levels of resilience in the families. The main things which helped produce buoyancy were early diagnosis with clear information; good family support, especially extended family support wherever possible; good respite care; supportive school placements; larger families; structure and routine and informal support networks of friends and colleagues and professionals who understand about autism and can be available for families when they are needed.

All the families in this study did cope with very complex and difficult situations; they all showed buoyant coping for the majority of the time but all also had episodes when their coping became perilous. By dealing with some of the problems that caused the perilous periods the families showed that

they could return to buoyancy again. A greater awareness in both professionals and families about which factors contribute to perilous episodes should promote family cohesion.

### 9.8.1 Recommendations

#### For Clinicians

- 1 The main source of support which improved coping in this cohort was the family and the extended family. It is therefore extremely important that as many family members as possible are included in the assessment process and the feedback session at the end of the assessment for the diagnosis of autism. If grandparents could attend these sessions more, that might improve their understanding of autism, point them in the right direction for obtaining further information and improve the likelihood of their supporting the affected family.
- 2 Another way of improving support from the extended family would be to offer the Early Birds programme specifically for grandparents or to include grandparents more in the existing programmes.
- 3 Clinicians need to share their diagnostic thoughts with families as early as possible in the assessment process to improve the rate of acceptance of the diagnosis by parents.
- 4 Clear information about possible causes of autism should be given at diagnosis, in particular the absence of evidence that MMR is a causative factor.

- 5 Clinicians could do more to explore informal support networks at the time of diagnosis and subsequently.
- 6 The perilous and buoyant coping models could be used to predict problems with coping.
- 7 The risks of having a second or subsequent affected child should be shared with families following the diagnosis of the first child.
- 8 Some of the novel approaches to child minding such as the lodger 'pseudo- grandparents' could be shared.
- 9 Clinicians need to be more aware of the effects of additional diagnoses on the coping abilities of families.
- 10 Children with autism would benefit from information sharing with them to improve their understanding of their condition.

#### For schools

- 1 Early referral of children with bewildering behaviours can lead to extra support. The more schools understand about autism and its various presentations the better for all children with autism in school.
- 2 Good planning for future educational placements leads to happier parents and schools alike and ultimately to calmer children.
- 3 Children in mainstream school would benefit from understanding more about ASD as a way of preventing bullying.
- 4 All professionals need to be aware of the likelihood of 'Safeguarding' problems in these families.

#### For Social care

- 1 The implications of service cuts such as respite care and 'direct payments' would lead directly to perilous coping.

- 2 The benefits of the provision of extra rooms should be more widely known about as a major help, and source of improvement in coping.

#### For the Voluntary sector

- 1 An abbreviated summary of this study could be made available to the National Autistic Society (NAS).
- 2 The range of cognitive strategies discussed by parents could be shared with the NAS to help future parents.
- 3 The use of digital media as a way of communicating between parents could be enhanced, and many parents would welcome this.

The main recommendation from the study is that this complex group of families is capable of considerable resilience. The message about having children with autism needs to change, from one which is quite negative and frightening for parents, to one which demonstrates the great joys these children can bring to the family and that in spite of added problems these children are capable, in most cases, of enhancing family life if the right supports are put in place.

## **9.9 Conclusion**

Families with more than one child with autism are a very uplifting group to study who have many positive messages for the non disabled world. Their diagnoses need to be made early so that appropriate strategies can be

implemented quickly to the benefit of the whole family and society. The fact that a family has more than one child with autism is not a negative situation and the non autistic world could do well to adapt its views on autism from a position of pitying to one of embracing the differences that autism brings to a family which can be mainly positive. At the same time the appropriate services need to be in place to support these families.

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