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# Coping with Autistic Spectrum Disorder: Parental challenges and the role of School-Based Family Counseling

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The accurate diagnosis and subsequent advice and support for the parents of a child diagnosed with Autistic Spectrum Disorder (ASD) are crucial in ensuring that the child's specific needs are appropriately met, both before and after the child enters formal schooling. This article addresses three issues – difficulties experienced by such parents; their comprehension of autism and what is needed in order to cope effectively; and how professional intervention pertinent to School-Based Family Counseling (SBFC) can be of help. The first two issues are addressed through a qualitative research investigation, with data collected by means of personal interviews with parents. The results indicate that parents often do not initially understand the lifelong nature of autism; they do not know how to adjust their family lives to meet the needs of the autistic child and other children in the family; and they are often overwhelmed by how to manage their ASD child. Therefore they are in need of professional intervention. In addressing such need for professional help, this article considers how it can be provided through SBFC.

Key words: Autistic Spectrum Syndrome (ASD), Parental challenges and strategies, School-Based Family Counseling (SBFC).

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#### Introduction and theoretical foundations

Autistic Spectrum Disorder (ASD) is a lifelong disability, identifiable before the age of three years, and characterized by a triad of impairments - in social interaction; in language and communication; and in behavior and imagination (Kluth, 2003). Stillman (2005) describes such children as having a lack of response to human interaction, deficits in language and communication, and repetitive, stereotyped behavior responses to stimuli. Parents typically find

it difficult to accept that their child is not developing 'normally' (Gray, 2006). Therefore, they need to be empowered to manage and cope with the change in family dynamics within the home (Sicile-Kira, 2003). In this regard the work of Scorgie, Wilgosh, Sobsey and McDonald (2001) focuses on 'effective life management'. In similar vein Hastings and Beck (2004) suggest the use of what they refer to as 'cognitive behavioral techniques', including 'problem-solving, cognitive restructuring, and monitoring of thought and feelings' to effectively manage life. Parental 'positive perceptions' are strongly related to managing and coping with a disability (Hastings, Allen, McDermott & Still, 2002). Grant and Whittell (2000) also emphasize the 'positive psychological states' of parents as being important in helping them to cope.

A systems model explains that contact exists between all nested subsystems in which a person operates. All different structures, including the learner, the family, the school, the peers, and the community, have an effect on each other. The context of the family, as the primary social system in which the learner operates, has a profound influence on that learner's school achievements and social behavior (Marchetti-Mercer, 2008). If the family is facing problems, it can have a severe impact on the learner's school achievements (Carter & Evans, 2008; Smith, 2011). The school, as the learner's secondary social system, also has an important impact on learners' accomplishments and school success (Donald, Lazarus & Lolwana, 2002; Stainback & Stainback, 2002). For this reason it is vital that the relationship between the school and the parents be enhanced and treasured. Collaboration in addressing the learner's challenges will enable the learner to achieve greater success in becoming a worthy member of society (Evans & Carter, 1997).

School-based Family Counseling (SBFC) is a term that was first coined by Adler as early as the 1920's (Gerrard, 2008; Smith, 2011). Such counseling is widely considered as a potent approach, where school counseling and family counseling are combined within a wider systems approach to address the learner's challenges (Gerrard, 2008) - correlating with Bronfenbrenner's (1979) notion of nested subsystems within the broad system in which the learner operates. In this article it is argued that community-based family counseling should be recognized as the initial form of professional counseling that plays a pivotal role in assisting the family of an ASD-diagnosed child (Gupta & Singhal, 2005). Once the child enters the school, school-based counseling can and should build onto such earlier community-based counseling for the family, thus ensuring integration and continuity in professional help through a systemic approach (Marchetti-Mercer, 2008), to maximize the child's further school success. This article presents a South African perspective on the ASD-related challenges of parents, against the framework of research done in other parts of the world.

### **Nature of the research investigation**

The aim of this investigation was to investigate what specific challenges parents of ASD diagnosed learners experience daily; what they need to cope in their specific situation at home; and how helping professionals, in particular SBF Counselors, can assist them.

For that reason the following primary research question was asked: "How can the challenges of parents with ASD-diagnosed children be addressed effectively?" In addition, the following secondary research questions were formulated to illuminate the focus: What are the

specific ASD-related challenges faced by parents? How do parents comprehend ASD? What are the specific needs of parents with regards to handling their child diagnosed with ASD? How can professional intervention be of help to such parents?

This research is firmly grounded in a constructivist, interpretive multi-systemic philosophical framework (De Vos, 1998; Rodwell, 1998; Terry, 2002), and approached according to the conceptual framework of Bronfenbrenner's eco-systemic model (Bronfenbrenner, 1979). A qualitative research design was followed for the investigation (Creswell, 2003). The participants were parents with ASD-diagnosed children (American Psychiatric Association: Diagnostic and Statistical Manual of Mental Disorders IV Revised, 2000), purposively chosen from an availability sample (Struwig & Stead, 2001). Of the total sample of eight participants, two were female and six male; five were married and three divorced; seven were white and one colored. All were recruited from the Eastern Cape Province, South Africa.

The investigation took the form of a series of individual semi-structured interviews (Mouton, 2002) in the natural context of the parents' homes (Holloway & Wheeler, 2002). Field notes and observations during the interviews provided a 'within-method triangulation' (Holloway & Wheeler, 2002). Each interview lasted for 40-50 minutes. All recordings of interviews were transcribed verbatim. The data was analyzed (Creswell, 1994) until definite patterns emerged (Bogdan & Biklen, 1992). The literature review generated a theoretical framework for the study. The findings were compared with those of existing scientific data (Holloway & Wheeler, 2002). These findings determine the contributions and recommendations of this study.

Guba's model (as explained in Creswell, 2003) was applied to ensure trustworthiness, according to the criteria of credibility, transferability, dependability and confirmability. The interview transcripts, field notes and data were collected from an audit-trail file, thus authenticating the research (Rudestam & Newton, 2001). Informed, written consent from the participants was obtained (Latimer, 2003), and anonymity, confidentiality and voluntary participation were assured.

## **Results of the research investigation**

The thematic content analysis of data obtained indicates the presence of a variety of developmental challenges that parents of ASD-diagnosed children face, and how these may be addressed effectively. These can also be related to findings elsewhere in the research literature, and include the following:

Theme 1: Specific challenges faced by parents and children.

Delayed motor skills development of the child. Some infants may be delayed in reaching their developmental milestones (Wing, 2002). One participating parent confirmed this finding in that "His hand-eye co-ordination is basically very limited."

Social problems. These include the impact on siblings and peers. It is difficult for other children to deal with an ASD-diagnosed child, yet they can also be very accommodating and caring

(Stillman, 2005). One parent reported that "He's [the brother] very patient and has taught him how to use the computer. He will sit and read to him." Social problems also include how the parents handle the ASD-situation influences with the other children in the family (Gray, 2006), which often displays apathy and shows this in the form of hurtful remarks. In this regard, one parent said: "The mothers were very nasty to me, I was in tears." As a result, the social life of the family can become restricted, because parents are sensitive to negative attitudes towards their child. It can become very stressful for parents to take their ASD-diagnosed child out (Wing, 2002). Parents often prefer to avoid others in order to protect themselves and their ASD-diagnosed child (Gray, 2006; Scorgie et al., 2001). One mother commented as follows: "You can't control the child. I could not take her anywhere."

Communication problems of the child. If ASD-diagnosed children cannot effectively communicate their needs, it can become problematic. Delayed speech is a great cause of concern for the parents; and this is often the initial symptom forcing them to seek professional advice (Gray, 2006). Sometimes ASD-diagnosed children show limitations with regard to communication skills. One parent explained: "He didn't sort of communicate very much at all. I would yell and say, 'Talk to me!' -- because he wouldn't." Children with limited communication skills generally use other methods of communication, as one of the participating parents explained: "She wants to say 'hello', but she'll pull a face."

Additional aggravating conditions in the child. Numerous additional aggravating conditions may accompany the condition of ASD, such as aggressive behavior and depression. One of the parents reported that: "He chased the teacher with a hammer and hit her. He chased the kids with blocks of wood ...".

Personal parental problems. Parents often experience many different emotions and reactions in their ASD family. Depression is one of their most common problems, as confirmed by one parent in the study: "Because my sister's ... got bipolar, too. My mother was a manic-depressive. So there's a lot of depression in our family." ASD has an impact on the emotional relationship between the parents. In the Canadian study of Scorgie et al. (2001), parents indicated that their relationship was coming second. The rate of divorce amongst parents who have an ASDdiagnosed child is higher than that found in the broader population (Whitman, 2004). In the present study, one mother expressed her thoughts as follows: "He's very difficult and I'm surprised he's still alive, ... that I haven't murdered him.". The issue of physical wellbeing is mentioned by Hastings and Beck (2004, p. 1338), and by Schopler and Mesibov (1983). Parents often place their own health and wellbeing below the needs of their children, risking the creation of a physical illness, such as cancer. One mother referred to her own illness in the following words: "I had brain cancer and ... it was inside of me for a long time ...". Researchers often note that parents of ASD-diagnosed children experience financial constraints (Whitman, 2004). Medical aid normally only pays a portion of the cost, causing an additional financial burden for the parents. Two parents separately alluded to such expenses: "You've gotta pay therapists"; ... "It's extremely expensive."

Theme 2: Parental comprehension of ASD is essential to effective coping
Both international research and the present study confirm that parental comprehension of the various aspects of ASD is essential for effective family coping. These include the following:

Acceptance. It is important for parents to realize that their child is not autistic because of something that they did wrong (Whitman, 2004). Acceptance is necessary in order for the parents to become proactive and empower themselves with regard to ASD (Scorgie et al., 2001; Stillman, 2005). In the present research investigation parents found it difficult to acknowledge the situation and accept the diagnosis. One parent expressed this fact as follows: "... the biggest problem at the beginning, was ... to accept there's something wrong." Acceptance can also be made more difficult when the diagnosis is problematic for some of the professionals, and that may further contribute to the parents' misconception and confusion regarding ASD. Frith (2004) reiterates that parents often have horror stories to tell about how long it took for their child to be diagnosed after they had sought professional help, as one parent explained: "She (the psychologist) had no idea what was wrong. They don't notice autism."

*Understanding.* Parents need to understand the specific needs of the ASD-diagnosed child. However, sound guidance about the needs of the child is not always forthcoming. One parent articulated this in the following quote: "It's been a long road .... No-one tells you what they can do to help you."

Routine. These children need routine, as noted by researchers like Wing (2002), who emphasizes how the child's environment must be ordered. In the present study, parents experienced that routine was needed by their child; for example: "He needs constant guidelines, ... structure ..."

Life and social skills. In order for them to function adequately in society, these children need to learn socially acceptable life skills, and it can take a lot of patience and perseverance from most parents to teach them such skills (Stillman, 2005). Several parents in the present investigation illuminated various aspects thereof in the following words: "Toilet training was horrific!"; "I'm just hoping ... that she would be able to look after herself - just basics."

Discipline. Implementing the discipline these children need is problematic for many parents. Parents have to explain the terms of behavior in such a way that the ASD-diagnosed child can follow (Stillman, 2005). Lovaas (1993) postulates that the best stress reduction is accomplished if the 'parents experience some control' over the child. Schopler and Mesibov (1983) confirm this perspective from the USA. In our study, a participating parent made the problem with discipline clear: "I struggled to discipline him, because I didn't know what to do."

Quality time. The ASD-diagnosed child needs more organized quality time and good time management from the parents (Lovaas, 1993; Sicile-Kira, 2003). As one parent in the present study explained: "Just the amount of time you need to spend extra on her ...."

*Diet.* Many participating parents indicated that they watched their child's balanced diet very closely. In one words of one participating parent: "If you don't put vegetables on his plate, you haven't given him supper!"

*Medication*. ASD-diagnosed children may lag behind in the development of skills, such as gross motor skills (Sicile-Kira, 2003). Medication is often administered to children diagnosed with ASD (Whitman, 2004). According to the participants in this study some medications prescribed

had a positive effect on the behavior of the child, while others did not. One parent thought that"The Ritalin and the Ritafin just made him worse."

Theme 3: Parents need specific attributes to deal effectively with their ASD-diagnosed child In further addressing the second issue in this article, Scorgie et al. (2001), from Canada and Hastings et al. (2002) from the UK, refer to the positive outlook of the parents. A positive psychological state of parents (Grant & Whittell, 2000) is seen as a strength that helps them 'bounce back'. Their findings relate well to those in this South African study, where respondents emphasized the need for positive, proactive parental attributes, including the following: Patience. In this regard parents proclaimed that: "The biggest demand has been patience. I'm not the most patient person at times, ... it's frustrating.", and "Never give up."

Faith and prayer. This can give strength, as noted in research in Canada (Scorgie et al., 2001) and Australia (Gray, 1994; 2006). One of the current parents alleged: "... if people haven't got faith, then I don't know how they will cope".

Treating the child as normal. Whitman (2004) states that when parents become strong 'advocates' for their ASD-diagnosed child, this attitude assists them in coping, a view also supported by the research findings of Scorgie et al. (2001) in Canada. Participants in our South African study agreed that it was important to treat their children as normal. One parent noted in this regard: "Don't treat them like they are any different to any other children ..."

## Theme 4: Parents require professional and social support

The third issue in the research project has major implications for SBFC, with the respondents indicating a high need for multi-disciplinary support. This includes the following:

A multi-disciplinary professional approach. Professionals can and must provide essential support to parents of ASD-diagnosed children (Scorgie et al., 2001). Apart from general medical practitioners, other experts like counselors, therapists, psychiatrists and pediatricians could well be involved in such a team. The following statement confirms one parent's experience: "... she had no idea what was wrong ... then she sent us to x (a specialist) in Cape Town. About half an hour and x had diagnosed it, spot on!"

In addition to a multi-disciplinary approach, respondents indicated a strong need for supportive relationships of two kinds. Firstly, they reported that the immediate family was most acutely affected by the presence of an ASD-diagnosed child. Initially, the family often ascribes the behavior of the child to incorrect child rearing, or 'naughtiness'. One parent articulated her experience as follows: "My Mom actually said: He must come and live with me ... I'll sort him out!" Participants generally experienced increased support from the family, once it had been explained that the child had been diagnosed with ASD - and what that meant, and how it should be dealt with (Luther, Canham & Cureton, 2005). Secondly, and importantly from a SBFC perspective, participants indicated a need for help from organized support services. For schoolaged children, the first organized support was seen to come from the school. One parent explained her support as such: "... with a psychologist's help at the school, ... then we went to a social worker. She gave us coping mechanisms as well." Unfortunately, the research survey did not pursue this issue further by investigating what kind of support was sought or prioritized. All of the participants also indicated that they would welcome a regular support group for expressing

and sharing their feelings and experiences. This was also highlighted in Australia (Gray, 2006) and the United Kingdom (Hastings & Beck, 2004).

## Summary of findings

The results of this research survey demonstrate that parents and their ASD-diagnosed children face multiple and formidable challenges, a finding amply supported in the literature. The preschool ASD-diagnosed child experiences difficulties with developing motor skills, communication strategies, behavior patterns, and social relationships. These difficulties are further complicated by academic and peer group pressures as the child becomes involved in the educational system. Faced with these, parents experience many challenges in their own right. Some of this has to do with trying to understand their developing child's problems – problems which most have never encountered before. They struggle with conflicting personal reactions to their child's problems, as well as with their own sense of confidence and worth. And this, of course, constitutes a challenge to the couple's resourcefulness – its ability to provide appropriate parenting strategies, family routines, quality of family relationships, and at the same time maintain the integrity of the couple relationship. Parents also look for support from family and friends, and from professional resource personnel who will, hopefully, act in a constructive and multidisciplinary manner. While the research survey focuses primarily on the many needs of parents and families during the pre-school years, it raises major questions over how these needs will challenge families and their professional helpers during the child's school years. It is at this point that the concept and practice of SBFC comes into play.

## Relevant conceptual frameworks for intervention – SBFC and couple resilience

As noted in the survey, the challenges facing the family with an ASD-diagnosed child are formidable and multiple. It is vital that the family, and in particular the parents, are fully involved in the process of enhancing the child's functioning at home and at school. The survey did not discuss a rationale to underpin the actions of helping professionals involved. However, it is our strong contention that such a rationale must explicitly link school and family. This is exactly what SBFC as a conceptual framework addresses. The survey results highlight the central position that parents hold in guiding the family's response to the needs of their ASD-diagnosed child. Where there is a parenting couple, therefore, helping professionals need a conceptual framework that defines the core components of a well-functioning couple relationship, enabling them to respond appropriately to the needs of their ASD-diagnosed child. The concept of couple resilience, developed in New Zealand, provides such a conceptual framework (Everts, 1999; Everts, 2008; Everts & Wu, 2004; Wong & Everts, 2002). It emphasizes the importance of four major components – the personal resourcefulness of each partner, the quality of their emotional relationship, relationship skills, and social support. These are the very resources highlighted in the research study, and ones which can be enhanced through psycho-educational training or counseling. Thus a couple resilience framework or a family resilience one (Grant & Whittell, 2000) within a wider SBFC process provides a powerful conceptual tool, to be used by helping professionals to help them understand what parents/couples face, and how these families may be best helped. The research survey highlights how many and complex the needs are that must be addressed.

## The importance of a multi-disciplinary team

The survey emphasizes the need for a multi-disciplinary team to provide continuity of intervention over time. Faced with the complex situation that families with an ASD-diagnosed child face, it is unlikely that a single SBFC helping professional exists in South Africa or, for that matter, in most other countries, who operates from the above conceptual framework, and is also in a position to coordinate intervention strategies. It is more likely that a number of helping professionals are involved within the family-school context, addressing the multiple needs of the family and in particular those of the parents. This article emphasizes the need for those professionals to work together from a SBFC perspective, as a multi-disciplinary team, and in a coordinated manner.

This implies that information and intervention strategies must be shared – between what has happened during the child's preschool years and now; between those who work within the community and those who work within the school context; between those who come from different disciplinary backgrounds; and between those who operate from different theoretical paradigms. The research data indicates that a coordinated multi-disciplinary approach must be inclusive and respectful of all contributions. Within such a context, SBFC offers a relevant and powerful paradigm for understanding the needs of parents and families with ASD-diagnosed children, and for guiding intervention strategies. How all that can be worked out is the stuff of future intervention and research projects, incorporating points raised in this article. In the process, it is also expected that the tenets and practices of SBFC will be challenged and elaborated.

### Some practical recommendations for SBFC intervention with parents of ASD children.

The foregoing data in this article suggests that consideration be given to the following:

- Parents need up-to-date information on the developmental capacities and needs of their ASD child physical, cognitive, emotional, moral and spiritual. They need information on the nature of the educational processes within which their child operates, year by year (Scorgie et al., 2001).
- Parents need help in using such information to develop their skills so that they can act in an appropriate parenting role. In that role they can, for example, develop a schedule for the day's routines at home, as well as house rules which dovetail with the child's school schedule (Grant & Whittell, 2000; Gray, 2006). They can be helped to develop consistent and comprehensive discipline practices, or 'parental control' (Lovaas, 1993). Parents can be assisted with expanding strategies of communication; for example approaching a non-verbal child through communication by means of a regularly updated photo album of the home, family, friends, school and special occasions; or the use of electronic media that fit with the child's life at school.
- At the same time, parents need support in spending quality time with their child at home, especially when that child enters school and the pressures of time at school cumulate (Lovaas, 1993). Parents should be helped to understand and engage in regular, shared healthy outdoor physical and recreational activities.
- Parents need counseling time to deal with their personal feelings and couple relationship issues. The research data has highlighted how success in this is important for their ability to

provide the above-mentioned quality of parenting for their ASD-diagnosed child and others in the family (Hastings et al., 2002). The SBFC-orientated counselor is excellently provisioned to provide such help. Parents should also be convinced of their need for 'time out' for themselves (Scorgie et al., 2001).

• In line with the research on couple resilience (Everts, 1999; Everts, 2008; Everts & Wu, 2004; Wong & Everts, 2002), the support of extended family members and friends is vitally important during the school-going phase in their child's life (Gray, 2006; Grant & Withell, 2000; Schopler & Mesibov, 1983). Parents should be encouraged by SBFC-orientated helping professionals to be strong advocates for their ASD-diagnosed child in the school system, because of their first-hand experience of ASD in the family, even before school entry (Whitman, 2004). For example, an annual autism awareness campaign could be established on local and national levels, to enable educators and community-based support systems to become more aware of ASD. Thus, through a SBFC-style integrated program of community-based and school-based family counseling, all sub-systems in the family - couples, parent-child, siblings, grandparents and the extended family can be addressed (O'Connell, 1985) in order to enhance the family's resilience in dealing with ASD throughout the different stages of their child's school career.

These issues require careful and serious consideration by all professionals involved in counseling. Carter and Evans (2008; 2011) explain that such an approach will have to evaluate both the family and school systems by assessing whether proper listening and communication takes place; whether participants are open and flexible in joining forces to find solutions; whether all parties are committed to improving the situation; whether follow-up and follow-through is taking place; and whether ongoing evaluation is undertaken.

#### Conclusion

The parents of ASD-diagnosed learners who participated in the research expressed themselves openly regarding their need for professional support. This article highlights the importance of community-based counseling to address such parental needs during the pre-school years and as the child enters the school system. Over time, this is augmented or replaced by a coordinated SBFC perspective that focuses on enabling the parents strengthen their own resilience, to help their child cope with academic learning and peer group challenges, and to develop the child's social competence, self-confidence, positive attitudes, and self-esteem. Recommendations deduced from the research study and SBFC literature have been used to provide pointers to helping professionals for the empowerment of parents dealing with ASD-diagnosed children during their school years.

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