An exploration of an Internet discussion forum for Autism Spectrum Disorders in relation to Self-Help/Mutual Aid groups and helping processes.

Thesis submitted to the University of Leicester in partial fulfillment of the Doctorate in Clinical Psychology.

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2007

Acknowledgements

I would like to thank Marilyn Christie for all her thought, hard work and inspirational discussions. I would also like to thank Alison Eviors for her thoughtful comments and useful suggestions. Many thanks are also due to the members of the online forum, as without their interest, consent and encouragement this project would never have happened.

Thanks are also due for the efforts of my family, especially my husband, in keeping me motivated and giving me encouragement throughout the long process of completing this project.

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Overview

The Literature review examines parenting a child with a developmental disorder focusing on what factors may contribute to parental stress and coping strategies employed to manage it. The review examines how three models of coping and adjustment predominately used in this field (Lazuras and Folkman's (1984) Process Model of Coping, McCubbin and Patterson's (1983) Double ABC-X model of Adjustment and Adaptation and Antonovsky's (1987) model of Sense of Coherence) relate to the findings on how these parents cope. Families found numerous styles of coping and varying resources helpful as long as it was responsive to a particular event or crisis. Ultimately, the paper highlights the need for more services that are tailored to individuals and families needs across the whole life-span and further research into how clinicians can assist parents to develop more coping strategies and resources.

The research paper explores an Internet discussion Forum for Autism Spectrum Disorders. 135 message threads were downloaded from an online group and analysed using Template Analysis. The first analysis aimed to investigate how the forum was being utilised and the second analysis explored whether helping processes as identified by Finn (1999) were present. Analysis one showed that the site was used to share personal stores, evoke a sense of community, exchange information as well as provides advice on how to manage professional input. Analysis two showed that helping processes were present and that providing support, catharsis, universality and providing information were key processes within the group. The group appeared to provide a service for carers and may be of benefit to others living with a disorder and could be an adjunct to professional services.

The critical appraisal explores some of the methodological considerations that arose during the study of the online forum.

Literature Review:

Parenting Children with Developmental Disabilities: stress and coping

1. Abstract

Objectives: To review the literature on parenting a child with a developmental disorder focusing on what factors may contribute to parental stress and coping strategies employed to manage it. Design: The review examines how three models of coping and adjustment predominately used in this field (Lazuras and Folkman's (1984) Process Model of Coping, McCubbin and Patterson's (1983) Double ABC-X model of Adjustment and Adaptation and Antonovsky's (1987) model of Sense of Coherence) relate to the findings on how these parents cope. Results: Families found numerous styles of coping and varying resources helpful as long as it was responsive to a particular event or crisis. Conclusions: Ultimately, the paper highlights the need for more services that are tailored to individuals and families needs across the whole life-span and further research into how clinicians can assist parents to develop more coping strategies and resources.

2. Introduction

Research has indicated that parents of children with developmental disabilities[1] are at greater risk of developing psychological difficulties than parents of children without disabilities (Bromley, Hare, Davison, & Emerson, 2004; Fombonne, Simmons, Ford, Meltzer, & Goodman, 2001; Sanders & Morgan, 1997). Caring for a child with special needs frequently requires the parent to learn specialist knowledge and skills, as well as to find the time for extensive care-giving tasks and collaboration with health care professionals (Hill & Zimmerman, 1995; Traustadottir, 1991). Research has been conducted among families of children with developmental disabilities (DD) spanning across the parental experience of receiving a diagnosis of a disability, family adjustment, parental health and wellbeing, family interaction, and the needs of parents and families. One of the aims of this research has been to understand the unique challenges these parents may face, helping clinicians predict and therefore pre-empt these challenges in the hope of reducing stress and psychological difficulties. What will become evident in the current review is the need for further research into how and when parents feel stress, as well as continuing need for services that are tailored to meet the needs of individuals and families across the whole life span. In addition there is a need for greater appreciation for how families are coping with raising a child with a DD and understanding of how clinicians can assist parents to develop more coping strategies and resources.

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[1] The term Developmental Disorders refers to a diverse group of pervasive conditions that are diagnosed in childhood and are due to mental and/or physical impairments. Some of the conditions that fall within this category include Autism, Asperger Syndrome, Retts Syndrome and Fragile X syndrome. The severity of the conditions can vary from mild impairment to severe impairment.

The aims of the current review were:

1. To briefly review the research on factors contributing to parental stress when caring for a child with a developmental disability.

2. To outline the models of coping and adjustment predominately used in this field, and;

3. To explore the research evidence on coping and parenting a child with a developmental disability in relation to three models of coping and adjustment.

The current review is relevant to health care professionals and their practice because of the implicit objective and role to reduce distress and increase coping throughout the health care field. Furthermore health care professionals need to be aware of and understand the impact that developmental disorders have on wider systems, removing the focus from the individual, so that they can develop services and interventions that are appropriate for families and various institutions.

The literature was sourced from several databases, including PsychArticles, Psyinfo, ScienceDirect, Ingenta, ASSIA and INFOTRAC, as well as searches of reference lists in books and journals. The majority of the literature falls between 1990 and 2007, although a few papers have been included from the 1980's or earlier as they were key articles. The keywords that were used were Developmental Disability, along with carers, parents, caring for, care-giving, living with, coping, stress, strategies, support and self-help. What this review has excluded are papers that have examined

caring for physically disabled children, including brain injuring and any papers that solely examined the properties of a psychometric scale in relation to parenting a child with a developmental disorder.

3. Factors contributing to stress when parenting a child with a developmental disability.

It is generally considered that parenting a child with a developmental disability (DD) is uniquely challenging and can produce immense stress (Dyson, 1997; Smith, Oliver, & Innocenti, 2001). Lazarus and Folkman (1984) described stress as a continuous relationship between a person, environmental factors and the emotion experienced when a situation is appraised as demanding or threatening and exceeds their resources to cope with it. Abidin (1990) went on to categorise parenting stress as stress observed by the parent that occurs from the demands of being a parent. Research has suggested that there are multiple reasons for, and factors contributing to, parental stress when parenting a child with a DD. These have included the difficulties associated with parent-child interactions, financial hardship, stigma, limited time and difficulties with care-giving tasks and challenging behaviour (Ello & Donovan, 2005; Gray, 1997; Shultz & Quittner, 1998). However, there is some research that suggests that not all parents of a child with a DD experience more stress than parents without a child with a DD (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006; Dyson, 1991). It is therefore important to identify the factors that contribute to the experience of stress and the barriers that hinder a particular parent or family from coping with them. This is so that

professionals can have a greater understanding of what the experiences and needs of families that are experiencing stress are, and can develop services and interventions targeted at reducing barriers to coping.

3.1. Individual Characteristics

Much of the scientific research has focused on family characteristics and ability to adjust to the 'tragedy' of having a child with a DD (Kearney & Griffin, 2001). Models of attachment and stages of the grieving process (Bowlby, 1980; Lavoie, 1995), as well as psychoanalytic models of denial and defence mechanisms (Brown, 1993) have been used to interpret and understand parental reactions to having a child with a DD. Individual characteristics and wider environmental factors have also been examined using various methods to understand and predict parental stress. What follows is a brief summary of the research that has been conducted into some of these factors.

3.1.1. The Gender of the Parent

The gender of the parent has been examined in an attempt to establish if there are any measurable factors that can predict parental stress. Studies have produced variable results, some of which indicate that females are more vulnerable to stress than males (Weekes, MacLean, & Berger, 2005; Aneshensel, 1992). Other studies suggest that mothers and fathers with a child with a DD are both susceptible to stress, but that different factors may influence this vulnerability (McCarthy, Cuskelly, Van

Kraayenoord, & Cohen, 2006; Keller & Honig, 2004; Krauss, 1993; Beckman, 1991).

Researchers have relied heavily on self-report questionnaires and/or interviews with

parents and there are a limited number of longitudinal studies examining gender when

parenting a child with a DD. Nevertheless, a number of studies have indicated that

fathers' stress appears to be related more to the child's temperament and their personal

relationship with their child, whereas mothers' stress is reported more in terms of role

restriction and marital relationship (Keller & Honig, 2004; Krauss, 1993; Houser &

Seligman, 1991). These findings can help clinicians understand varying parental

adjustment to and coping with raising a child with a DD. When working with families,

the different reasons attributed to feelings of stress should be borne in mind and inform

any assessment or formulation of the family's and the individuals coping with stress and

adjustment to parenting.

3.1.2. Marital Relationship

Marital relationships have also been investigated in an attempt to unravel the reasons

for and experience of parental stress when caring for a child with a DD. Marital

relationships have been identified as an important aspect to well-being and family

functioning (Sloper, Knussen, Turner, & Cunningham, 1991). Some research has

identified the quality of this relationship as a significant predictor to parental stress in

families who have a child with a disability. Dissatisfaction and distress with the marital

relationship could be suggestive of parental stress or an extra stressor placed on the

parent; it could also adversely affect the parent's perception of the child with a DD

(Sloper *et al*, 1991; Cuskelly & Dadds, 1992). Whereas, a good marital relationship may be considered as a resource for the parent, acting as a buffer from the impact of caring for a child with a DD (McCarthy *et al.*, 2006). Kersh *et al.* (2006) found, after analysing 67 married couples using a variety of self-report questionnaires, that parents of children with a DD had lower quality marriages than others in the general population married for a similar length of time. However, the findings were only slightly linked to characteristics of the child, suggesting that something outside of directly caring for their child with a DD was contributing to marital quality. McCarthy *et al.* (2006) on the other hand found that parents of children with fragile X syndrome had similar marital quality to that of the general population. Baker *et al.* (2005), after examining data from 214 families with and without a child with a DD, also found no difference in marital relationship between the two groups. Further research needs to be conducted with larger numbers, different groups of parents caring for children with different developmental disabilities and over longer periods of time to establish if parenting a child with a DD affects marital quality. Nevertheless, it is important for clinicians to be aware that, and assess for, other factors outside the primary task of care-giving that may be contributing to the stress experienced by a family presenting to services.

3.2. External Factors

There have also been a number of researchers who have focused on factors outside of the individual parent or marital relationship. This body of research has found that there are various practical implications to parenting a child with a DD that may

contribute to parental stress. These include child-care difficulties, employment problems, child behavioural problems and social support (McDonald, Poertner, & Pierpont, 1999; Shultz & Quittner, 1998; Seltzer & Heller, 1997; Bernstein, Svingen, & Garfinkel, 1990).

3.2.1. Characteristics of the child

Greater parental stress has been found to be associated to characteristics of the child, for instance, through demanding and difficult behaviour, emotional problems and the level of functional communication abilities the child has (Ello & Donovan, 2005; Hastings, 2002; Baker, Blacher, Crnic, & Edelbrock, 2002; Stores, Stores, Fellows, & Buckley, 1998). Plant and Sanders (2007) examined data collected from 105 mothers of preschool-aged children with DD on predictors of parent stress. They found that difficult care-giving tasks and child behaviour problems during care-giving tasks were the most significant contributors to parent stress. They also found that the level of a child's disability was linked to higher levels of stress, although to a lesser degree. However, only the mothers' of children with DD, who had self-referred to the study, had provided self-report data therefore limiting its generalisability. Baker *et al.* (2005) also found that child behavioural problems were a high predictor of lowered maternal well-being. Herring, Gray, Taffe, Tonge, Sweeney, and Einfeld, (2006) conducted research over a one-year period with 123 families of children with DD. They used several standardised and self-report measures to assess the developmental age and adaptive functioning of the children, as well as parental mental health and stress and an

evaluation of family functioning. They found that child behavioural and emotional problems and parental distress were positively correlated. However, they concluded that the parents subjective experience of stress could have influenced their perception of their children's problems and objective measures, such as from teachers, could have corroborated their reports. Furthermore the uneven and unpredictable pattern of development is a continuous source of stress for parents raising a child with a DD (Schumtermann, 2002). However, further research needs to be conducted with larger sample sizes and diverse participants to verify these findings.

3.2.2. Demographics

Demographics have also been considered in relation to parental stress when caring for a child with a DD. Mixed findings have been reported in relation to the comparative weight that factors such as age and gender of the child as well as the marital and socioeconomic status of the parent in families raising a child with a DD have (Harrison & Sofronoff, 1997). Some research has indicated that mothers with higher education or qualifications have higher-self esteem, which may be considered a coping resource when negotiating with services or difficult caring-tasks, leading to reduced stress (Argyrakouli & Zafiropoulou, 2003; McConkey, Truesdale-Kennedy, Chang, Jarrah, & Shukri, In Press). Further research spanning all socioeconomic clusters and cultural variability needs to be conducted. Yet, what is important to note is that research overall has indicated that, regardless of socioeconomic status or level of education, the odds of a mother providing intensive home care for their child was the same (Leiter, Krauss,

Anderson & Wells, 2004). Therefore, in general, as it is the mothers who provide the

bulk of the on-hands care of the child, it is vital that clinicians explore the impact of this

with mothers in terms of their parental expectations, their role, self-esteem and identity.

3.2.3. Parental Employment

Fewer parents of children with disabilities are employed compared to parents of

children without a disability (Beresford, 1995). Employment has been conceptualised

as a break or buffer from the difficulties related to caring for a child with a disability

and can play a 'vital and positive role' in financial, health and psychological well-being

(Freedman, Litchfield, & Warfield, 1995). Despite this, parents of children with a DD

may find it difficult to secure adequate childcare and assistance from family and friends

to support their role as a worker (Freedman *et al*., 1995; Warfield & Hauser-Cram,

1996; Quitner *et al.,* 1990). Seltzer, Greenberg, Floyd, Pette, and Hong, (2001) found

that parents of children with a DD continuously reduced their working hours over their

adult life. This may be a reflection of the different life cycle that a child with a DD will

have and how it impacts on parents. Parents in general can usually anticipate that as

their child grows older they become more independent, whereas a child with a DD will

often require life long assistance and support on a daily basis. However, parents of

children with a DD who do manage to work and experience the stress buffering effect

of it (Freedman *et al.,* 1995) still encountered childcare problems that are a barrier to

managing both caring and working roles (Kagan, Lewis, Heaton, & Cranshaw, 1999).

This is of critical importance to services and individual clinicians attempting to engage

families in therapeutic interventions. The practical difficulties faced by these parents

may make it near impossible to carry out any treatment programme offered or even to

attend appointments and should not be overlooked as a source of stress.

3.2.4. Social Support

In addition, researchers have investigated inadequate social support as a source of

stress for parents of a child with a DD. It has been established that parents of disabled

children's networks of informal support is likely to be small leading to less availability

of 'unofficial' care and may contribute to higher levels of parental distress (Beresford,

1995; Quitner, Gluekauf, & Jackson, 1990). Research has also shown that parents of

children with disabilities are more likely to experience social isolation and

stigmatisation and that social support can protect and maintain physical and

psychological health and lessen the impact of stress (Kazak, 1987; Cohen & Wills,

1985; Lindberg, Bohlin, & Hagekull, 1994). Also negative societal attitudes towards

disability can have an adverse affect on the stress of the parents (Dyson, 1993).

3.3. Summary

In summary it is clear that there are a number of contributing factors to parental

stress when caring for a child with a DD. Both internal and external factors play a role

in generating stressors, although it is clear that individual parents can respond to

different stressors in different ways and that they do not necessarily lead to the

experiences of stress (Lam, Giles, & Lavender, 2003). How parents appraise their child's difficulties and a carer's style of coping, as well as the social support they receive will all affect the family's stress in an ongoing process (Lam *et al.*, 2003). Yet, when a parent feels overwhelmed by stress the effects can be negative for them and the whole family (Plant & Sanders, 2007). Higher levels of coercive parent-child interactions, drop-out from parent training and parental depression are all examples of the impacts of care-givers stress (Moes & Frea, 2000; Andra & Thomas, 1998; Gray 2002).

4. Models of coping

Psychologists have extensively studied the coping process and there are several models that attempt to explain the different ways in which people cope with stressful situations. Within the literature regarding caring for a child with a DD, three models are prominently applied: Lazuras and Folkman's (1984) Process Model of Coping; McCubbin and Patterson's (1983) Double ABC-X model of Adjustment and Adaptation; and Antonovsky's (1987) model of Sense of Coherence. The following section briefly outlines these models before going onto explain how they may be applied to research on parents caring for a child with a DD.

4.1. Process Model of Coping

According to Lazarus and Folkman (1984) the process of coping is a dynamic effort that moderates the effects of stress on an individual's well-being, consisting of coping strategies that attempt to manage the problem. The model stipulates that the individual's evaluation of the stressor is a key component to coping and allows for individual differences regarding the appraisal of similar events and circumstances. Coping itself has been divided into three main approaches or strategies that the individual engages in: Emotion-focused, Problem/Task-focused and Avoidance. Emotion-focused coping strategies concentrate on changing the emotional reaction to the stressor, whereas problem-focused strategies focus on changing the environment through an active reaction. Avoidance strategies focus on seeking to deny or avoid the stressor. Coping resources (namely what is available to that individual, e.g. social support) are then engaged to assist the person to achieve a positive outcome. Emotion-focused and problem-focused strategies have been associated with more successful adjustment whilst avoidance strategies have been connected to poorer adjustment (Heiman, 2004). This model encapsulates the active approach taken in response to a direct stressor but it seems to suggest that coping is less dynamic, offering only fixed coping strategies that do not appear open to change or development. There is also no description of how individuals have developed their coping strategies or how much time is necessary before the strategies are implemented or discarded if not working.

4.2. Double ABC-X Model of Adjustment of Adaptation

Hill's (1949) ABC-X model of stress was expanded by McCubbin and Patterson (1983) into the Double ABC-X model. The later model is fluid and can be adjusted to a family's current situation bearing in mind that this situation may change over time. The model incorporates post-crisis variables, such as additional demands being placed on the family at that time. The process is broken into five stages: aA) the initial stressor including the severity of it and the pile up of demands, bB) the family's adaptive resources applied to manage the stressor, cC) the family's appraisal, changing definitions and understanding of the stressor, BC) the coping strategies employed and XX) outcome\adjustment. This model incorporates the research that has found that the severity of a stressful event as well as the amount of demands being placed on a family have a role in whether an event is conceptualised as a crisis. Once a crisis has been identified the family's social and psychological resources for meeting the demand are engaged. The family also attributes meaning to the whole experience, including the initial and additional stressors, resources and thoughts about resources that are needed to rebalance the family. This is a vital role as the meaning that is placed on the situation can either facilitate or diminish the ability to adjust to it. McCubbin and Patterson go on to suggest that coping in itself is a bridging process between the cognitive perceptions, behavioural responses and resources available so that balance is restored. How this is achieved is through the mechanisms identified by Lazarus and Folkman (1984) i.e. task or problem focused strategies and emotion focused strategies. Finally, adjustment is the outcome of the family efforts to achieve a new level of balance. This

model is similar to Lazarus and Folkman's (1984) Process Model of Coping in that it is a dynamic model that incorporates the family's current circumstances, well-being and resources into the process of adjusting. However, the actual coping strategies engaged are still statically described, although there is an implicit assumption that appropriate strategies will be utilised depending on the present state of the family and their interpretation of the stressful event and the type and amount of resources required to cope with it.

4.3. Sense of Coherence Model

Antonovsky's (1987) model of Sense of Coherence is based on the suggestion that to predict the effect of stressful situations on an individual we must first know something about their view of themselves and the world as well as their current health and well-being. This is because a person develops an understanding over time about stressors and stimuli, which cumulates in a pervasive and enduring, yet dynamic, sense of confidence that the world is comprehensible, manageable and meaningful, which he called a sense of coherence. If an individual has a strong sense of coherence they are more likely to define a stressful event as non-stressful or less threatening and assume that they can adjust or adapt to these new demands than someone with a weak sense of coherence. Individuals with a strong sense of coherence can draw on implicit resources, such as an underlying belief that there will be resources available to manage the stressful event, which can lessen the emotional arousal evoked by a stressor. Therefore a person's appraisal of the event will affect how they cope with it. Using Antonovsky's

ideas, it could be assumed that individuals with a strong sense of coherence would be more likely to have confidence in their ability to manage and work through a crisis and therefore may choose the more active coping strategies, such as social support or task orientated problem-solving. Whereas individuals with a weak sense of coherence would be more likely to have less confidence that things would work out and therefore perhaps be more passive and avoidant in their choice of coping strategies (Olsson & Hwang, 2002).   Antonovsky's concept of the individuals' worldview having a significant impact on their ability to manage stressors can also be conceptualised in terms of an individuals' actual or believed power in the face of stressors. This power dynamic has been outlined in other models and theories such as locus of control research (Gianakos, 2002), self-efficacy (Caprara, Pastorelli, Camillo, Scabini, & Bandura, 2005), self assertion (Bauman, 2005), and learned helplessness (Peterson, Maier & Seligman, 1993) which all connect individual positive power dynamics with psychological well-being, and lack of power with psychological illness (Orford, 1992).

4.4. Summary

These three models have several things in common and can conceptually work well together. They all incorporate the idea that a person's appraisal of the situation is key to their ability to access coping resources and select appropriate methods of managing the event. They are all dynamic models that acknowledge the effect of cumulative experiences and varying demands on an individual at any one point in time. All three models also draw on Lazarus and Folkman's (1984) ideas about the actual coping

strategies open to someone (i.e. task focused, emotion focused or avoidant). Lazarus and Folkman's (1984) model and McCubbin and Patterson's (1983) model both hint at the issue and effect of availability and access to practical support such as social and financial support. This seems to be a crucial element to any coping process as an individual may be able to positively appraise a situation and identify task or problem focused strategies to cope with it, but may simply not have access to any resources in which to achieve these aims. Therefore such a person would be unable to cope with the events and would remain in a crisis, unless they could access emotion focused coping strategies. This has particular relevance to parents raising children with a DD as research has indicated that they may be more socially isolated, more financially impoverished and socially stigmatised, limiting their access to resources. Therefore their ability to successfully engage emotion-focused strategies appears to be essential. It is also important to note that the models all talk about a dynamic fluid element to the process of coping and that therefore individuals may need to re-assess or change coping strategies or use several together in order to successfully adjust to a crisis, although none of the models elaborate on this or give any indication of how much time may elapse before changes to coping strategies occur.

The three models of coping and adjustment outlined above can help clinicians to gauge where a family or individual is in relation to reacting to a stressor or an accumulation of demands and help them to move through the process, re-evaluate it or to develop strategies to successfully cope with it. They may also give us an insight into why a family is coping or has stopped coping due to an accumulation of demands, a

negative appraisal of the situation or an inability to access appropriate resources. As highlighted previously, clinicians should also be aware of the social and financial implications of raising a child with a DD and how this will affect their ability to appraise a stressor as non-threatening and to engage successful strategies to manage it.

5. Coping with parenting a child with a developmental disorder.

In an effort to test out the theories on coping, researchers have examined what coping processes parents of children with a developmental disability employ and the effectiveness of these strategies. Each of the models described above highlight the importance of appraising the event and the interaction between the appraisal and the coping strategies employed by the person to manage the situation. What follows is a summary of the relevant literature framed within the processes (i.e. appraisal of the stressor) described in the models outlined about.

5.1. Appraisal of the Event

Lazarus and Folkman (1984) and McCubbin and Patterson (1983) both state that the individual in context of their current situation and personality factors appraises the event or stressor. Antonovsky (1987) also refers to a person's cumulative experience as contributing to their worldview and therefore their interpretation of an event or stressor. Research into coping with parenting a child with a DD has shown this initial process to be a helpful theory. Trute and Hiebert-Murphy (2002) promote the usefulness of

assessing parents' initial appraisals of the impact of having a child with a disability as both the positive and negative appraisals have been found to be prominent predictors of caregiver psychological well-being. Research has also made the link between personality type and the coping strategies employed by the individual. For example, Neuroticism has been strongly linked to emotion-focused coping and Extraversion has been related to rational action, support seeking and positive thinking (Costa, Somerfield, & McCrae, 1996). This suggests that numerous factors and influences must be considered when thinking about how an individual or family has appraised a stressor, but also that the initial evaluation of the event has an impact on the coping process. Clearly further research into this stage in the coping process needs to be undertaken. Questions about the weight of factors such as personality, accumulation of demands or our worldview need to be addressed. Practitioners could then make accurate assessments regarding the impact that circumstance or personality has on the appraisal of stressful events and therefore how an individual or family may proceed from this position.

5.2. Meaning Making

Research has also examined the process of finding meaning in parenting a child with a DD as one of the ways in which a parent may cope with it. This idea sits well within Antonovsky's (1987) theory of Sense of Coherence.   Essentially he argues that individuals who inherently believe that the world is meaningful and comprehensible have a stronger sense of coherence and are therefore able to interpret challenges or

stressors as less threatening and more manageable than individuals with a weak sense of coherence. McCubbin and Patterson (1983) also stress the importance of the families' understanding of the stressors and how this may change with time, which helps them to evaluate what resources they need to overcome it. Other researchers (i.e. Taylor 1983; Taylor & Armourm, 1996) suggest that cognitive adaptations such as, benefit finding, or 'meaning-making', help individuals to reduce the negative impacts of a stressor and helps to maintain self-esteem. Within Lazarus and Folkman's (1984) model this process may be conceptualised as an emotion focused coping strategy.

Kearney & Griffin (2001) explored the meaning that six parents had placed on raising a child with DD and found that although it was often times challenging, each parent had clearly described developing new perspectives on life, finding new meaning and being strengthened by the experience. All of this made it easier to cope with the challenges of raising a child with a DD. Pakenham, Sofronoff & Samios (2004) explored the meaning and benefit-finding that 59 parents of children with Asperger Syndrome had. They concluded that the severity of the stressor was unconnected to the meaning variable yet there were higher levels of benefit-finding and sense-making when there were increased demands. The study included data from both mothers and fathers, using qualitative and quantitative methods but relied solely on self-report data. Other studies have also found that parents of children with medical illnesses or disabilities (Krauss & Seltzer, 1993; Patterson & Leonard, 1994; Park, Cohen & Murch, 1996; Affleck, Tennen, & Rowe, 1990, 1991) have reported personal growth, strengthening of relationships and changes in life goals and priorities as benefits of

facing adversity, as well as increased levels of finding meaning. One explanation for these findings is that the difficulty faced by these parents is so powerful that it disrupts and challenges individuals' worldviews and sense of purpose in life, which drives the search for meaning (Tedeschi, Park & Calhoun, 1998).

5.3. Re-assessment of the Stressors

The dynamic process of appraising or making sense of an event or experience highlighted in all three models could incorporate the need to reassess a stressor if the coping strategies initially engaged does not lead to successful coping. There is increasing evidence that positive reframing of stressful or traumatic events could be one of the only effective ways of coping with a situation in which it is extremely difficult to directly reduce the impact of the stressor. Hastings and Taunt (2002) go further and suggest that parental positive perceptions about children with severe disabilities might operate as an adaptive function by helping them to cope with the high levels of stress. In the main, sense making has been shown to be associated with better adjustment of parents with children with disabilities (e.g. Behr & Murphy, 1993) however, further research with larger sample sizes, randomised sampling and cross sectional designs needs to be conducted to continue to support the findings.

5.4. Engaging Coping Strategies

Once the appraisal or sense-making of an event has occurred, the models of coping

and adjustment describe a process of engaging coping strategies that will hopefully lead

to a positive outcome. The choice of coping strategy appears to be based on two things.

Firstly the appraisal of the situation as discussed previously has an influence on what

strategies are employed. Antonovosky's (1987) theory suggests that if the stressor is

deemed manageable or meaningful it is more likely that the individual has a strong

sense of coherence and will probably therefore engage active coping strategies (Olsson

& Hwang, 2002). Secondly, Lazarus and Folkman (1984) and McCubbin and Patterson

(1983) both suggest that the resources available to the individual or family has an effect

on what strategies are used. Bearing in mind that the previously discussed research

suggested that parents of children with DD have reduced social support and are less

likely to be gainfully employed (Beresford, 1995), will already influence what parents

are able to access in terms of active or positive coping strategies.   Along with other

stressful situations that have been investigated, the research into coping with raising a

child with a DD has generally found that parents who have engaged problem-solving or

social support strategies have reported more positive adjustment outcomes than those

parents who have employed escape, avoidance or denial focused strategies (Stone-man

& Gavidia-Payne, 2006; Abbeduto, Seltzer, Shattuck, Krauss, Orsmond, & Murphy

2004; Essex, Seltzer, & Krauss, 1999). However, further research needs to be

conducted into whether coping strategies are trait or state dominated and how individual

differences influence their use and effectiveness (Lazarus *et al*., 2006; Krohne, 1996) which makes it difficult to draw concrete conclusions from the body of research.

Nevertheless, the research that has been conducted has found that women use a more emotional and expressive manner and are more likely to look for social support from family and friends and that men use an inexpressive and uncomplaining manner of coping (Thoits, 1995). Thus the research (i.e. Borden & Berlin, 1990; Kvam & Lyons, 1991; Lazarus, 1993; Sigmon *et al*., 1995) has generally continued to distinguish between problem-focused and emotion-focused coping strategies as found in Lazarus and Folkman's (1984) model of coping and referred to in McCubbin and Patterson's (1983) Double ABC-X model and Antonovsky's (1987) model of Sense of Coherence.

Research in the area of parents raising a child with DD has found that parents of children with a DD engage in all three styles of coping strategies as outlined by Lazuras and Folkman's (1984): problem focused, emotion focused, and avoidance. Hastings, Kovshoff, Brown, Ward, Espinosa and Remington (2005), when investigating the coping strategies that both mothers and fathers used, found that problem-focused coping strategies were not connected to parental stress or mental health. They did however find that active avoidance coping strategies were linked to increased stress and mental health problems for both parents, although larger samples sizes will need to be used to verify this finding. Pakenham, Samios and Sofronoff (2005) also found in mothers of children with Asperger Syndrome that problem-focused coping strategies were unconnected to adjustment. In addition, other research (Dunn, Burbine, Bowers &

Tantelff-Dunn, 2001; Hastings and Johnson, 2001) has found that active avoidance coping strategies are unhelpful when attempting to manage the demands of raising a child with DD.

Sivberg (2002), when examining the coping behaviours of families raising a child with autism, found that parents used 'distancing' and 'escaping' more than families with non-autistic children who used social support and problem-solving coping strategies more. However, they only compared their sample with families with typically developing children rather than with families with children with other disabilities or DD, meaning that this result could be unique to the experience of autism rather than DD. Kravetz, Nativitz, and Katz (1993) found that there was no differences between females and males when engaging problem focused coping strategies but that females used more emotion focused coping strategies. Conversely MacDonald, Fitzsimons and Walsh (2007) found that female carers reported that problem solving coping strategies were more helpful than did male carers, although the sample may have been skewed due to the self-selecting nature of participation. One explanation for this could be that as mothers are generally the predominant caregivers that task orientated or problem solving coping strategies are more useful in tackling the daily caring tasks. This idea was supported by Gray's (2003) research that found that mothers of children with a DD had to manage different tasks and therefore concluded that it was not that mothers were coping less successfully than fathers, but that their situations and stressors were fundamentally different.

Although the research provides useful insights into which coping strategies may be employed by both mothers and fathers raising a child with DD, more research needs to be conducted to verify the findings. The findings need to be compared to other families with disabled children and non-disabled children. Different measures and methods need to be engaged, as there is a strong leaning towards using questionnaires. Longitudinal studies also need to be conducted to examine the effects of time and whether parents continue to engage the same strategies throughout the life span and if they continue to be effective. Yet, Lazarus (1996) suggests that the division made between the two styles of coping strategies is more present in principle than in practice, as he has found that people tend to use a complex mix of both strategies when dealing with particular stressors. However, in terms of current professional practice, it is important for clinicians to be aware of the research so far. This is because even though emotion focused coping strategies, especially benefit-finding or meaning-making appear to be more effective in producing reduced stress and improved mental health, it is still important for parents to know how to engage in problem solving strategies, while encouraging the development of other emotion or cognitive based coping styles.

5.4.1. Social Support as a Coping Strategy

A substantial amount of research has also investigated the use of social support as a coping strategy. This can be viewed in terms of both task and emotion focused strategies. However, it is often viewed more as a problem-focused coping strategy as it is person-orientated and requires a request for assistance (Glidden *et al.*, 2006). All

three models highlight the process of engaging resources to cope with a stressor and social support can be considered one of the resources that a person might engage to put their chosen coping strategies into effect. Social support is however considered to serve an important role in preventing negative responses to crisis and stress (Dunst, Trivette, Hamby, & Pollock, 1990; Honig & Winger, 1997). Generally, informal support (i.e. spouse or support groups) has been found to buffer the effects of stress when parenting a child with a DD although formal (professional) support has its place, especially in providing information or specific strategies (Boyd, 2002; Ello & Donovan, 2005).

Glidden *et al.* (2006) found that mothers of children with DD used problem-focused strategies, including seeking social support and planning strategies, slightly more than fathers. Essex *et al.* (1999) came to the same conclusion. However, this is not based on longitudinal data and as the models of coping and adjustment suggest, coping strategies may change or incorporate new strategies over time. Other researchers have also found a significant relationship between mothers' perceptions of family functioning and informal support. These relationships has also been found with professional support although less often (Duvdevany & Abboud, 2003; Saloviita *et al.,* 2003). Pakenham, Samios and Sofronoff (2005) also found in mothers of children with Asperger Syndrome that their adjustment was related to higher levels of social support, an emotion focused coping style and lower levels of stress severity (i.e. reduced child behaviour problems). The study incorporated a quantitative analysis of multiple measures of adjustment although it did rely on self-report and cross-sectional rather than longitudinal data. Satisfaction with social support and a person's social support

network has also been linked to sense-making and benefit-finding (McCausland & Pakenham, 2003). Research has shown that parents of autistic children who receive social support scored lower on measures of anxiety, depression and anger and that a good predictor of depression and anxiety was lower levels of social support (Gray & Holden, 1992). However, the parents' subjective perceptions of depression and anxiety were not examined. Overall, it is considered that social support is only related to adjustment if it is responsive to the needs created by the stressor (Cohen & Wills, 1985). Generally, social support is considered to be a significant mediating factor in reducing stress and enhancing coping in families of children with disabilities (Dyson, 1997). Clearer links between social support and adjustment or coping could still be made, but further research needs to be conducted using different methodology and measures that are more sensitive to the nuances of the impacts of social support both formal and informal.

5.5.2. Religious Belief as a Coping Strategy

Religious belief has also been recognised as a cognitive coping resource. There is research that focused on religion as a problem solving or social support coping strategy that family's access in times of crisis or challenge (Erin *et al*., 1991; Ferraro & Koch, 1994). There are mixed results as to whether families find support provided by church organisations and clergy helpful (Marshall, Olsen, Mandleco, Dyches, Allred & Sansom 2003), although a continual process of transformation through positive reframing based on religious belief and faith has been described (Marshall *et al*., 2003). There is some

research to suggest that using religion as a coping resource may reduce stress and depression in families with a child with autism, although this finding is not consistently reported (Tarakeshwar & Pargament, 2001; Sonuga-Barker, Thompson, & Balding, 1993). Further research needs to explore religion within a social support framework and as a solitary entity to support its efficacy when coping with raising a child with a DD. Research that has focused on the value of religion as a coping strategy for various clinical populations has been incongruent (Pargament, 1997). Some of the reasons for this include the difficulty of defining religion as opposed to spirituality as well as the almost sole reliance on qualitative methods used to explore its meaning and impact on someone.

5.3. Summary

Researchers have investigated the support and resources that parents have reported to be helpful (Baxter *et al.,* 1995). What has been found is that needs of parents change over time depending on the context and timing of the stressor. Their needs are dynamic as are the models of coping and adjustment used to understand the processes that these families experience. A combination of internal coping and formal and informal networks of support are reported as helpful. Parents recollected that they needed to draw on different resources at different times, for instance friends and family were particularly helpful when they received the diagnosis and professional support and legal support was helpful when their children started school or needed to consent to an event. An important outcome of this research was that the support received was only

considered helpful at the time it was specifically needed in response to a particular stressor. This is in line with the models' concepts that each stressor is appraised and evaluated within the unique context in which it arose and then coping strategies are engaged and sought that will hopefully lead to a positive outcome.

The dynamic fluidity of the models seems to fit with the mixed coping strategies that parents employ and incorporates the differences that men and women have. They may also explain why some parents appear not to be coping as they may not be able to use emotion-focused coping strategies successfully or may select the least effective strategy or not have access to resources that are appropriate for that particular stressor at that particular time. A mix of personality factors, accumulation of demands, life experience and access to appropriate resources all impact on whether an individual or family can successfully cope with a stressor. However, further research needs to be conducted into the longitudinal effects of raising a child with a DD as the models seem to be more suited to reactive coping rather than describing the process of coping with prolonged and enduring stress.

6. Conclusion

The current review has examined the factors contributing to parental stress when raising a child with a DD. It has also outlined three of the models of coping and adjustment predominantly used in this field and presented findings on how parents cope with caring for a child with a DD framed in these models. What has been discussed

highlights the multi-level and complex factors that can contribute to parental stress. However, some parents do not report feelings of stress and are able to manage the numerous and time consuming activities related to providing care for a child with DD. This led to the exploration of three models of coping and adjustment in relation to the coping strategies used by these parents to gain a greater understanding of the process of coping and how this may hinder or enhance an individual's or family's ability to cope. Several factors contributed to the coping process, from the initial appraisal of the event to the engagement of different coping mechanisms. Mothers and fathers were reported to engage different coping strategies, with mothers using more problem-focused strategies than fathers, and mothers engaging more emotion-focused strategies. Both parents were also found to engage avoidant and distancing strategies although these were found to be unsuccessful at reducing stress, whereas benefit-finding or meaning-making were found to be related to more successful coping. It is also important to consider the availability of resources that help the family engage in the coping strategies and the impact of having resources, including social support, available when it is needed. Ultimately, families found numerous styles of coping and varying resources helpful as long as it was responsive to a particular event or crisis.

6.1. Limitations

A limitation of this current review is the focus on developmental disabilities as a whole rather than as a number of individual disorders. Although various developmental disorders share many aspects in common the nuances of the impact that individual

conditions and disorders may have has not been examined here. The majority of research has been conducted using the wider category of developmental disabilities but there is research investigating the unique characteristics and challenges faced by families of children with specific conditions which may be lost when evaluating this population as a whole. Future research could continue to examine the differences and distinctive elements of specific developmental disorders such as downs syndrome or fragile X. A second limitation of the paper is discussing parents and family as a whole unit rather than distinguishing individual members and the effects that gender or position, i.e. being a stepparent may have on the experience of raising a child with a DD.

6.2. Further Research

Throughout this paper several areas for further research have been raised. Continuing research needs to be conducted into the implications of gender, marital relationships and demographics on a family who has a child with a DD. Further research into the effects of the characteristics and behaviours of a child with DD, as well as the effects these have on accessing social support and employment needs to be completed. Additionally, more research that supports or refutes the usefulness of the models of coping and adjustment used in this field needs completing. Life cycle studies could be carried out in an attempt to capture the changing needs of families, as could research into what factors or resources are actually helpful to parents in terms of specific strategies or services. Finally, research into coping strategies and resources at

both the formal and informal level, including different types of social support or educational and legal assistance, needs to be provided so that families and clinicians can both utilise effective resources and strategies to help families to cope.

6.3. Clinical Implications

Clinical psychologists and health care professionals should be aware of the causes and the effects of parental stress so that they can assess a family's needs and plan intervention appropriately. Assessment of families with children with DD should look beyond the needs of the child or the specific problems they are presenting with and investigate other factors that contribute to parental and family stress. It is important to identify the factors that are causative of their unique experience of stress and what is facilitating them managing it and what is hindering them coping with it. Assessment should also incorporate an evaluation of the family's coping process, including their appraisal or sense-making of the current situation. Clinicians should also be working with families to develop their task-orientated coping strategies but more importantly their emotion focused strategies and work with the family to increase their access to appropriate social support, whether this is formal or informal. The need to create a balance between recognising the coping skills that the family already possess and helping them to develop more is essential. Clinical Psychologists and other health care professionals are well placed to help a family develop skills so that they are able to access the appropriate coping strategies quickly and with greater success.

In terms of services, there is a clear need for ongoing, continuous support that is responsive to differing needs at different times in the life cycle of parents and children individually and as a family unit. Furthermore as McConkey *et al.* (2004) suggest, interventions for families may need to be broader than focusing entirely on the child and develop resources that help to support families. To help services facilitate this, clinicians can draw on the health and social policy that is recognising the difficulties these families face through the introduction of the Assessment Framework for Children in Need and their Families (Department of Health, 2000), with its considered comments on social exclusion and assessment needs of children with disabilities and the National Service Framework on Autistic Spectrum Disorders (Department of Health & Department for Education and Skills, 2004), with its example for positive interactions between professionals providing services to children and families.

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Research Report:

An exploration of an Internet discussion Forum for Autism Spectrum Disorders in

relation to Self-Help/Mutual Aid groups and helping processes.

1. Abstract

Objectives: The current paper explores an Internet discussion Forum for Autism Spectrum Disorders with the aim to investigate how it is being utilised and whether helping processes as identified by Finn (1999) were present. Design: Message threads were downloaded from an online group and analysed using Template Analysis. Method: The first phase analysed 75 threads to establish how it was utilised and the second stage analysed 135 threads using Finn's categories. Results: Analysis one showed that the site was used to share personal stores, evoke a sense of community, exchange information and advice on how to manage professional input. Analysis two showed that helping processes were present and that providing support, catharsis, universality and providing information were key processes within the group. Conclusions: The group appeared to provide a service for carers and could be an adjunct to professional services.

2. Introduction

It is generally recognised that families of children who have a disability experience difficulties in conducting a normal family life and experience higher levels of stress than other families (Bristol, 1984; DeMarle & Le Roux, 2001). Parents may also experience feelings of sadness and isolation. (Batshaw & Perret, 1986; Simmons, 1987). The implications of overwhelming feelings of parental stress are generally assumed to be negative. Higher levels of coercive parent-child interactions, drop-out from parent training and parental depression are all examples of the impacts of care-givers stress (Moes & Frea, 2000; Andra & Thomas, 1998; Gray 2002). Barriers to coping have been identified as financial hardship, stigma, limited time, difficulties with care-giving tasks and challenging behaviour. Parents of children with a diagnosis on the Autistic Spectrum have been found to experience these challenges (Frey *et al.*, 1989; Gray, 1997; Shultz & Quittner, 1998).

Research has suggested that parents of developmentally disabled children are at greater risk of developing psychological difficulties than parents of children without developmental disorders (Bromley *et al.*, 2004; Fombonne *et al.*, 2001; Sanders and Morgan 1997). This could partly be due to reduced social networks and unavailability of informal care, which may lead to greater parental stress (Beresford, 1995; Quitner *et al.*, 1990). This could also lead to feelings of greater social isolation, as could the time and energy that care giving tasks take, leaving no room for social activities (Rodrigue *et al.*, 1990). Sharpley *et al.* (1997) reported that the three most stressful issues arising

from parenting a child with ASD were: the permanence of the disorder; the lack of understanding and acceptance of autistic behaviours by family members and society; and the low levels of support offered by health and social care services. Researchers have suggested that social support can protect and maintain physical and psychological health and lessen the impact of stress (Goode *et al.*, 1999, Kazak, 1987; Cohen & Wills, 1985; Lindberg *et al.*, 1994). Coping resources, such as social support, for parents of children with a developmental disability have been associated with lower levels of parent stress (Goode *et al.,* 1999). Seeking support outside of professional services, from family, friends or the volunteer sector, is an established way for families to access support and increase coping. Therefore exploring how parents are utilising an online group and whether Helping Mechanisms are present will provide an insight into the needs and type of support sought and used by these parents.

2.1. Self Help/Mutual Aid Groups

While recognising that voluntary support has been a long standing part of human society, documentation of Self Help/Mutual Aid (SH/MA) groups for single issues began in the 1970's (Munn-Giddings & Borkman, 2005). The groups have been described as an attempt by people with a shared problem to manage circumstances that affect their lives (Finn, 1999). These groups have grown exponentially and comprise a wide range of social and health issues that cover the entire life-cycle (Kurtz, 1997; Orford, 1992). In a study conducted in 2000 it was estimated that four percent of the adult population in the UK belonged to a self-help group (Elsdon *et al.*, 2000).

SH/MA groups have traditionally been face-to-face groups or telephone help-lines in which there is an implicit principle of 'peer reciprocity' rather than that of 'user' or 'client' as seen in the more traditional services (Munn-Giddings & Borkman, 2005). There is no agreed upon definition of SH/MA groups but there is a consensus among researchers that there are at least three common factors: 1) they are run for people and by people who share the same social or health issue; 2) their chief source of knowledge is sharing experience; and 3) they occur as voluntary collectives mainly in the third sector of society rather than in the statutory or private sectors (Munn-Giddings & Borkman, 2005). The groups have been categorised in two broad ways: a) personal-change groups, which are mainly interested in members' individual change and b) no personal-change groups, which focus more on education and support without using behaviour-change principles or engage in advocacy objectives. The current study is predominately interested in the latter categorisation of SH/MA groups.

The SH/MA groups and user movements have suggested that many people benefit from support and information that comes from persons who have shared similar experiences to them, for example experiences of depression or delusions (Borkman, 1990; Elsdon *et al.*, 2000; Faulkner, 1997). Research that has focused on the impact of peer support programmes suggests that positive outcomes such as increased social support and networks, empathy, sense of belonging, personal empowerment and positive psychosocial well-being, information and education, and new coping strategies

are found. (Kyrouz, Humphreys & Loomis, 2003; Hatzidimitriadou, 2002; Roberts *et al.*, 1999; Kyrouz & Humphreys, 1996; Levin, 1988).

2.2. Online groups

Accessing the Internet has become a relatively commonplace activity in western society. Many people have access to the Internet at home but many more still have access to it at work, through public libraries or through 'Internet Cafes'. The huge growth of the Internet has in part been due to user-friendly interfaces that make it easy to search and navigate around the information 'superhighway', meaning that practically anyone of any age or background can use the services available. This has not only led to more convenient service provision such as online banking or supermarket shopping but has opened up communication through email, mailing lists and message boards. Rheingold (1993) even suggested that computer communication has provided individuals with an alternative sense of community. From about 1980, online SH/MA groups developed that can be found on Internet bulletin boards and commercial information sites (Jensen & Potts, 2005). These sites have the advantage of being accessible to a large population, some of whom may be disabled and/or find it difficult to move freely through society (Finn, 1999). These online groups are used by a wide variety of people such as parents of sick or disabled children, people with physical disabilities or health concerns, survivors of abuse and people with addictions (Green *et al.*, 2006; Jones, 1997; Sparks, 1992). Online Forums or message boards can also facilitate contact between people who are experiencing a relatively unique situation and

who are geographically widespread, for example parents who give birth to term babies who require intensive care treatment (i.e. Strohm, 2007).

A lot of these online groups appear to share a similar philosophy to the more traditional face-to-face groups (Finn, 1993; Scheerhorn, Warisse & McNeilis, 1995), with the added advantage of circumventing any logistical difficulties such as a physical meeting place or a fixed time of day (Strohm, 2007). They also incur little expense as there are no travel costs or rent charges to pay on a room; all that is required is access to a computer, which may be at home incurring an initial cost or in a public place such as a library. These groups are accessible 24 hours a day, 7 days a week and 365 days a year and may even incorporate international members. It has been suggested that online groups or Forums can mirror face-to-face interaction as exchanges can take place within seconds, minutes or hours (Davison & Pennebaker, 1997) and be accessed on a needs driven basis (Salem, Bogar & Reid, 1997). This means that rather than having to wait for the weekly meeting to access information or support, an individual can log on at any time and have a multitude of information, personal stories, hints, tips and strategies from others in similar position at their fingertips as well as one-to-one exchanges of a more personal nature. There is also the advantage of being able to selectively respond to other peoples' messages, receive immediate or delayed responses and access all the previous exchanges as they are archived so that people can return to them if necessary (Sparks, 1992).

One of the theories behind the popularity of Internet groups is their anonymity, as many participants log on using usernames or pseudonyms and their location, gender, age and race are all unknown. This has been hypothesised to be an advantage when disclosing personal information as many people feel uncomfortable discussing personal information face-to-face, due to concerns about confidentiality and stigmatisation (Levey & Derby, 1992). However, some theories have suggested that such anonymity could also be a disadvantage as it is difficult to verify with whom you are exchanging personal information; people have to trust that those using the Forum are genuine individuals experiencing similar problems. Other hypothesised areas of potential negative consequences of using online support have been; access to inaccurate information, development of inappropriate relationships, harassment or stalking and 'cyber-addiction' (Finn & Banach, 2000; Young & Rogers, 1998). One of the most broadly reported findings from researchers who have investigated interpersonal facets of online interactions is that people are more disinhibited than during face-to-face interactions (King 1995; Reid, 1994; Sproull & Kiesler, 1995), supposedly because of anonymity. The repercussions of this are still being explored. In addition, it has been suggested that online communications allow people to broaden their social network; differences are hidden and relationships are based solely on the receiver's perception of the individual who can control their public image through selective writing, which in turn can enhance a sense of group membership (Wellman, 1996; King & Moreggi, 1998).

A few researchers have conducted surveys of online participation. They found that the participants of the group considered it to be beneficial and that it had some therapeutic value (Dublin *et al.*, 1997; Cummings *et al.*, 2002). Dublin, Simon and Orem (1997) conducted a survey with 52 people who used online self-help groups and found that people were using the groups to assist their recovery from various disorders, alongside professional help. Benefits from group involvement were reported to be the variety of participants in the group and being able to share their experience with others from their own homes. Cummings, Sproull and Kielsers' (2002) survey of an online support group for people who were experiencing hearing loss found that online support was associated with benefits. Nevertheless they concluded that online social interaction was lacking in comparison to more personal communication and that a mix of real world and online support produced the most benefits to the individual.

Other researchers have set up their own online groups and have found that they have been accessed and used, and that there appears to be positive outcomes from participation. Dunham *et al.* (1998) donated computers to 42 young single mothers so that they would be able to contact each other from home to provide emotional support and advice on coping strategies. A descriptive analysis of the messages and self-report data showed a high level of use with over half the exchanges being of a supportive nature and an overall decrease in the level of reported stress. Strohm (2007) set up an online message board for parents of newborn children in intensive care. Although no formal evaluation of the messages has been conducted, Strohm reported that mothers used the message board more than fathers. It appeared that the small core of parents on

the site seemed to form strong links and messages were posted expressing gratitude about the existence of the board.

Research has also investigated the use of communication patterns from existing online groups for mental health and physical problems. One of the most prominent usages found from online groups was personal disclosure and the giving of information. For example Haker, Lauber, and Rossler (2005) investigated how online self-help Forums for people suffering from schizophrenia were used. They conducted a content analysis of the message threads and found that the main messages were about daily problems related to symptomology and the emotional impact of the illness. They also found that self-help mechanisms mainly consisted of self-disclosure and providing information and that emotional interaction were relatively uncommon. After examining 376 postings of an online group for problem drinkers, Klaw, Huebsch and Humphreys (2000) found that self-disclosure was the most widespread form of communication. They also found that the second most common form of communication was providing information and that in general, the communications were 'warm and supportive'. Winzelberg (1997) found that the most common postings of 306 messages on an eating disorder online group site were firstly self-disclosure, then information and thirdly, providing emotional support. He also found that the group members used the site most in the evening and late at night when traditional services were unavailable. In a study of socially supportive communication in an online support group for people with irritable bowel syndrome, Coulson (2005) found that the primary communication was giving informational support. Offering guidance and support on symptom

interpretation, how to manage the illness and interactions with health care professionals were found to be the main purposes of communication. He also suggested that emotional support was present, although less evident than informational support.

Bell (2003) also investigated the nature of support present in an online group for individuals living with a rare medical condition. During online interviews, members supported the development of personal interactions and found the absence of visual cues an advantage when sharing personally shameful events. Participants also felt that the group provided a safe atmosphere in which they could develop intimate bonds online. Bell also commented on the flexible and flowing style of the social support due to the changing network of people who accessed the site at any one time. Furthermore, in a study exploring the reasons for participation in an online group for food allergy suffers, Coulson and Knibb (2007) found that members considered the benefits of participation to include: accessibility; social support; and guidance on identifying and using coping strategies. The disadvantage identified via the online structured interviews was the uncertainty related to judging the accuracy and reliability of the information posted by other members without any visual cues to assist them. Finn and Lavitt (1994) also found that participation in five online groups from survivors of sexual abuse brought distinct advantages of being able share shameful experiences anonymously, which decreased levels of anxiety. Finn did however question the therapeutic value of some peoples' participation as they wrote short notes that didn't contain full stories. He concluded that women felt the openness of the public domain problematic. Anecdotal

data from this study indicated that many of the benefits of face-to-face SH/MA groups were present in these online groups.

Finn (1999) explored messages for the presence of Helping Mechanisms from an online self-help group for issues related to disability. He had drawn on literature from the self-help and group work field (e.g. Caplan, 1974; Katz & Maida, 1990; Lieberman, 1976; Riessman 1965, Rose, 1977) and social support categories developed by Cutona and Suhr (1992) when generating his categories. He had also incorporated Rose's (1977) theory that effectual groups must deal with both task and socio-emotional needs. For example task-orientated communications deal with specific information and problem solving with issues not associated to interpersonal relationships whereas socio-emotional messages relate to social discourse, personal feelings and interpersonal relationships. Using these ideas Finn was able to develop 14 categories of Helping Mechanisms (both socio-emotional and task-orientated) that he applied using Content Analysis to an online group about issues of disability. He found that the group provided many of the processes used in face-to-face SH/MA groups with mutual problem solving, information sharing, and expression of feelings, catharsis, mutual support and empathy as prominent factors.

Although the findings from these studies are mixed, there appears to be some general consensus that online SH/MA groups have the potential to provide effective social support and useful information alongside a space in which to share personal stories of distress or success. However, research is still required to explore the theories

surrounding online participation, such as the theories of anonymity, convenience, and

peer reciprocity found in traditional face-to-face SH/MA groups, as well as how

effective social support can be delivered online. Further research is also needed to gain

insight into the process, functioning and value of these groups across a variety of

populations, problems and organisations over extended periods of time (King &

Moreggi, 1998; Finn, 1999; Eysenbach *et al*., 2004).

2.3. Study Aims

The following study aimed to:

- Investigate how an online Forum for Autism Spectrum Disorders was being

  utilised and;

- To explore the message 'threads' to investigate the extent to which Helping

  Mechanisms, as identified by Finn (1999) were present.

3. Method

3.1. Design

A phenomenological approach was considered appropriate considering the focus on the members' experiences of the group. A qualitative analysis using Template Analysis (TA) was conducted in two phases. The first phase was an analysis of 75 message threads in an attempt to establish how the Forum was being utilised, resulting in a master template. The second phase was the coding of 135 message threads using Finn's (1999) Helping Mechanism categories as an initial template to establish if they were being used in the Forum.

3.2. Data Source/Participants

Using a web based search engine a search was conducted using the keywords 'asd', 'self-help' and 'Forum'; there were 25,800 hits. Several of the online Forums identified were accessed and information was read pertaining to the sites 'philosophy', policies and copyright stance. One of the Forums that welcomed users who were interested in "serious discussion" regardless of whether they themselves were affected by ASD, a relative, friend or professional, provided free access and did not copyright the postings was chosen to be the focus of this study.

Information that was gathered from the Home pages of the online Forum showed that there were 2420 group members at the time of the study, although guests could visit the site without registering their details. Over the last year the group had an average of 200 new members registering each month. The Forum had 8 separate 'rooms' in which specific topics were highlighted for discussion, such as an 'Education room' or the 'Beyond Adolescence room'.

Twenty-eight continuous days of message threads were downloaded from the 'general discussion' room on the Forum. A message thread is like a conversation online. It consists of a person posting an initial message that includes a title, the time it was posted, the username of the person and the message they have typed. The message can be as long or as short as the person wishes and can contain symbols or pictures as well as text. The title and username are visible on the Home page of the discussion room and to read the complete message, you must click on the title. Once the message is visible you have an option to reply to it or not. If other people have replied to the message you are able to read their replies (or posts), which are placed under the initial message along with their username and the time and date of the response.

There were 135 message threads, amounting to 1471 postings downloaded. There were 156 unique usernames, which were categorised by the author using statements made in their postings. One hundred and fourteen usernames were categorised as parents, 10 as person with a diagnosis, 5 as a person with a diagnosis and a parent of a child with a diagnosis and, 27 as other.

3.3. Analysis Procedure

Template Analysis was chosen for this study as it is a set of techniques that can be used with a wide range of epistemological approaches and can handle large data sets (King, 1998). It is also a technique that has fewer specified procedures and is more flexible than other approaches such as grounded theory (e.g. Strauss and Corbin) (King, 1998). It is a type of thematic analysis that can be used with any type of textual data and allows the researcher to pre-select categories that are of particular interest or are particularly salient with the research questions (King, 1998; King 2007). *A Priori* themes are used as a guide for the researcher but are only provisional and should always be open to modification. Within TA, parallel coding is permitted, meaning that the same section of the text can be coded under two or more themes. Template analysis aims to organise qualitative data into meaningful and constructive themes using a coding template with hierarchal themes. The high-order codes are broad themes that are made up of groups of similar themes. The lower-order codes include more detailed codes that allow for finer distinctions to be made within the broader themes (King, 1998). These levels of codes are derived from what the researcher finds to be helpful or meaningful when thinking about the research question.

Finn's (1999) Helping Mechanism categories were chosen for the second phase of the analysis as *a priori* codes because they had already been developed for use in a study of an online group. The current study used his 14 categories as *a priori* codes (shown in Table 2.). Using template analysis rather than content analysis allowed for

the use of these codes without being hemmed in by them and allowing for the possibility that new codes may be found if none of Finn's were able to fully encapsulate a portion of the text. It also allowed for the author to go beyond counting how many times a helping mechanism category was found in the text and organise the codes into a meaningful way, through the use of hierarchical coding (King, 2007).

The method followed was described by Miles and Huberman (1994) and developed by King (1998). The process involves constructing a coding template that contains codes that represent themes identified in the data. This is done through careful reading and rereading of the text until the researcher believes that they have attained a full description of the data without reaching a condition at which the description is so minutely detailed that any attempt to bring together an interpretation becomes impossible.

Phase one of the current study consisted of analysing fourteen days' worth of postings from the general discussions Forum. A seven-day gap was left between the first seven days and the second seven days in an attempt to allow any topics to be finished and new topics to be initiated in the hope of getting a cross section of the group discussions. This also allowed for an initial template of the data to be tested on the second set of data, with the aim of validating the template. Some descriptive data was also gathered from the site with the aim of providing further insight into how the site was being used. The data was the time of the initial posting at the start of each thread and the time that elapsed until the first response.

The analysis began with the identification of *a priori* themes, shown in Table 1. These codes were based on the authors' clinical experience of working with families with a child with a diagnosis of ASD and common themes identified in the literature.

Information	a) sharing b) seeking
Experiences of ASD	a) sharing b) seeking reassurance about
Community	a) for comfort b) for understanding c) for acceptance

Table 1. Phase one *A priori* themes

Each thread was then read before the initial coding began. After each transcript had been read it was re-read and notes were made in the margin next to any section of the data that were relevant to the research question and where possible *a priori* codes were attached to the section. Several new codes were identified and after the first seven days of threads was analysed an initial template was produced (Appendix A.).

The initial template was then applied to the second seven days worth of message threads using the same process of reading through the transcripts and marking the parts of the text that 'fitted' the code. New codes developed during this part of the analysis and the template was modified to incorporate these new themes. The new template was then applied to the entire data set (all 14 days) and the template was modified again to incorporate lesser levels of codes and the hierarchy was changed as the author became more familiar with the data set. A master template was then produced that was again applied to the whole data set.

Phase two of the project consisted of analysing 28 days' worth of message threads using Finn's (1999) Helping Mechanisms categories as *a priori* codes, (Table 2) (For a more detailed description of Finn's categories refer to Appendix B).

Helping Mechanisms: Socioemotional
1. Expressing feelings or catharsis
2. Providing support or empathy
3. Chit Chat
4. Universality
5. Friendship
6. Extra-group relationships
7. Taboo topics
8. Damaging statements
9. Poetry and art
Helping Mechanisms: Task Orientated
10. Asks information
11. Provides information
12. Problem solving
13. Computer talk
14. Group cohesion

Table 2. Finn's (1999) Helping Mechanisms

As described above, the transcripts were read before the initial coding began. The helping mechanism codes were then applied to the data and after 14 days' worth had been coded, an initial template was produced. This was then applied to the entire data set and modification was made where necessary to produce a final template.

3.4. Quality Assurance

During the course of the study the author attempted to remain reflexive towards the data and in an effort to check on the quality of her coding engaged the assistance of other researchers at varying stages of the project. Throughout the project the author had regular meetings with her supervisor to discuss the coding, templates and interpretations of the data. Also seven members of a qualitative support group each coded two sections of the data independently and then discussed the similarities and differences together, assisting to develop cohesive and constructive codes. Once the master templates had been formed a research assistant and fellow researcher discussed the themes with sections of the data to hand with the author to 'challenge' her interpretation of the data.

3.5. Ethical Considerations

Currently there is no consensus about Internet research (Finn, 1999; Eysenbach & Till, 2001). One viewpoint is that messages are in the public domain and that group members are aware that their postings can be read by anyone and at any time, therefore permission to use this material for research is not needed. The other viewpoint is that members never intended their messages to be used for research and to do so without permission would be unethical. The online Forum that was chosen for this study makes it clear in its literature that anyone can read the postings and that therefore members should consider what they choose to write carefully, use pseudonyms rather than real names and write no identifying information about themselves or others without

permission. However, the University Ethics Committee stipulated that the users of the website should be aware that their responses may be used for research purposes. The author contacted the site moderators via email, explained who she was and outlined the research project and asked permission to used archive message threads. The site moderators gave permission to analysis archive message threads as long as members who wished to opt out were given a chance to do so and that peoples' messages would not be used for quotes unless express permission was given to do so. The author joined the online Forum and posted a message outlining the research and asking people to opt out if they wanted to. In the post was information about the analysis technique and the steps that would be taken to insure anonymity. The moderators followed the author's post with their own, supporting the research and asking people to let us know if they did not want their messages used.

Additional procedures put in place to ensure anonymity were that:

1. The name of the Forum would not appear anywhere in the write up of the research.
2. All usernames and dates of the postings would be changed.
3. Any quotes used in the write up would be run through search engines to make sure they did not lead back to the site and if they did changed accordingly.

One member of the Forum requested that their messages not be used in the research and four others gave express permission for their messages to be used as supporting quotes as long as the anonymity procedures were adhered to.

4. Analysis

4.1. Stage one

The aim of the initial phase of the current study was to investigate how the online Forum for autism spectrum disorders was being utilized by its members. Fourteen day's worth of message threads were analysed, totalling 75 message threads amounting to 743 postings. The mean number of postings in a thread was 10, with a range of 58.

The time of the first post from each of the 75 message threads was recorded to identify the time of day that members were initiating contact with the Forum. Figure1. shows the number of message threads started in each hour. The majority of initial message thread posts were sent between 8am and 11pm while only one was sent in the early hours of the morning. The peak times to start a new thread appeared to be at 6pm and 10am although there were new message threads being started throughout the day. Visual examination of Figure1. highlights a wave effect with small peaks and troughs throughout the day with more message threads being started around mid-day and early evening.
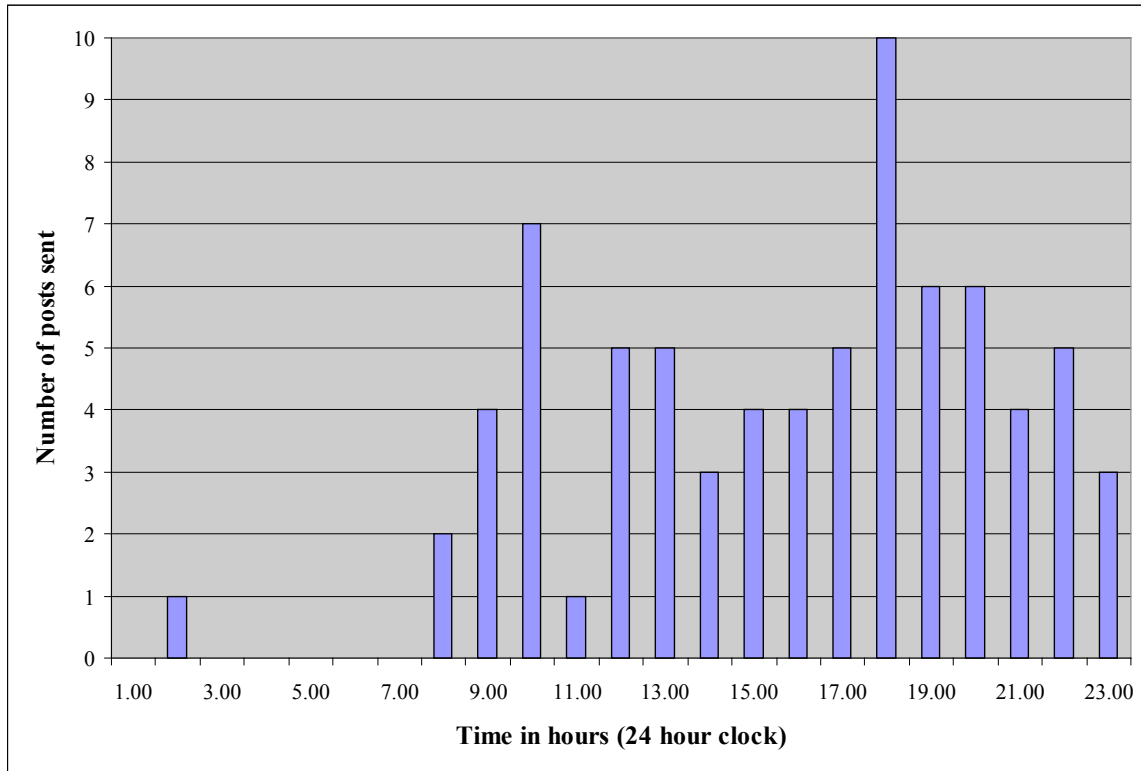
Figure1. The number of message threads started in each hour.

The number of minutes between the initial post and the first reply was also calculated. There were 71 replies. Figure2. shows the number of replies posted within 60 minute blocks. The majority of reply posts were made within the first two hours of the original post, 64% in the first 60 minutes and 14.6% in the following 60 minutes. Four posts were not responded to at all and some posts received replies after 5 hours although this was rare (6.6%).
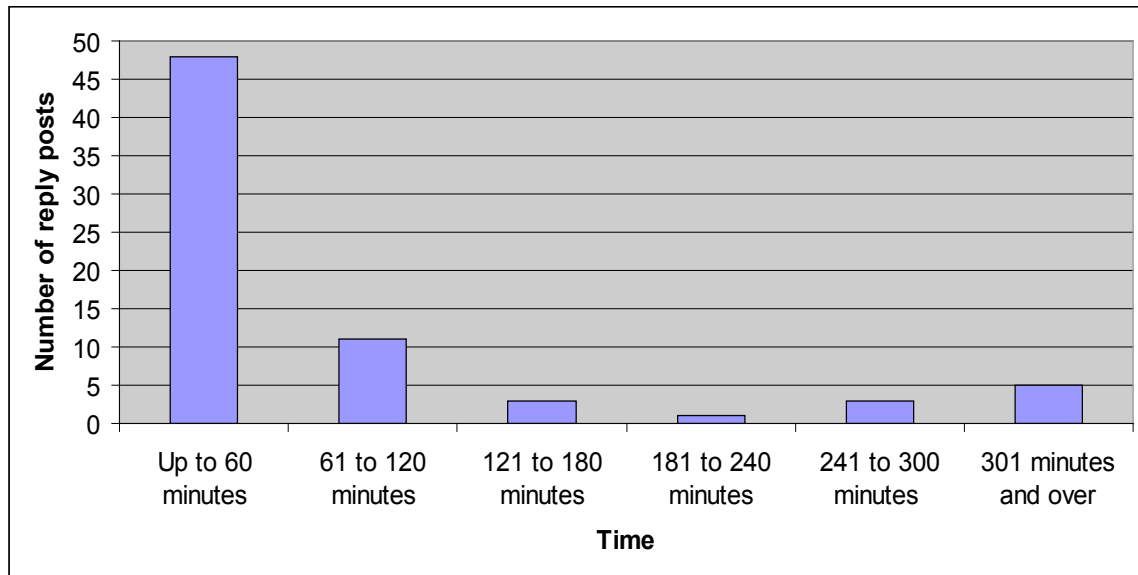
Figure2. The amount of time taken to reply to the initial thread message post in 60 minute blocks.

Figure 3. examines the 48 replies that were made in the first hour after the start of a message thread, to identify how quickly a response was given. The minutes were broken down to 5 minute intervals. As can be seen, the majority of messages were responded to within the 6 to 10 minute window, closely followed by the 11 to 15 minute and 21 to 25 minute window.
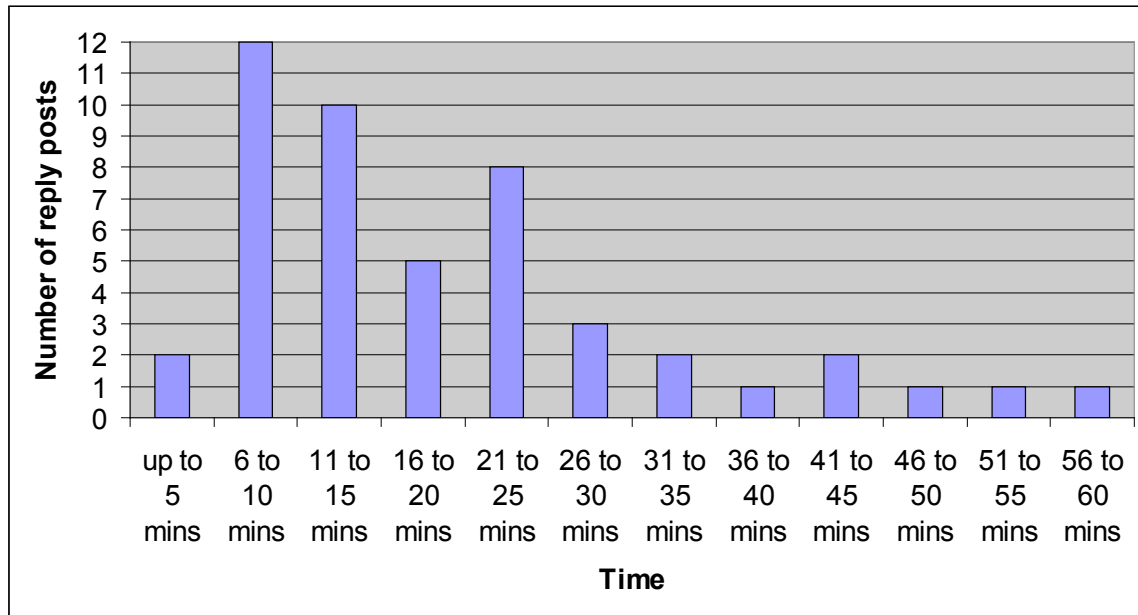
Figure3. A breakdown of the number of posts sent within an hour of the initial message.

Overall the quantitative data gathered in the current study shows that the online Forum is being used throughout the day, especially in the evenings and that members generally respond to each others posts quickly.

Table 3. below depicts the master template produced after analysing the 75 message threads in the first phase of the study. Four main themes were produced and a number of level two and three codes were identified in the interpretation of the data.

Level 1 Codes	Level 2 Codes	Level 3 Codes
1. Sharing Personal Stories	1. Sharing Parental Experiences	1. Sharing a story/journey with others 2. Seeking similar experiences 3. Asking for advice. 4. Sharing readjustment
	2. Using stories to Connect	1. To give advice 2. To share a similar experience/ to normalise an experience 3. To give hope
	3. To support a perspective 4. As an individual with ASD	
2.Having a sense of a Community	1. Giving support/encouragement 2. Giving acceptance/understanding 3. Expressing emotion (symbols and text) 4.Asking for support 5.Acknowldeging support/usefulness of being part of the online forum 6.Promoting inclusion and exclusion in the group 7.Expressing attitudes/beliefs about ASD	
3.Communicating Information	1.Seeking factual or practical information 2.Sharing factual or practical information/advice 3.Reviewing information 4.Giving information/Clarifying information 5.Sharing Opinion	1.About media 2.About research
4.Issues about Services/Professionals	1. Experiences of professionals and services 2. Advice seeking on how to 'handle' professionals 3. Information/ raising awareness on services 4. Raising awareness of services – including charity/volunteer	

Table 3. Master Template developed from analysing 743 postings from the general discussion room of the online forum.

Theme One – Sharing Personal Stories

The act of sharing personal stories permeated the majority of the message threads on the Forum. There were a variety of stories shared in a mixture of ways. The bulk of stories appeared to be written by parents although there was a number by people with a diagnosis of ASD and relatives or friends. This is not surprising however as the majority of members of the Forum appeared to be parents. A large proportion of the threads initial postings started with a story. The aim of this appeared to be to contextualise the comments or questions that followed. Personal stories were often shared in a response to other people's stories. A lot of stories were based around personal facts, for example how many children the writer had and which child had ASD.

My son has never mentioned his birthday to anyone at school. Last year was the first year he asked for a 'party'. I had strict instructions about who could come to the house, what toys they could play with and exactly what they could all have to eat.

Thread 25, Post 2, 19P.

The aims of these personal stories were often about relating a journey or daily experience of having or living with ASD; these stories could contain happy, negative or concerning experiences. The personal stories were being used to connect with each other's experiences and share advice or strategies highlighted within the story. Sometimes members would share something that had made them laugh or feel pride and would ask if others had had similar experiences.

> *We were in a cafe and he whispered in my ear 'Is it ok to tell that lady that she has the most beautiful eyes??'. So i said - 'well, that's a nice thing to say - but we don't   know her, so it's not a great idea to say it out loud to her, but it's a kind thought to think in your head.....'*
> *Two minutes later, after introducing himself to her   (IMG:blink.) , he told her...*
> *'You have the most beautiful eyes, but your hairs is messy'.......... (IMG:blink.)*
> *(IMG:huh) (IMG:ohmy) (IMG:laughing) (IMG:laughing)*
>
> *Thread 96, Post 3, 29P.*

Personal stories were also used to share experiences that supported a point of view or argument. These could be associated to personal experiences, such as a parent's encounter with a schoolteacher or to support a particular perspective. Furthermore, stories were used to express change or adjustment. Some of the stories had a cathartic nature and others stories had a nature of reassurance about them, showing that either the child had changed, the situation had or the person's perception had. These stories let the recipient know that growth in understanding or acceptance had happened and could happen for them.

> *im doing a positive post before i go mad,[xxx] hasent (sic) been to any after*
> *school clubs for years but i found one which deals with asd children, he went*
> *along tonight and he really enjoyed it, got 12 other kids there of his age and*
> *coaches from [xxx] football club, i was nervous about him going as other*
> *supposedly asd clubs he been to have not have good results,…*
> *anyway he scored a goal tonight (IMG:dance.) (IMG:dance) and is raring to go*
> *next week*
>
> <div align="right">*Thread 89, Post1, 41P.*</div>

Theme Two – Having a Sense of Community

The second theme manifested itself in numerous ways. Generally it was a sense of collectiveness in which each individual understood the plight or experiences of the next individual. It was also the sense of caring and holding each other in mind that appeared to generate a sense of community. Help or advice was offered even if the sender had no direct experience of what the individual was experiencing, for example:

> *Hello (IMG: smile) I've no personal experience – as my son is an only child. But, this website may give you more information …*
>
> *Thread 69, Post 3, 19P.*

Messages of support and encouragement were also sent about each other's difficult experiences. Many posts responding to an expression of worry, exhaustion or negative experience were short but full of expressions of caring and symbols that seemed to be chosen to demonstrate caring, praise or sadness.

> *No words really, will be thinking of you (IMG: hug) (IMG: hug)*
>
> *Thread 74, Post 21, 41P*

> *Hi you (IMG: hug) Sorry to hear you've had such a difficult time (IMG: sad)*
>
> *Thread 18, Post 4, 19P*

The sense of community was also shown through messages that discussed everyday events that were slightly removed from ASD, such as which footballers someone liked or that a family member had become ill. These messages were responded to with humour or messages of care and well wishes.

dad was rushed to hospital last night as he had very bad tummy pains, they think its a blockage caused by a tumour, having some sort of dye tomorrow to see what it is, hes crying out in pain and hes such a strong man, i went there today and everytime the doctor came in i went out the room, my nerves went, hes going through so much and im a wreck, we are very close and i dont know what to do,

Thread 81, Post 1,41P

Some people would post messages asking for reassurance about an event that had happened, such as a disagreement with a teacher. The group as a whole would respond with messages of reassurances and concern. Some people might offer a different opinion to what had been originally shared but would do so with care and respect. Also displays of acceptance and understanding for each other's circumstances were given which all facilitated a sense of one community working through various challenges and experiences.

i agree, you didnt over react at all, i think he done very well, he wasent (sic)

being naughty he had trouble coping, we know theres a difference

Not gonna comment on the 'should I /shouldn't I's' right now 'cos I think they are

very big questions that only you can answer... I DO think though that to be able

to answer them you have to be in the 'right' place yourself, and from everything

else you've said I don't think you are there right now (IMG:sad) (IMG:hug.)

………

A few of the posts also talked about how useful or helpful the online site had been
for them. This too seemed to generate a sense of community in that people responded
to these posts with similar expressions. There was a sense of valuing the group and the
people in it. Some posts also promoted inclusion or exclusion in the group. This was
achieved through the values that they would promote among themselves, such as
appreciating your child with ASD no matter how hard things were getting at home or
school.

All sorts of people use this forum for all sorts of reasons: We have carers,

classroom support staff, researchers, medical specialists, all of whom pick up all

sorts of interesting and useful bits and pieces that are relevent (sic) to both

spectrum disorders AND all sorts of associated/co-morbid conditions...

<div align="right">

Thread 12, Post 2, 48P

</div>

Theme Three – Communicating Information

   The third theme of Communicating Information was also a large part of the

exchanges that took place in the main discussion room. This theme centred around the

factual and practical information that was posted on the site. Some of these posts were

about giving information without asking for a reply, such as giving details of an

upcoming conference. Some of the posts were seeking or giving information, for

example about a particular diet or a therapeutic technique like TEACH.

If you mean the nature's first chocolate stars brekkie (sic) cereal it is GF/DF(?)

In a nutshell - if the indications are that there's an intolerance it seems logical

to try the diet... a six month test should give you some firm indications...

<div align="right">

Thread 21, Post 4, 48P

</div>

Sharing and seeking information also included asking for clarification about aspects of ASD. Parents who were learning about ASD or those who were unsure if behaviours displayed by their children were connected to ASD, sought other people's opinions. The information that was shared was descriptive and gave explanations for certain behaviours and traits. It was often given with some confidence and could be viewed as reassuring. Many of these types of posts included links to other archived message threads or websites outside the Forum.

> *the 'uneven profile' you mention is very common... One of the easiest descriptions I ever heard (an NAS course years ago) was to think of the 'triad' in terms of the graphic equalizer on a stereo... The 'bass' may be really heavy, with the 'mid range' cut back to almost non -existent and the 'treble' hovering around the 'nominal' setting - or any variation thereof!*
>
> *Thread 8, Post 2, 48P*

Some of the posts were about giving helpful hints and tips about resources available in the community through websites, organisations, clubs and books. Often this was in response to a request for help or further explanation in an attempt to understand their child's perspective or behaviour.

A book I've recently read is The Jumbled Jigsaw by Donna Williams – it

describes this perfectly (IMG: smile).

<div align="right">

Thread 8, Post 6, 19P

</div>

Have you seen the little cards the NAS make?? I have some that i hand out if

people make nasty comments about my son. I don't think people mean to be

nasty (IMG:hug) it's just a lack of understanding. I've not had to hand out many

- but when i have, the attitude of the person totally changes. And, with any luck -

they wont be so ignorant in the future.

<div align="right">

Thread 94, Post 3, 19P

</div>

The remainder of the information communicated focused on sharing opinions and reviewing information about media programs or articles. This went beyond expressing their personal attitudes about ASD (as in Theme Three; Having a Sense of Community) and expressed more political or personal values and opinions.

I agree completely that the lack of provision, postcode lotteries etc very much

need   *highlighting, but the main thrust of this programme is that it does so (allegedly)*

by   *demonizing (sic) the person needing that support, ...*

<div align="right">

Thread 26, Post 10, 48P

</div>

Theme Four – Issue about Services/Professionals

The final theme was about the posts related to negotiating the education, health and social care system, as well as the private professional arena. Postings were made asking questions or giving information about how to make referrals to certain professionals or how to 'handle' professionals with whom they were having conflict or misunderstandings. Messages were also sent about what certain professional roles were and what services were available.

If she is already in treatment for mental health issues, it should be relatively easy to get a referral to a psychologist – she may have to go through the Community Mental Health Team (CMHT) and see a Community Psychiatric Nurse (CPN) first. She needs to make it very clear to her GP that this is a long-term issue (even if she might not have brought it up until recently), and that she feels that she needs more than medication. It might not even be worth mentioning Asperger's to the GP, since they are not the ones diagnosing anyway.

Thread107, Post 7, 2Dx

Posts were also sent discussing the input that a child or family were receiving and how things may be improved through service provision or more professional understanding. Many of these posts seemed to promote parental empowerment and encouraged the recipient to follow up on the suggestions by talking to the school or health professional.

I hope the appointment goes well – at the very least, I would be asking what understanding/training the teacher has in ASD's.

Thread 83, Post 10, 19P

Just wanted to ask – how supportive are you sons school? You could ask them if he's on School Action or School Action Plus – here's a link to ACE, if you scroll down it explains it all. Regardless of what diagnosis your son has – the school should be helping him.

Thread 90, Post 13, 19P

Within the posts, discussions about professional or service involvement were also stories about the difficulties of getting a diagnosis from professionals. As part of the discussions there were several postings suggesting that others had had similar disappointing or difficult experiences with the wider professional systems, although a few posts were positive.

Hiya S (IMG: hug) Horrible when they sit on the fence like that I know… Hope they offer you some sort of conclusive dx [diagnosis] soon.

Thread 17, Post 7, 48P

4.2. Stage two

Phase one of the analysis explored how the online group for autism spectrum disorders was being utilised by its members and demonstrated that there were elements of support and a sense of community present. Phase two of the analysis aimed to investigate if the Helping Mechanisms as identified by Finn (1999) were also present. Finn's categories were developed from literature on self-help, group work and social support fields. Twenty-eight day's worth of message threads were analysed, totalling 135 message threads amounting to 1471 postings. The mean number of postings in a thread was 11, with a range of 63. The following template was developed using Finn's (1999) codes as *a priori* codes.

Level One Codes	Level Two Codes
1. Providing support, empathy	1. Encouragement
2. Expressing feelings or catharsis	1. Personal stories
	2. Using symbols
3. Universality	
4. Providing Information	1. Experiential experience/ learning
	2. Factual
	3. Practical
5. Asks Information	1. Opinion
	2. Factual
	3. Practical
6. Chit Chat	1. General Conversation
	2. Sharing opinions
	3. Humour
7. Group Cohesion	
8. Problem Solving	
9. Friendship	
10. Taboo topics	
11. Poetry and Art	
11. Damaging Statements	

Table 4. Master template of the Helping Mechanisms found after analysing 1471 posts from the general discussion room of the online Forum.

As can be seen in Table4. above, the master template developed from the current analysis moved away from Finn's analysis slightly. A few of the codes were added to, to encapsulate what the principle investigator was reading in more detail, but no new codes were found. Two of the Helping Mechanisms identified by Finn were not discovered in the message threads downloaded from the online Forum for ASD these were: extra-group relationships and computer talk. Parallel coding was an advantage as some of the posts seemed to fit into several of the helping mechanism codes. Finn also distinguished between the socio-emotional mechanisms and the task orientated mechanisms, which was helpful when thinking about the codes and how they had been developed from previous research. However, the principle investigator felt it was less

meaningful to distinguish between them when producing the template as the segregation between the mechanisms was not apparent within the data.

Providing support and empathy

Finn (1999) described messages containing support and empathy as those that give helpful or comforting words and show understanding for another person's circumstance. Encouragement has been added by the principle investigator as a level two category to emphasis this style of support shown in many of the Forums posting. There appeared to be a strong sense of encouraging each other to continue living with or caring for someone with ASD and all the difficulties and successes that might entail.

Very Very best to you all

(IMG:hug) (IMG:hug)

Hope you have some news soon, and that it's all good.

Thread 85, Post 13, 48P

Expressing feelings or catharsis

Expressing feels or catharsis is categorised by Finn as the messages that are self revealing or tell of an emotional or traumatic event. Within the current message threads analysed, the majority of posts had elements of this nature, much expressed within a personal story. Symbols (i.e. cartoon characters) were also frequently used to express emotions with some of the posts being made up almost entirely of symbols depicting feelings. These stories and expressive symbols seemed to assist the members to communicate complex feelings and events to one another resulting in some emotionally powerful messages.

> *just waiting 4 dad to go in theatre, anaehitist (sic) just been, found a computer,*
> *im so frightened, going to cut tumour out, keep on about risks and thats all im*
> *hearing, i feel erratic so im typing on here to keep busy, all do a prayer, thanks*
> *for support*
>
> *Thread 118, Post 1, 41P*

Universality

Finn described universality as the sense that each of the members is sharing a similar experience and that each one feels that they are not alone in their situations or feelings. Within the current analysis this was a consistent theme running through the online Forum. Even when an individual was unable to completely identify with an experience, there was an understanding of and appreciation for that experience that suggested they lived with similar thoughts and feelings.

> *(IMG: sad) (IMG: hug) (IMG: hug)*
>
> *Have you got anyone who can come along to these meetings with you? Just saying, because i always feel stronger with someone to back me up - and it doesn't hurt to have someone to write down what's said.*

Thread 83, Post 17, 19P

Providing Information

Providing information was considered by Finn to be those messages that conveyed factual or useful information relating to a specific subject or problem. Although this description fitted well with many of the online posts found in the current study, it seemed to need expanding to describe the experiential and practical information sharing that was occurring within this group. All of this type of information appeared to be useful and appreciated by other members.

Here's a good place to look ...xxx

It depends from area to area what provisions are available ... But, as with schools, some pre-school settings are more ASD/SEN [special educational needs] 'friendly' – so it's worth having a look about/ visit each setting for yourself. (IMG: smile)

<div align="right">

Thread 112, Post 2, 19P

</div>

Asks Information

Finn described this category as the messages that asked others for information or facts about specific treatments, policies or subjects. Again within the current study there were several examples of members using the Forum is this way, but opinion seeking was also strongly represented in the present data set. Asking for facts and opinions generated a lot of replies and helped the group form cohesive understandings of specific issues.

I hope this question isnet (sic) too deep but does anyone know how a word can come out like that and then why sometimes do they not say it again? Its always puzzled me, then again I get puzzled very easily (IMG: blink)

<div align="right">

Thread 23, Post 2, 41P

</div>

Chit Chat

Chit Chat was categorised by Finn (1999) as general conversation using everyday talk that does not address any other codes. Initially the author had some difficulty with this code as she felt it didn't fully describe some of the talk found within the postings. However, expanding the code to include people's opinions on everyday topics and the humour that was shared between members meant that it encapsulated the sense of general communication that went beyond communicating facts and experiences.

> *Completely hatstand, but I did hear once that MEN can lactate too if something stimulates the right (right?) hormones to kick in… Now that really is extraordinary!*
>
> *…*
>
> *Thread 111, Post 3, 48P*

Group Cohesion

Group cohesion was described by Finn (1999) as the messages that showed how the members felt about their group. There were a number of postings of this nature within the current data set, all of which were positive. Many of the group members expressed sentiments that the group had been really helpful for them emotionally and factually. Unfortunately none of the individuals who gave express permission for their messages to be used as quotes wrote this type of message within the data set used.

Problem Solving

Finn (1999) described problem solving as an exchange of ideas in which individuals often asked questions or offered advice to solve a particular problem. Some of the messages posted onto the current study's Forum asked for advice on specific problems usually related to a child's behaviour or how to manage specific situations. Members responded with advice, tips or anecdotes designed to assist the individual with their problem. If members were unable to provide experiential knowledge they often exchanged resources, such as books or websites that they had found useful.

> *AOW [Autism Outreach Worker] has the right general idea, but I wouldn't*
>
> *begin with removing the ear defenders at the start of lunch …it would certainly*
>
> *be too much for my son, and would probably ruin the rest of lunch break, and*
>
> *possibly afternoon. I'd 'suggest' (IMG: devil red) that this is a great strategy*
>
> *etc … but you feel it may be more beneficial removing his ear defenders for a*
>
> *short time at the end of lunch time. By then, he will have become more tolerant*
>
> *of the noise, sights, smells, etc … and would be better able to manage. Stacks of*
>
> *praise and lots of 'well done', no matter how short a time he manages (IMG:*
>
> *biggrin) (IMG: notworthy). That way, if it is too hard for him, he has at least*
>
> *eaten, and will probably have a spare bit of time to wind down somewhere quiet*
>
> *before he goes out to play.*
>
> *Thread 133, Post 2, 19P*

Friendship

Friendship was described by Finn (1999) as the posts that directly expressed friendship or making friends within the group. These types of posts were fairly sparse within the current data set although there appeared to be an implicit communication of friendship. Some posts did ask after members who had not posted for a while or who were going through a negative experience.

im so bloomeing (sic) pleased for you mate (IMG:laughing) (IMG:laughing)

Thread 51, Post 15, 41P

Taboo Subjects

Taboo subjects rarely came up in the data set from the ASD online Forum. Finn (1999) described them as subjects or problems not generally open for discussion and that are considered private such as sex, suicide, or 'things for which others may place negative judgement on the person' (Finn, 1999). The two posts of this nature in the current data set discussed difficulties with having a low sex drive and guilt about drinking whilst pregnant and the fear that this caused their child's ASD. The quote below was taken from the middle of the discussion about losing sexual desire and part of it refers to the secondary discussion of whether this type of post is appropriate for the group.

Well personally, I thought Mojo's were those little liquorice sweets you got

along   with Fruit Salads and Black Jacks… I was thinking maybe this post was

meant for the 'sweet's nostalgia' thread we had running.

Anita- I don't think I can really add very much to what has already been said,

other than to echo the sentiments that being honest and not feeling pressured

are very important factors. I hope you and your partner can find a better

understanding soon, and would agree that a good chat with your GP might

reveal more than is readily apparent form discussions amongst yourselves L&P

(symbol: biggrin) (symbol: hug)

Post 60, Thread 14, 48P

Poetry and Art

Poetry and Art identified by Finn (1999) was rarely used in the current data set from

the ASD online Forum, although there was one poem posted. No quote is given on this

topic as the member who posted it did not give permission for the message to be used

for quotes.

Damaging Statements

Only one Damaging Statement (Finn, 1999) was found within the current data set.

Damaging statements were considered by Finn to be a 'statement in which a participant

acknowledges being hurt by someone's comments … or any message that may cause

hurt through verbally hostility' (Finn, 1999). This statement was expressing a personal

opinion relating to individuals who seek government benefits for children who may not

be disabled. Other members of the group strongly disagreed with this statement, whilst

others attempted to clarify the comment and pacify those offended. Unfortunately no

quote is available to highlight this category as none of the individuals who gave

permission for their posts to be used as quotes were part of the discussion.

Extra-group relationships and computer talk

Finn (1999) described extra-group relationships as interactions between members

using other methods (i.e. telephone) outside of the electronic support group. Although

some members indicated that they had sent private messages using the group's email

system to one another, no messages suggested that individuals were interacting outside

of the group.

Computer talk, was described by Finn (1999) as discussion of computers, modems,

lurkers or computer jargon. Although some acronyms were used in the current message

threads these were not discussed in the data set and neither were any of the other components of computer talk.

4.3. Summary

Overall the current study found many of the Helping Mechanisms identified by Finn (1999) in the data set from the online Forum for ASD. However, the principal investigator expanded five of the categories in an attempt to describe the helping processes identified in the data fully. The categories were also placed in a hierarchical template in order to convey the principal investigators interpretation of the primary processes present with the data set.

5. Discussion

The aims of the current study were to investigate how an online Forum for ASD was being utilised and to explore whether Helping Mechanisms as identified by Finn (1999) were present. From the first stage of the analysis it appeared that the online group was being used to impart personal stories, to promote a sense of community and to share information and advice on how to manage living with ASD and the education, health and social care system. The second stage of the current analysis found that Helping Mechanisms were present within the group messages. The analysis suggested that the primary helping processes were giving support and empathy, as well as providing a space in which to express personal feelings. It also established that promoting a sense

of universality and providing information were important and active processes within the group.

5.1. How the Forum was being used

The online Forum for ASD chosen for analysis in the current study was used predominately by parents of children with a diagnosis of ASD. A few of these parents indicated that they had a diagnosis of ASD themselves and some professionals and adults with ASD also used the site. To begin exploring how the site was utilised, data on the time of day that the initial messages had been posted online were collated. The data indicated that initial messages were posted throughout the day with the majority of the posts being sent between 8am and 11pm, with a peak at 6pm. This suggests that the members valued being able to access the group at any time of the day. The pattern may also be representative of the time available to carers after they have completed daily care-giving tasks as the majority of messages were sent within the evening when a child may be having tea or going to bed, or in the morning after a parent may have taken a child to school. This could reflect the findings in the research literature that parents of children with a developmental disorder have little time for social activities due to the high demand for care-giving tasks (Beresford, 1995; Rodrigue *et al*., 1990), and therefore value the home-based accessibility of the Internet Forum. The observed pattern of initial postings throughout the day may also suggest that members were accessing the group on a needs driven basis rather than at a particular time of the day or

week, which is in line with other theories about online participation (Salem, Bogar &

Reid, 1997).

The current data collected established that the majority of responses to the initial

messages were sent within an hour. This time frame is less than if an individual was

accessing a face-to-face self-help group, where they may have to wait a week to express

their feelings or receive answers to questions. The ready availability of support and

information may account for the current groups' apparent popularity, attracting roughly

200 new members each month. Some researchers have suggested that the exchange of

messages online can mirror face-to-face interaction (Davison & Pennebaker, 1997),

whereas others have suggested that the lack of visual cues has led to difficulties of

members judging the accuracy and reliability of information posted (Coulson & Knibb,

2007). Throughout the posts analysed in the current study, images were used

extensively. These seemed to help the reader understand the tone in which a post was

written and expressed emotion on behalf of the sender. This could perhaps go some

way to convey the components of communication lacking in text-based exchanges.

5.1.1. Sharing Personal Stories

In line with other research conducted with online groups, both stages of the current

analysis suggested that sharing personal stories and disclosing personal feelings was

one of the primary functions of the group (Haker *et al*., 200; Huebsch & Humphreys,

2000; Winzelberg, 1997). It appeared that sharing personal stories and catharsis were

promoted and valued within the group and this could be for several reasons: firstly, because it provided a unique setting to share private and difficult experiences; secondly, because the action as well as the content of the stories promoted a sense of universality or community; and lastly because they enabled people to impart experiential knowledge. Previous researchers have suggested that the anonymity provided by the Internet may account for the high levels of self-disclosure; it affords a sense of confidentiality and allows for stigmatising or shameful stories to be shared without the repercussions of immediate face-to-face interactions, which may be negative (Levey & Derby, 1992; Lavitt, 1994). Also providing experiential knowledge has been hypothesised to be a benefit to group members (Salem, Bogar & Reid, 1997; Borkman, 1997). Experiential knowledge not only provides useful information to other people in similar positions but also allows the giver to pass on wisdom that they believe is truth gained from their personal experiences. Reissman (1965) called this 'helper-therapy' suggesting that providing support for others is more beneficial than receiving support.

5.1.2. Having a Sense of a Community

The sense of community permeated most of the message threads from the Forum in the current study. Having a sense of community has been suggested to lead to decreased feelings of stigmatisation and social isolation, which is felt by parents of children with DD (Sharpley *et al*., 1997; Levine, 1988). Cutrona and Suhr (1992) categorised social support as action- facilitating or nurturant. Action-facilitating support is aimed at assisting a person to solve or remove the problem that is causing

their distress, such as providing information. Nurturant support involves actions to comfort or console the individual, including giving a sense of belonging. Both stages of the current analysis suggested that both action-facilitating and nurturant support were present in the online group for ASD. Providing information that encouraged problem solving and tangible solutions as well as information that encouraged emotional support were key elements of the online communications. Advice giving regarding interactions with services was usually action focused and empowering and appeared to be a unique area of support offered by the group. Coulson (2005) also found this type of support present within an online group for irritable bowel syndrome, suggesting that this could be one of the unique uses of such online groups.

The sense of universality that was found in both analyses is also a component of social support. This could be one of the reasons that the online group appeared to be successful in meeting the needs of its members as each of them felt there was someone else having similar daily life experiences to them. The style in which this was conveyed could also have been an important factor. Bruner (1986) suggested that communicating in the narrative that is to convey meaning through a story, is a long way away from the discourse of the professional who relies on logical and scientific methods. Parents of children with ASD can feel socially isolated, stigmatised, unsupported by family and professionals as well as emotionally and physically stretched (Gray & Holden, 1992; Jones, 1997; Sharpley *et al*., 1997). This study suggests that the online site can provide a place where social support is given and expressions of difficulty accepted and understood, without the carer having to leave the house or seek professional help.

5.1.3. Helping Mechanisms

Helping Mechanisms as identified by Finn (1999) in a study of an online group focusing on issues of disability were found to be present in the online messages. Although Finn's categories were useful they did not capture all eventualities found within the online communications. However, his codes are a helpful way to analyse online group discussions although they should only be used as a starting point and not blind the researcher to other mechanisms or communications present. However, the presence of the Helping Mechanisms could suggest that members of the Forum for ASD not only valued having a space in which to share personal stories but also enjoyed and valued other aspects of the online Forum. Chitchat was an interesting component because it was a reflection of the social aspects of the group that went beyond exclusively discussing ASD and allowed the members to share other stories and jokes with one another. However, it is important to note that there was an overwhelming sense that the site was there to discuss and exchange information about ASD rather than to develop friendships in general. A few of the mechanisms identified by Finn (1999) were rarely present in the message threads; in particularly there was only one damaging statement. This could be a result of the self-selecting nature of the online Forum, in that individuals are able to make a judgement about their 'fit' with the group before joining (King & Moreggi, 1998). They are also able to chose to participate or not in message threads, which may be more difficult to do in a face-to-face setting.

Although the second stage of the current analysis of an online Forum for ASD suggested that helping processes were present, the assumption cannot be made that the recipients of the messages felt that they had been helped. Several researchers have suggested that a variety of factors influence to what degree help-intended communications are actually helpful. These include whether the help was provided spontaneously or after a request, the timing of the communication, the relationship between the helper and recipient, the personality of the receiver and the nature of the event that provoked the need for help (Cutrona, Cohen, & Igram, 1990; Hobfoll, Nadler, & Leiberman, 1986; Jacobson, 1986; Hobfoll *et al*., 1986; Cutrona, 1990). Within the current messages analysed, there were some posts thanking other members for their advice and information, suggesting that helping had taken place. However, to clarify this it would be essential to get the views of the members directly, as it is the subjective perspectives on help that determine if the processes are helpful or not.

5.2. Limitations of the Study

The current study has suggested that members of an online group for ASD, particularly parents of children with ASD, benefited from its use through sharing personal stories, establishing a sense of universality and giving and receiving information. However, this study had several limitations. Firstly the anonymity of online participation means that there is no way to verify individuals' identity or gather demographic information on the participants. Secondly, the results cannot be generalised to the wider population of parents of children with ASD or adults who have

a diagnosis of ASD as participation in the online Forum is purely voluntary. This means that only those seeking this type of interaction and presumably those that find it helpful maintain participation in the group, resulting in a biased sample. Thirdly the results are not generalisable to other online Forum's for ASD as each group may be set up and managed differently and have different members participating in it. Also the study analysed 28 days' worth of message threads from the general discussion room from the Forum. This is a limited and specific time frame, which may not be representative of the activities of the group over a longer period or within different rooms. Lastly, the finding that Helping Mechanisms were present within the online group was based solely on the principal investigator's analysis and interpretation of the data and not on what group members said. However, this type of research provides a unique real-time data set that does not rely on retrospective interviews or experimental design and provides a distinctive insight into how individuals are engaging with the Internet Forums, coping with stressful situations as well as to learn from experiential knowledge.

5.3. Future Research

Future research from the current study could go in many directions. One could be to relay the current findings back to the members of the online Forum and ask whether they feel that therapeutic processes are present. Online interviews could also be conducted with members of the online group to establish why they use the Forum and what they find helpful and unhelpful about the group. This would give further insight

into how these groups function and what purpose they fulfil in people's lives. Other research could include analysing longer periods of activity on the site, as well as comparing the activity and analysis with other online groups in general for people living with ASD. This would help determine if the findings from this study are representative of this populations needs as well as how online groups are being utilised. It may also help establish some of the components that make an online group successful, whether this be good moderation, shared values or low levels of conflict within a group. Entire message threads could be coded as a whole rather than individual separate posts as replies are sent in response to an initial message and Helping Mechanisms may be more prevalent after certain types of initial posts. The current study also made no attempt to measure the quality or accuracy of the information exchanged on the site although, anecdotally it appeared to be of high quality, further research could analyse this.

5.4. Clinical Implications

The findings of the current study have clinical utility, as they contribute to the knowledge base surrounding the function and role of online support groups. It can also raise professional awareness of the type of support that families are seeking and help to respond appropriately in similar situations (Wilson, 1995). The findings of the current study suggest that families with children with ASD need more support and information than they are currently receiving within professional services and that this particular online group appears to be able to fill this gap. However, this leads to the suggestion that professionals may wish to consider involving themselves in these groups or

establishing their own online groups. In this way they could make sure the information

that is provided is based on current scientific knowledge and services as well as learn

from the experiences of the members what techniques and strategies actually work in

real life settings. However, professional involvement in SH/MA groups is controversial

as it would change the dynamic of the group if the professionals are not believed to be

equal members and participation would have to be managed carefully for it to be useful.

In the UK, many of the traditional SH/MA groups have tended to work towards

partnership and co-operation with social and health professionals (Munn-Giddings &

Borkman, 2005) and this could continue into the virtual world.

 If the effectiveness or usefulness of these online groups continues to be supported,

then health professionals could start to consider them as part of the referral process, and

they could be utilised as waiting list alternatives or as follow-up after time-limited

intervention (Finn 1993, 1995) or as supplements to professional input. Further

research is needed however to assist families, individuals and professionals to make

judgments as to the accuracy and helpfulness of online Forums.

5.5. Summary

Overall the current study found that the online Forum explored was used by

individuals living with ASD to share their daily experiences and create a sense of

universality. The analysis suggested that helping processes were occurring within the

group and that it served a purpose for those individuals that professionals were not able

to. It also appears that the online group was providing a unique service for carers who may have limited time, child-care and mobility problems, as well as an unobtrusive source of support that fitted into their daily lives. These Internet groups are worth researching further as they may be of benefit to other carers or individuals living with a disorder and could be an adjunct to professional services.

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Critical Appraisal

1. Abstract

The critical appraisal explores some of the methodological considerations that arose during the study of the online forum.

2. Origins and Planning of the Study

As with any research project, this has been a long journey of highs and lows with many issues and components being considered at any given time. What follows is a critical appraisal of some of the key elements of the project from design to completion.

2.1.How the study originated

The current research, as with most research, developed from a number of different places. Firstly I have had a long-standing interest in the impact of chronic illness or disability on an individual or their family, especially if the difficulties have been present since birth. Therefore it seemed almost inevitable that I would choose to conduct research with a group that fitted this description. Through one of my clinical placements I did a lot of work with families of children with Autism Spectrum Disorders (ASD) and became very interested in their varying needs in both practical and emotional areas, with varying intensities and revolving difficulties. This highlighted a dearth of services related to providing support that was continuous and sometimes low level rather than focused on a specific intense time limited difficulty. Although there was some access to parent support groups run by community members many of the parents would talk about the usefulness of being able to access the National Autistic Society online to get further information or hints and tips on how to manage certain problems. This tapped into another interest of mine, which were the virtual communities accessed through the Internet.

In my opinion, the growth of the Internet appears to have had an effect on many aspects of our society. The information that is now readily accessible is an immense change that we are still adjusting to. For example when completing my undergraduate degree I still had to visit the library's physical location several times a week to access the books and journals I required; since that time I have stepped into a library maybe a handful of times as I can now access everything online either through institution paid subscriptions to journals or through free WebPages or paying for access to academic works myself. Lay knowledge is also increasing as can be seen in the acknowledgement of the expert patient, which I believe in part has been influenced by access to information from the Internet. Anecdotal observation has established that all of my friends and relations now look up any symptoms they have or the prescriptions and tests they have had at the Doctors online and will either be comforted by what they read or distressed further by it.

However, the Internet has not just provided information about academic, medical or scientific pursuits, it has also been used extensively to sell and provide services. This includes online banking, insurance policies, auction sites and dating agencies. My 82 year old grandmother has often talked about the usefulness of being able to access her banking account from the comfort of her own home and pay her bills without any paperwork. Although the Internet is not as readily accessible to everyone in this society or in the world, it is becoming increasingly easy to gain access through public locations such as libraries and Internet cafes and the majority of our schools are now 'online'.

However, there are some individuals who condemn the Internet for allowing easy access to damaging or socially inappropriate material. One of the main arguments used against the uncensored availability of the Internet is that incorrect and potentially damaging information is shared with a large number of the population. No matter how we view it, the Internet is an ever growing resource that is accessed daily by millions of people and therefore should be considered by those who are interested in the pursuits and behaviours of people.

This awareness and interest in the Internet as a new resource was further provoked when working with families who had just received the diagnosis that their child had ASD. The first action that was taken was to give the family information, regarding what ASD is and where they can access further information and support including a self-help/mutual aid group. A professional had created this particular group and continued to have input into the group and facilitate access to the location used by the group. However, some parents struggled to access the group because of childcare arrangements, distance from where they lived or a discomfort with meeting strangers. This led me to think about the information that may be available online and also about whether there were any groups, forums or communities I could recommend to these parents. However, this train of thought soon led me to wonder how I could recommend something I knew very little about and whether or not this type of support would actually be helpful to these parents. Could I be professionally comfortable with signposting a client to a service I had no information on or control or influence over or

that was not recommended by the service as a reputable voluntary organisation? Hence the development of this study.

2.2. Planning the study

Planning the study involved several stages of thought and action. Firstly I wanted to make sure that my study was clinically relevant and appropriate enough to complete for my final year project. I was therefore interested to read Goldstrom *et al.'s* (2005) comments on the 'New Freedom Commission on Mental Health' that concluded that knowing where or how to get care was one of six barriers people faced to recovery. They believed that self-help/mutual support groups and organisations could help to overcome this barrier by providing a source where people can learn about community-based services and supports. It was also suggested by Rosen (1993) that psychologists were the most appropriate group of professionals to evaluate and assess the clinical efficacy of self-care methods as they were trained to systematically investigate and clarify instructional formats, therapeutic progresses and programmes. Lastly, carers of children with developmental disabilities are recognised to face extensive physical and emotional demands as a result of care-giving tasks and are at greater risk of developing psychological difficulties than parents without children with disabilities (Gray & Holden, 1992; Bromley *et al*., 2004). There is also health and social policy that recognises the difficulties these families face, such as 'The Assessment Framework for Children in Need and Their Families' (Department of Health & Department for

Education and Skills, 2000) and 'The National Service Framework on Autistic

Spectrum Disorders' (Department of Health, 2004).

Research that had been conducted into online groups highlighted some of the design

issues that would have to be considered when planning this study. There were some

advantages to collecting data online, such as the easy access to numerous types of data,

from first hand accounts to real-time message boards and twenty-four hour access with

no travel required. The disadvantages included not knowing exactly who the researcher

was collecting data on. The anonymity, which is hypothesised to be an advantage to

those who wish to self-disclose, is a disadvantage to researchers who want to find out

about a particular population as there is no way of verifying individuals' identity. This

was a concern but I believed that a few measures could be taken to help increase the

possibility that I was accessing people who were genuine carers of children with a

disability. This included accessing sites that were designed specifically for this

population and spending some time reading the posts to gain an insight into the

discussions to verify that they were about living with a child with ASD.

After I had decided that I could access the population online, I had to decide whether

to explore one group, several groups or do a comparison study with a face-to-face

group. Even though I feel that comparisons with face-to-face groups can yield

interesting insights into the comparative helpfulness or amount of support an individual

is receiving, that was not my primary question in relation to online groups. I was

interested in whether they, as a separate entity, were being used, how they were being

used and if we could draw any conclusions about their helpfulness. I did seriously

consider looking into several online groups to firstly establish how they were each

being utilised and then to compare the findings with each other but due to the time and

length limitations of this project I felt it would be pertinent to explore one group in-

depth rather than three.

Further consideration then had to be given on how to choose the online group to be

studied and what methods to use to conduct the study. This will be explored in the

following sections.

3. Ethical Considerations

The ethical considerations of conducting an online study proved to be my greatest

challenge and learning curve within this project. I had initially started from a position

of ignorant naivety, which was based on the assumption that the Internet was considered

a public space that anyone could access and therefore use for research. After doing a

little searching and giving it some initial thought I realised that I had perhaps chosen an

area to research that was not so straightforward after all. After reading some of the

arguments present about the use of Internet transcripts for research purposes (Finn,

1999; Eysenbach & Till, 2001) I realised that there were two fairly distinct points of

view. I then preceded to bore anyone I could find with the ethical dilemma that I had

been presented with; did I consider the Internet to be a public domain in which

information was given freely with the knowledge that it was accessible to anyone,

therefore to researchers or did I consider it unethical to use data that the sender had never intended to be used for research purposes although displayed in a public setting? Of course the answer is never as simple as the question and I soon discovered that I had argued myself into a set of rules or boundaries that I considered to be acceptable and 'would do no harm' to my participants. These ideas were that every effort would be made to maintain anonymity of the online group and their participants; that an online group with an 'open' philosophy that welcomed professionals, researchers and members of the public to utilise the site would be used; that no site with a copyright on the postings would be used; that the name of the group would not be identified and usernames changed; and that I would join the site as a member and inform the moderator that I was a researcher but not the members as a whole. In this way I felt that the moderators could question my reasons for being a member or any member could email me but that I would not be disrupting the natural group process by being an overt observer or participant. I also felt that this was in line with other research projects of a similar nature (Finn, 1999; Mulveen & Hepworth, 2006).

Unfortunately, the university ethics committee did not agree with my ideas of ethical research practice with Internet groups and requested that I made the group aware of my research project so that they could refuse participation if they wanted to. When I got this feedback I was particularly unhappy. Due to circumstances outside of my control the approval had come very late in the year and I was feeling the pressure to get a project in on time and I was incredibly fearful that I would be unable to identify a site that would let me analysis their postings. This reaction itself made me start to

reconsider my own ethical position, because if I really believed that no-one could object to their posts being analysed if anonymity was maintained, then why was I worried someone would say no? In due course, I approached the moderators of a site I had identified and outlined my research proposal to them. The site I had chosen was open to anybody using the forum as long as they had a genuine interest in ASD. They had over a thousand members, which made me feel confident that it wasn't a small private group and they allowed 'lurkers' which I had discovered some sites did not. This had originally made me confident that they would be open to my being an inactive member and would not notice the intrusion. After an agonising wait of a few days, the moderators got in touch and told me that they would be happy to assist me in my project. I asked if I could download archived material partly because I felt I didn't have time to wait for a month's worth of data and I could therefore collect it in two days. The moderators explained that they were happy for me to draw general conclusions from the data set but if I wanted to use any posts as quotes that I would need permission from the author of the post. They proposed that I wrote a message to the whole group, posting it in the general discussion group and they would follow my post with an endorsement of my research. After we had done this, I received a few messages of interest in the research and was asked if it was a comparison study and how I had got ethical approval. I also received a nice message from a person with ASD who asked me not to use them in the study, as they were concerned about their anonymity. I of course immediately assured them that I would not use anything of theirs and answered the other questions as best I could.

The whole process had made me rethink my position on Internet ethics. Although I

still consider the Internet, including forums, to be in the public domain and therefore

open to anyone, I realised that these individuals had considered the forum to be a

private space. No matter the technicalities, these people had felt safe to post messages

of a personal nature within the virtual walls of their forum and it would now have felt

like a breach of trust to use their messages without permission. Although I only

received four explicit invitations to use peoples messages as quotes, with added

provisos of anonymity, I chose not to pursue any further individuals' permission as I

felt privileged that the group as a whole had explicitly or implicitly given me

permission to analyse their thoughts and feelings and I did not want to disrupt that in

any way. If I were to continue to do research on the Internet, I would now want to do it

from the beginning in partnership with the members of the group, although this may

limit some areas of research such as private, taboo or closed forums.

4. Analysing the data

4.1. Which method?

Qualitative research techniques have been used to analyse personal websites and

online groups (i.e. Jones *et al*., 2001; Huws *et al*., 2001; Fleischmann, 2004; Finn,

1999). As I aimed to explore an Internet forum it was appropriate to choose a

phenomenological approach as the emphasis needed to remain on the participants'

experiences and the meaning they may place on the online exchanges. I also wanted to

use an approach set within a contextual constructivist (Madill *et al.*, 2000) framework as I believe there can be multiple interpretations of the same phenomenon. I explored the use of Grounded Theory and Interpretive Phenomenological Analysis (IPA) but chose to use Template Analysis. I believed that Grounded Theory was an inappropriate method as it aims to build a model or theory and does so by taking an active role, deliberately testing a theory by using purposive and theoretical sampling. IPA could have been used as it is a discursive and reflexive approach that has its roots in constructivism but the analysis process is less conducive to handling large data sets and is interested in an in-depth examination of each case, including gender and age and background information, which I could not provide. Template Analysis was chosen, in part as it is a technique that can be used in a theory-driven way, allowing the researcher to acknowledge their prior knowledge of the subject and to suggest some of the themes they believe they will find. It is also a technique that can incorporate large data sets into a meaningful template and fits a phenomenological approach.

4.2.The process

When analysing the data several issues arose. Firstly the development of *a priori* codes was a thought-provoking experience. The juxtaposition between being open and reflexive to the data, as called for in a phenomenological approach, and acknowledging and anticipating preconceived findings was challenging. I did not want to blind myself to possible themes within the data by over emphasising previous research findings in the *a priori* codes but felt it was useful to recognise my thoughts and assumptions on

what I would find. Remaining open to the development of new codes was a constant yet rewarding challenge as it really made me think about what I was reading and how I was defining the essence of the exchanges. Drawing on Finn's (1999) codes was a new experience for me. Having completed the first stage of the analysis and finding many elements that related to Finn's categories made me question the usefulness of examining the data with his codes as *a priori* themes. Although the first stage of the analysis had highlighted the different ways in which the members were using the forum it had not explored whether the processes of helping as identified in self-help and mutual aid literature were present. It had alluded to the presence of these processes but had not explored this in-depth. Finn's categories were chosen as they had been developed based on self-help, mutual aid and social support literature and had already been used to examine an online group for disabled people, which was a similar field to my study. Using his categories as *a priori* rather than fixed codes allowed me to explore whether they were present but also to challenge my interpretation of the data and look for other possible processes that were taking place. Learning how someone else had defined themes was a useful process that helped me to question how valuable each code was in representing a helping process and whether it conceptualised what I felt was present in the data.

During the analysis process I was also grateful many times for the use of parallel coding within Template Analysis, as there were many passages that seemed to fit into a number of themes. Although some of the messages were very short they often appeared to convey a large amount of information and emotion. I also had to decide whether or

not to include the symbols as part of the data to be coded and finally decided that they appeared to be such an integral part of the messages that it would be misrepresentative of the data sample to leave them out. Lastly, there were several times when I wanted to respond to the messages, either to add my well wishes or to expand on the information given. Although, at no point did I feel the need to correct any information posted on the site, there were times when I wanted to elaborate on it or give the reasons why some professionals may be taking their time over a diagnosis or responding in particular ways. I also found reading some of the stories a very emotive and powerful experience, as some described some very difficult or worrying times for the families. It was difficult not to jump online and ask if there was any way in which I could help or to add my own words of thought and encouragement. Reading the postings gave me a unparalleled insight into these parents' lives, thoughts and fears and also what aspects of parenting brought them joy and pride. Although I have worked with families with a disabled child and been privilege to some of these experiences I felt that I gained a greater insight and understanding from reading these messages, that I am sure will transfer into my clinical practice. These sites may be useful to other health care professionals to assist in developing a contextualised understanding of the impact of caring for a disabled person.

5. Hindsight and Development

Now that this project has come to an end, I am more clearly able to reflect on the strengths and weakness of its design as well as the learning that has taken place. Firstly

it is clear that any project generates more questions that it manages to answer and that these questions could go on infinitely. If I had time left to continue this project I would very much like to take my findings, especially regarding the presence of Helping Mechanisms, back to the members of the forum and ask their opinion on it. This is because I realise what an intrinsic part of the analysis they are and that it is their perceptions and understandings of the group that determine its usefulness. I will be providing the group with a summary of my findings and they may wish to continue the project with me.

In hindsight I would probably use a content analysis for the first part of the analysis rather than template analysis. This is because a content analysis may have more readily addressed how the site was being utilised while finding the same themes within the data. Although the template allowed me to make an interpretation as to what I believed the site was being utilised for, a content analysis may have been less subjective as it shows the number of times a theme is present within the data. However, the question remains that if something is present more often then something else, does that mean it is valued more? The template analysis also allowed for parallel coding which I felt was invaluable as it was often difficult to pigeon hole a piece of text into just one theme and I believe I would have struggled to identify the primary theme to complete a content analysis. However, the fact remains that the content analysis may have been more useful in exploring how the site was utilised and the analysis for the presence of Helping Mechanisms could have been used to highlight the presence and apparent importance of sharing personal stories and communicating information.

I have also learnt to spend a lot more time on designing a project and thinking through its limitations, strengths and ethical considerations more fully than I had previously done. Although completing a research proposal facilitates this process I was less engaged in that process than I could have been and was more concerned about receiving ethical approval than considering the possible outcomes of my study. Although this study is a starting point for undertaking further research with online groups and parents caring for children with ASD and could have some implications for clinical practice, I am aware that it has several limitations. These limitations would not have prevented me from undertaking the research but I could have built into the design other aspects of the study to strengthen it. These could have included a feedback and interview component or downloaded threads from several points over a year or two from the archives. I could also have engaged in a group poll to get more information on the group members, for example if they were male or female or the cultural majority or minority. All of these components would have made my results more robust and perhaps more generalisable.

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Appendix A:

Initial Template developed in stage one of the research study.

Level 1 Codes	Level 2 Codes	Level 3 Codes
1.Communicating Information	1.Seeking Information 2.Sharing Information 3.Reviewing Information 4.Giving Advice 5.Sharing Opinion 6.Giving Information 7. Clarifying Information (?)	1.About media 2.About research
2.Personal experiences of living with ASD	1.As a parent (positive and negative) 2. As a individual	1.Seeking similar experiences from others 2.Describing the unique role of being a parent of a child with ASD 3.Asking questions about parenting style 4.Sharing readjustment and realizations with other parents 5.Giving hope to other parents 6. Normalising experiences for other parents.
3.Sense of Community	1. Acknowledging peoples stories 2. Giving Support/encouragement 3. Giving acceptance/understanding 4. Expressing emotion 5.Asking for support 6.Attitude/beliefs about ASD 7.Promoting inclusion in the group	1. virtual (symbols) hugs 2. virtual (symbols) praying 3. sadness (text and symbols) 4. anger 5. joy 6. humour/sarcasm
4.Services	1. Experiences of professionals and services 2. Advice seeking on how to 'handle' professionals (?) 3. Information on services 4. Raising awareness of services – including charity/volunteer 5. Giving tips on services (?)	1. negative (emotional expression) 2. positive

The initial template for phase one of the analysis

Appendix B

Helping Mechanisms as identified by Finn and adapted from his paper 'An Exploration of Helping Processes in an Online Self-Help Group focusing on Issues of Disability' (1999), and used in the second phase of the analysis in this study.

Helping Mechanisms: Socioemotional	
1. Expressing feelings or catharsis	Involves expressing feelings, being self-revealing, or telling of emotional or traumatic events.
2. Providing support or empathy	Responding with helpful or comforting words, talking with someone about the emotional component of a problem or circumstance, or showing understanding of another's situation.
3. Chit Chat	General conversation between two or more people that emphases everyday talk and does not specifically address any other code.
4. Universality	Expressing the idea that people have the same experiences or report similar experiences, circumstances, or feelings; stating that the person is 'not all alone' and that others have experienced similar situations, feelings and emotions.
5. Friendship	Expressions of friendship, discussions of making friends in the group.
6. Extra-group relationships	Discussion about interactions outside the group, including phone calls, visits, 'snail mail', doing things they have in common, going out to dinner, and interacting in other personal ways – outside of the electronic support group
7. Taboo topics	Subjects, problems, or situations that generally may not be openly discussed. These are considered 'private' and include topics concerning sex, extramarital affairs, suicide, child abuse, drug use, or things for which others may place negative judgement on the person.
8. Damaging statements	Any statement in which a participant acknowledge being hurt by someone's comments on the conference or any statement that may cause hurt through verbal hostility.
9. Poetry and art	Thoughts, feelings or emotions expressed through verses, prose, or art.
Helping Mechanisms: Task Orientated	
10. Asks information	Asking if others know information or facts about a specific subject, topic, disease, treatment, process or policy.
11. Provides information	Stating or providing factual and useful information, information regarding specific problems or certain subjects.
12. Problem solving	An exchange of ideas, in which people offer specific advice or ask questions of others to solve specific problems.
13. Computer talk	Discussion about computers, modems, conferences, lurkers, problems with computers, or computer jargon used in conversation.
14. Group cohesion	Messages that provide a sense of how members feel about the group.

Helping Mechanisms as explained in Finn's (1999) paper.

Appendix C:

Example of Coding

82P	07:06 PM Post #2
	Hi 30P No I haven't had that happen. All I ever seem to get is the opportunity to explain waht ASD or whatever is. Today I told someone who has known me and the children for 10 years the my DD has just had a Dx and that she is on the Autistic Spectrum, she then asked what sort of medication that was. (IMG:style_emoticons/default/blink.gif) ... Rolls eyes back and lets out a huge groan! ... (IMG:style_emoticons/default/wallbash.gif) Glad to hear that you made a new friend though! (IMG:style_emoticons/default/clapping.gif) (IMG:style_emoticons/default/dance.gif) (IMG:style_emoticons/default/thumbup.gif)
100P	07:51 PM Post #3
	I've had a couple of experiences where I've mentioned ASD and the other mum als has kids on the spectrum, then there's an instant exchange of info and a kind of instant bonding and understanding. One mum who was about six months ahead of me in getting dx for her son, same age as DS2, gave me loads of contacts about benefits etc, and another mum who I met through nursery school gave me info about Statementing. All of that was hugely helpful, cos I didn't know anything back then. I hope I've managed to do the same for a couple of people who are similarly just behind us in the dx process. Knowledge is power! 100P (IMG:style_emoticons/default/dance.gif)

Appendix D:

Ethics Committee Approval Letter

Dear Jennifer

Your project (An exploration of an internet discussion forum for Autism Spectrum Disorders in relation to Self-Help/Mutual Aid groups and helping processes) has been approved by the Psychology Research Ethics Committee. I apologise for the quite unacceptable delay, which was not caused by the Psychology Research Committee -- indeed, I have been trying very hard to expedite this approval since you first submitted it.

We approve the research subject to two requirements. (a) Anonymity of participants must be guaranteed -- we do not consider it sufficient to say merely that "every effort will be made". (b) Your participants should ideally be made aware that their responses may be used for research purposes, so that it can be assumed that people using the web site that you use do not object to this. If you cannot identify a suitable web site in Phase 1 of the study, then you should not progress to Phase 2 without getting back to this committee. Please let me know if either of these stipulations appear problematic, and I can assure you of a swift response directly from me or this committee.

This e-mail is the official document of ethical approval and should be printed out and kept for your records or attached to the research report if required - this includes all undergraduate and postgraduate research.

We wish you every success with your study.

Andrew M. Colman
Psychology Research Ethics Committee Chair

Appendix E:

Letter from the online forum moderators

Hi again Jennifer -

Thanks for your e-mail 🙂

Considering the template analysis of the 'collective data' we think it would be problematic to ask all members who have contributed to individually approve the research... Some may no longer be active on the forum and others just may not notice your post if they are infrequent visitors.

The best option would probably be a post outlining how the data will be gathered/used and then we will post an 'endorsement' asking anyone who specifically wishes NOT to have their posts included to advise accordingly.

Both your own post and ours can then address the matter of individual references, stating that you would only use them with the express permission of the posting member, and with full assurance that both personal and forum anonymity would be safeguarded.

If that would satisfy the University protocol that would seem the easiest way to go.

Very best

The mod/admin team.

Happy info gathering!

L&P

BD 😄 (for the mod/admin team)

Appendix F:

Statement of Originality

The accompanying thesis submitted for the degree of Doctorate in Clinical Psychology entitled

'An exploration of an Internet Discussion Forum for Autism Spectrum Disorders in Relation to

Self-Help/Mutual Aid groups and Helping Processes' is based on work conducted by the author

in the Department of Clinical Psychology at the University of Leicester mainly during the period

between October 2006 and July 2007.

All the work recorded in this thesis is original unless otherwise acknowledged in the text or by

references.

Appendix G:

Notes for Contributors

The British Journal of Clinical Psychology publishes original contributions to scientific knowledge in clinical psychology. This includes descriptive comparisons, as well as studies of the assessment, aetiology and treatment of people with a wide range of psychological problems in all age groups and settings. The level of analysis of studies ranges from biological influences on individual behaviour through to studies of psychological interventions and treatments on individuals, dyads, families and groups, to investigations of the relationships between explicitly social and psychological levels of analysis.

The following types of paper are invited:

- Papers reporting original empirical investigations;
- Theoretical papers, provided that these are sufficiently related to the empirical data;
- Review articles which need not be exhaustive but which should give an interpretation of the state of the research in a given field and, where appropriate, identify its clinical implications;
- Brief reports and comments.

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers should normally be no more than 5,000 words, although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Reviewing

The journal operates a policy of anonymous peer review. Papers will normally be scrutinised and commented on by at least two independent expert referees (in addition to the Editor) although the Editor may process a paper at his or her discretion. The referees will not be aware of the identity of the author. All information about authorship including personal acknowledgements and institutional affiliations should be confined to the title page (and the text should be free of such clues as identifiable self-citations e.g. 'In our earlier work...').

4. Online submission process

1) All manuscripts must be submitted online at **http://bjcp.edmgr.com** .

First-time users: click the REGISTER button from the menu and enter in

your details as instructed. On successful registration, an email will be sent informing you of your user name and password. Please keep this email for future reference and proceed to LOGIN. (You do not need to re-register if your status changes e.g. author, reviewer or editor). <u>Registered users:</u> click the LOGIN button from the menu and enter your user name and password for immediate access. Click 'Author Login'.

2) Follow the step-by-step instructions to submit your manuscript.

3) The submission must include the following as separate files:

- o Title page consisting of manuscript title, authors' full names and affiliations, name and address for corresponding author - **Editorial Manager Title Page for Manuscript Submission**
- o Abstract
- o Full manuscript omitting authors' names and affiliations. Figures and tables can be attached separately if necessary.

4) If you require further help in submitting your manuscript, please consult the Tutorial for Authors - **Editorial Manager - Tutorial for Authors**
Authors can log on at any time to check the status of the manuscript.

5. Manuscript requirements

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript with their approximate locations indicated in the text.
- Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate page. The resolution of digital images must be at least 300 dpi.
- For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions: **British Journal of Clinical Psychology - Structured Abstracts Information**
- For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full.
- SI units must be used for all measurements, rounded off to practical values if appropriate, with the Imperial equivalent in parentheses.
- In normal circumstances, effect size should be incorporated.
- Authors are requested to avoid the use of sexist language.

- Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations etc for which they do not own copyright.

For Guidelines on editorial style, please consult the *APA Publication Manual* published by the American Psychological Association, Washington DC, USA (**http://www.apastyle.org**).

6. Brief reports and comments

These allow publication of research studies and theoretical, critical or review comments with an essential contribution to make. They should be limited to 2000 words, including references. The abstract should not exceed 120 words and should be structured under these headings: Objective, Method, Results, Conclusions. There should be no more than one table or figure, which should only be included if it conveys information more efficiently than the text. Title, author and name and address are not included in the word limit.

7. Publication ethics

Code of Conduct - **Code of Conduct, Ethical Principles and Guidelines**
Principles of Publishing - **Principles of Publishing**

8. Supplementary data

Supplementary data too extensive for publication may be deposited with the British Library Document Supply Centre. Such material includes numerical data, computer programs, fuller details of case studies and experimental techniques. The material should be submitted to the Editor together with the article, for simultaneous refereeing.

9. Post acceptance

PDF page proofs are sent to authors via email for correction of print but not for rewriting or the introduction of new material. Authors will be provided with a PDF file of their article prior to publication.

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