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Family-focused autism spectrum disorder research: A review of the utility of family systems approaches

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Keywords

review, utility, systems, family, approaches, focused, autism, spectrum, disorder, research

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Abstract

A family member with an autism spectrum disorder presents pervasive and bidirectional influences on the entire family system, suggesting a need for family-focused autism spectrum disorder research. While there has been increasing interest in this research area, family-focused autism spectrum disorder research can still be considered relatively recent, and there are limitations to the existing literature. The purpose of this article is to provide theoretical and methodological directions for future family-focused autism spectrum disorder research. In particular, this article proposes Family Systems approaches as a common theoretical framework for future family-focused autism spectrum disorder research by considering theoretical concepts such as Boundaries, Ambiguous Loss, Resilience and Traumatic Growth. We discuss reasons why these concepts are important to researching families living with autism spectrum disorder and provide recommendations for future research. The potential for research grounded in Family Systems approaches to influence clinical support services is also discussed.

Keywords

ambiguous loss, autism spectrum disorders, dyad, family functioning, family systems, holistic approaches, resilience, subsystem, support services, stress, traumatic growth

Introduction

Autism spectrum disorders (ASD) describe a variety of lifelong and pervasive developmental disorders that affect individuals and, importantly, their family in a variety of ways (Macks and Reeve, 2007; Reichman et al., 2008). For this reason, families who have a member with ASD can be referred to as families living with ASD (Neely-Barnes et al., 2011). Family-focused ASD research is critical for increasing our understanding of the impact of these disorders and informing clinical support services for these families. Such research is becoming more common, exploring issues such as the challenges and benefits ASD has on families, ways to support families living with ASD and the impact of ASD on siblings. However, the area of family-focused ASD research still remains underdeveloped as we are only beginning to understand the intricate, reciprocal influences between an individual with ASD and other family members (Orsmond and Seltzer, 2007).

This article briefly reviews key areas of existing family-focused ASD research to highlight the need for a common theoretical framework in this area. We propose that Family Systems (FS) approaches represent such a framework. Greater utilisation of FS approaches for future research is not intended to be a solution to all limitations of research in this area; however, these approaches could drive and inform future research. Our call for greater utilisation of FS approaches in this area is not recent (e.g. Trute and Hauch, 1988; Morgan, 1988) or in isolation (e.g. Jensen and Spannagel, 2011) but is necessary to bring more attention to this issue. In proposing FS approaches, we discuss the theoretical and methodological advantages of these approaches and discuss research and clinical implications.

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Family-focused ASD research to date and its limitations

It is recognised that having a family member with ASD poses a range of distinct challenges on family members. Such challenges include, but are not limited to, accommodation of inflexible daily routines, lack of spontaneity, management of unique intolerances and sudden mood changes and being mediators in social interactions (Attwood, 2007; Heiman and Berger, 2007; Macks and Reeve, 2007; Pakenham et al., 2005). Additionally, approximately onethird of individuals with ASD require assistance with selfcare, mobility, communication and cognitive or emotional tasks on a daily basis; the majority of this care is provided by family members (Australian Bureau of Statistics, 2011; World Health Organization, 2005). Due to these and other issues, many families living with ASD experience more stress than families with both neurotypically developing children and children with other disabilities (Altiere and Von Kluge, 2009; Hastings, 2003b; Johnson et al., 2011; Miodrag and Hodapp, 2010; Rao and Beidel, 2009). Additionally, some families living with ASD report negative outcomes on family functioning, evidenced by higher levels of psychological problems, greater emotion rather than problem-focused coping strategies and higher family conflict (Meadon and Stoner, 2010; Phelps et al., 2009b).

Many studies focus on the challenges for families living with ASD, and although these findings are useful, they can be limited by basic research designs, which often overlook the complexity of the FS. For example, 'stress' is often examined in a fragmented manner as studies rarely synthesise the broad range of contributing factors, such as dispersion of responsibilities, boundaries between family members and personal meanings of having a family member with ASD (Lecavalier et al., 2006; Miodrag and Hodapp, 2010). Another important limitation is that there is reliance on maternal perspectives as representative of the whole family (Phelps et al., 2009b; Smith et al., 2010). Maternal perspectives are important but may not necessarily reflect those of other family members (Seligman and Darling, 2007). Guite et al. (2004), for instance, compared responses of mothers and siblings of individuals with developmental disabilities and found some discordance, with mothers reporting more sibling adjustment problems compared to the sibling self-reports. Available research highlights the limitations of basic research designs in attempting to explore the complex interplay of factors contributing to the challenges for families living with ASD.

A comprehensive understanding of the challenges for families living with ASD also warrants investigation of coping and support mechanisms. Research in this area highlights the importance of both formal and informal supports for providing information: a means to communicate experiences, feelings, frustrations, expectations and achievements and practical help such as finances and respite (Heiman and

Berger, 2007; Phelps et al., 2009b). While there has been research interest focusing on the best types of support for families living with ASD (Hastings, 2003a; Luther et al., 2005; Müller et al., 2008), there remains minimal understanding of the ways different family members provide support for each other (Seligman and Darling, 2007). For example, preliminary research suggests mothers and fathers differ in the types of support they provide for their families (emotional versus practical support, respectively) (Seligman and Darling, 2007). Research focusing within families is critical for developing an understanding of how to best support families living with ASD. Furthermore, there is limited research focusing on the influence of support from extended family, despite preliminary research highlighting the unique contributions of such support on family functioning (Blackledge and Hayes, 2006; Davis and Gavidia-Payne, 2009; Hastings, 2003b; Rao and Beidel, 2009). For example, Davis and Gavidia-Payne (2009) found extended family member's support influenced parenting satisfaction and quality of family interactions.

Existing research also recognises the positive influences of ASD on family functioning, including psychological and emotional strength, improved communication skills and higher levels of empathy and patience (Bayat, 2007; Davis and Gavidia-Payne, 2009; Pakenham et al., 2011). For example, many mothers report various psychological benefits attributed to parenting a child with ASD including selflessness, compassion, peace during time of uncertainty and a refocus of energy (Bauminger, 2002; Bayat, 2007; Phelps et al., 2009b). Research into the positive impacts of ASD on families is encouraging but is only relatively recent. Furthermore, there are a range of areas that would benefit from further research, such as Resilience, Traumatic Growth, family connectedness, spiritual development, appreciation of life and enrichment of relationships (Brewin et al., 2008; Phelps et al., 2009a). This recommendation is in line with previous calls for positive psychology approaches within developmental disabilities research (Bayat, 2007; Hastings and Taunt, 2002; Pakenham et al., 2011).

The impact of having a sibling with ASD on neurotypically developing individuals has been another predominant research area. Research findings have indicated mixed results, with some reporting positive effects in areas such as self-concept and self-competence (Macks and Reeve, 2007; Rao and Beidel, 2009), and others reporting negative effects such as embarrassment (Mascha and Boucher, 2006; Orsmond and Seltzer, 2007) and increased emotional and behavioural issues (Dew et al., 2008; Meadon and Stoner, 2010). On the other hand, some researchers report no differential impact in areas such as self-concept, self-efficacy and locus of control (Meadon and Stoner, 2010; Vliem, 2009). These mixed results have been interpreted in various ways. For example, that having a sibling with ASD has positive, neutral or negative influences on neurotypically developing siblings. Alternatively, the mixed findings could

reflect the varied and dynamic nature of sibling relationships, suggesting that a straightforward 'cause–effect' explanation is too simplistic (Seligman and Darling, 2007). Additionally, the mixed findings can be attributed to factors not accounted for in research designs, such as age, sex or birth order of siblings; comparison group used (e.g. neurotypically developing dyads vs dyads with other developmental disorders); information source; family size; parental relationships and a range of demographic factors such as socioeconomic status, nationality and location (Ross and Cuskelly, 2006). These inconsistent findings and interpretations continue because studies are generally interpreted in isolation (Stoneman, 2005; Swanson, 1988).

Common theoretical framework

Although previous research addresses various important issues for families living with ASD, the literature lacks a common theoretical framework. The benefits of a theoretically driven body of work include utilisation of common terminology to improve communication of findings, research methodologies grounded in theoretically sound concepts and greater synthesis of results from various individual research studies allowing for detection of emerging patterns (Swanson, 1988). Without appropriate theoretical frameworks, studies are more likely to be influenced by extraneous factors such as social consensus, samples of convenience, opportunities for immediate applications and researcher preferences (Siegel, 1988; Swanson, 1988; Waterhouse, 2008).

FS approaches

Systems theories are derived from General Systems Theory, an interdisciplinary approach that has been conceptualised as a *Weltanschauung* or 'unique worldview' (Von Bertalanffy, 1950). General Systems Theory upholds the importance of interpreting events, situations and people within their environment rather than in isolation (Becvar and Becvar, 1982; Von Bertalanffy, 1950, 1974; Whitchurch and Constantine, 1993). From this perspective, the application of General Systems Theory to individuals involves understanding them in relation to the other people in their life.

Applications of systems approaches to families are referred to as FS approaches. FS approaches consider families as unique interactive and reactive units, with their own basic social system of rules, values and goals (Edwards, 2011). There is no single systems theory about families (Cox and Paley, 1997; Klein and White, 1996); therefore, throughout this article, the various FS theories will be referred to as FS approaches. These approaches encompass a wide variety of concepts and variables. Rather than discussing all of these in detail, Table 1 provides an overview of some of the main FS concepts, which are relevant to family-focused ASD research.

Macroscopic and microscopic FS approaches

FS approaches vary with regard to the scope of their focus. Macroscopic FS approaches (Table 1) focus on the ways families interact with other systems, such as the community, other families, schools and social groups (e.g. Turnbull et al., 1984, 1986). Microscopic FS approaches (Table 1) examine relationships within the family, such as maternal, marital and/or sibling subsystems (e.g. Bowen, 1995; Bowen and Kerr, 1988). Both macroscopic and microscopic approaches are important when researching families living with ASD, as they focus on different aspects of family functioning. For example, Brewin et al. (2008) examined parents' perspectives regarding factors contributing their child's quality of school experience. Major themes were identified across various systems including presentation of ASD in the child, classroom factors, school factors and institutional factors in the education system (Brewin et al., 2008).

Importantly, without utilising FS approaches, previous research has rarely explored relationships *between* subsystems. This is important for addressing key research areas such as ways in which the marital relationship influences the functioning of sibling relationships or the ways in which a maternal relationship differs from a paternal relationship. This distinction is important given that relations within *and* between subsystems affect family functioning (Hastings, 2003b; Meadon and Stoner, 2010).

Boundaries

According to FS approaches, the concept of Boundaries (Table 1) is central to understanding family functioning (Becvar and Becvar, 1982; Carroll et al., 2007) and is therefore relevant to researching families living with ASD (Seligman and Darling, 2007). The functioning of Boundaries is measured by their permeability (Table 1). Permeability of boundaries is necessary for families to manage life events such as job changes and moving house (Seligman and Darling, 2007). Optimally functioning families develop a balance between open and closed boundaries (Becvar and Becvar, 1982; Seligman and Darling, 2007). For example, Bayat (2007) reported that the most resilient families living with ASD in their study were able to be flexible in role and responsibility changes as well as communicate with each other about personal needs.

Poorly regulated boundaries can impact family functioning in various ways. According to FS approaches, two such ways are experiences of Boundary Ambiguity and Ambiguous Loss (Table 1). These experiences may be particularly important for families living with ASD due to the range of ongoing adjustments associated with ASD (O'Brien, 2007). For example, Boundary Ambiguity may result when neurotypically developing siblings become involved in some household and care-giving responsibilities

Table	١.	Definitions	of FS	concepts
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Theoretical concept	Definition	
FS	In general, describes all individuals a family counts on over time for comfort, care, nurturance, support and emotional closeness	
Family functioning	Complex interplay of various elements, such as emotional closeness, cognitive engagement, physical health habits, social connectedness, communication, expectations and interactions. Degree of functioning ranges from positive to negative	
Macroscopic approach	A FS approach that focuses on the FS in relation to other systems	
Microscopic approach	A FS approach that focuses on subsystems within the family	
Subsystem	Semi-independent systems operating within the FS. Common subsystems include 'maternal' (mother and child), 'paternal' (father and child), 'parental' (both parents with child), 'marital' (husband and wife) and 'sibling' (child and child). Subsystems are also referred to as dyads when referring to two person relationships	
Boundaries	Hypothetical borders between and within a FS and its environment. The External Boundary defines the family in relation to other systems. Internal Boundaries determine who is included and excluded in the subsystems. Individuals within a FS also have Personal Boundaries	
Permeability	Degree of difficulty or ease that information and system members have in crossing the Boundaries. Ranges from open to closed. Open systems can be 'weak' as boundaries are loosely defined resulting in confusion about family roles, identities and goals. Closed systems can be rigid and restrict information permitted into system, limiting physical, psychological and social growth	
Boundary Ambiguity	Confusion about roles and responsibilities experienced by family members resulting from poorly regulated boundaries	
Ambiguous Loss	Complicated or unclear loss resulting from either physical loss of a person while retaining their psychological presence (e.g. missing person) or the physical presence of a person while experiencing a loss or change in their psychological state (family member with ASD)	
Resilience	Ability to cope with challenging life circumstances. Includes physical, psychological, emotional and social resilience	
Traumatic Growth	An extension of Resilience where coping involves positive change as a result of challenging life circumstances. Such as increases in appreciation of life, personal strength, family solidarity and quality of relationships	

FS: Family Systems; ASD: Autism Spectrum Disorder.

usually reserved for parents (Smith, 2000). Boundary Ambiguity can also occur when the identities of individuals become enmeshed (Carroll et al., 2007). For instance, parents who are preoccupied with their child's ASD may have difficulty viewing their own life as independent from their child's experiences (O'Brien, 2007).

Families may also be more vulnerable to Boundary Ambiguity during transition periods (such as developmental changes), as these periods normally involve large adjustments of roles and expectations for all family members (Bray and Hetherington, 1993; Seligman and Darling, 2007). When considering families living with ASD, there are likely to be unique transition periods related to ASD such as the period of diagnosis (Phelps et al., 2009b; Seligman and Darling, 2007). Additionally, 'universal' transition periods, such as adolescence, are likely to involve different issues for individuals with ASD and their families (Phelps et al., 2009b). Such transition periods have not yet been adequately mapped (Phelps et al., 2009b).

Ambiguous Loss may be particularly relevant to families living with ASD (Boss, 1994). For example, family members may perceive the family member with ASD as physically present yet psychologically absent (Boss, 2004). This experience may be particularly evident during the period of diagnosis, as it often involves a range of emotions including uncertainty about the clarity and repercussions of the diagnosis (O'Brien, 2007). Other factors that may contribute to vulnerability to Ambiguous Loss in families living with ASD include the unpredictable, heterogeneous and challenging nature of ASD, the high day-to-day variability in functioning, wide ranging patterns of strengths and weaknesses and broad ranging responses to treatment (O'Brien, 2007). Furthermore, fluctuating emotional experiences ranging from hope for improved functioning (or for some families hope for discovery of a 'cure' for ASD) to feelings of hopelessness or frustration during difficult situations, mixed with feelings of love, pride and joy, may make some families living with ASD vulnerable to Ambiguous Loss (O'Brien, 2007). These experiences may

be further complicated by the feelings of guilt when reflecting on the 'negative' emotions mentioned earlier (Boss, 1999, 2004; O'Brien, 2007).

Notably, such reactions are not necessarily long term and do not develop in all families living with ASD. Instead, it appears that *most* families adapt and cope effectively with childhood disability (Seligman and Darling, 2007).The multilevel approaches supported by FS approaches are especially important for understanding *perceived* issues like Boundary Ambiguity and Ambiguous Loss as perceptions may vary across subsystems.

Resilience and Traumatic Growth

Resilience and Traumatic Growth (Table 1) are two positive facets of family functioning outlined in FS approaches. In this context, Resilience is apparent in families who make active efforts to spend time with each other, balance needs of the family member with ASD with needs of other family members, maintain healthy routines, hold shared values, find meaning in challenging circumstances, have flexible roles, utilise support services, openly communicate and have proactive approaches to challenges (Seligman and Darling, 2007).

In recognising the possibility of distress and growth coexisting, Traumatic Growth has been considered particularly suited to the challenging yet rewarding nature of ASDs (Heiman and Berger, 2007). Traumatic Growth is applicable for families living with ASD in a range of ways. As discussed, initially, a diagnosis of ASD for a family member may be perceived as a distressing loss as it involves realisations that they will not develop typically, possible confusion around the individual's identity and re-evaluating expectations and responsibilities of all family members (O'Brien, 2007). However, coupled with this may be experiences of relief, validation and over time understanding and acceptance of having a family member with ASD (Phelps et al., 2009a; Samios et al., 2012)

Implications for clinical support services

The importance of clinical support services on functioning for families living with ASD has been documented (Bradford, 2010; Seligman and Darling, 2007). Clinical support services are a type of formal social support that increases well-being, knowledge about the disorder, family functioning, Resilience and perceived competence and reduces subjective distress (Bagatell, 2007; Bradford, 2010; Phelps et al., 2009b; Seligman and Darling, 2007). Therapists may also provide informative and emotional support, help the family respond to grief or confusion, act as role models, improve family capacity building skills (Pinkerton and Dolan, 2007; Russo, 1999; Wetherby and Woods, 2006; Woods and Brown, 2011) and encourage acceptance and even appreciation for an individual's or family's situation (Bagatell, 2007; Bradford, 2010; Seligman and Darling, 2007).

There are several ways family-focused ASD research grounded in FS approaches can directly inform clinical support services, as follows.

- 1. FS approaches encourage research to focus on various aspects of the FS (e.g. individual, subsystemic and macroscopic). This will result in clinical interventions that can be targeted at individuals, subsystems and the systemic level. Importantly, the interrelations of subsystems can also be targeted.
- 2. FS approaches encourage inclusive approaches to research designs. Interventions based on such research will encourage all family members to be involved in therapy. This may involve including people outside the traditional scope of 'family therapy' such as extended family, friends or in-home therapists.
- 3. The utilisation of theoretically grounded FS concepts (such as Boundaries, Ambiguous Loss and Traumatic Growth) means clinical support services will be both theoretically and empirically evidenced based.
- 4. As FS concepts cover both positive and negative aspects of family functioning, research may inform holistic, strengths-based approaches. Strengths-based approaches help families utilise their own resources and recognise their own capacities for resilience (Bayat, 2007). The efficacy of such approaches is supported in the literature for both families with young and adolescent children (Allison et al., 2003; Cosden et al., 2006; Early and GlenMaye, 2000; McGuire, 2009; Sargent, 1991).
- 5. FS approaches recognise the heterogeneity of families and ASD alike. This recognition promotes individualised clinical support services for each family living with ASD.
- 6. FS approaches recognise that family functioning changes across time and in response to life events and transition periods. This recognition translates to clinical support services that promote opportunities for improved family functioning, regardless of current challenges.

Implications for future research

Based on the issues raised in this article, we recommend that the following areas be considered in future research. For each of these areas, we provide examples of research that has been conducted and requires expansion.

1. It is important to embrace flexible and inclusive approaches to researching 'families'. Such

approaches recognise the importance of involving various system members, and in doing so, gain a rich understanding of family functioning. For example, in comparing the efficacy of individual versus family therapy for individuals with Asperger's syndrome (AS), Stoddart (1999) interviewed individuals with AS, parents and also clinicians in order to understand the issue from all perspectives. The multidimensional perspectives highlighted the multifaceted ways family therapy impacts the FS at various levels (Stoddart, 1999). For example, one family reported that knowledge gained about AS affected their interactions with their family member with AS and also allowed them to communicate better with extended family members about AS (Stoddart, 1999).

- 2. Future research would benefit from investigating both positive and negative factors contributing to family functioning. This may include investigation of theoretical concepts grounded in FS approaches, such as Boundaries, Resilience, Traumatic Growth and Ambiguous Loss. For example, one study investigating the lived experiences of mothers reported benefits associated with living with ASD in a range of areas including social opportunities, health, employment and strengthening of family subsystems (Markoulakis et al., 2012).
- 3. There is a need to design studies targeted at various aspects of the FS (individualistic, subsystemic and macroscopic) to explore complex issues such as stress, coping and supports. For example, Hastings (2003b) explored the interrelationships of psychological well-being between mothers and fathers of children with ASD and found various ways in which the mental health of one individual affected their partner and other family members.
- 4. FS approaches recognise the importance of researching families during transition periods. Transition periods with minimal research attention include adolescence and young adulthood (Baker et al., 2011; Gerhardt and Lainer, 2011; Griffith et al., 2011; Levy and Perry, 2011). This continues despite preliminary research indicating a range of important issues for families and individuals with ASD during these periods. For example, the transition from primary school to high school requires management of large amounts of unstructured activities (bus rides, changing classes and study periods) (Adreon and Stella, 2001). A common theoretical framework for family-focused ASD research may help identify transition periods warranting greater research attention.
- 5. It is important to consider the impact of living with ASD (on individuals and families) across all developmental stages. The predominant focus of research

has been childhood (for both individuals with ASD and siblings), with little research focusing on young adulthood and beyond (Baker et al., 2011). Research focusing on 'childhood' may also be too broad to identify factors most influential during specific developmental periods (Bauminger et al., 2003; Orsmond and Seltzer, 2007). For example, a metaanalysis of the sibling ASD literature published from 1970 to 2005 indicated that 17 of the 21 studies had participants ranging from age 2 to 18 years (Dew et al., 2008). In recognising the importance of utilising developmental stage, research FS approaches may avoid this limitation.

- 6. The inclusive nature of FS approaches recognises the importance of involving individuals with ASD (Bayat, 2007). This suggestion may seem self-evident; however, numerous studies examining families living with ASD *do not* include the perspectives of the individual with ASD (Brewin et al., 2008; Dew et al., 2008; Rao and Beidel, 2009). This trend seems well ingrained in disability research. For example, a review of sibling research identified that the individual with a developmental disability was included in only 2 out of 21 studies (Dew et al., 2008).
- 7. As FS approaches recognise the fluctuating nature of family functioning over time, research grounded in these approaches may utilise longitudinal designs. Preliminary research suggests that the meaning of having a family member with ASD may change over time; however, the nature of such change and the ways the FS and other systems influence change remain unclear. For example, Altiere and Von Kluge (2009) interviewed parents about their families' meaning-making of living with ASD and found that various changes were reported to have occurred over time such as questioning, devastation, personal struggles, as well as personal, family and child benefits. To date, such research usually relies on recall of experiences rather than tracking participants over time, which may limit the validity of responses. Longitudinal research grounded in FS approaches could be one way of addressing this limitation.

Methodological implications

There are a range of methodological considerations when designing and conducting research with individuals with ASD and their families. Consideration of the range of potential difficulties in conducting research with individuals with ASD and their families is likely to have deterred some researchers from pursuing research in this field. Yet, importantly, the potential difficulty of conducting research in this area does not decrease the need for research with families living with ASD. FS approaches not only provide a theoretically sound framework for conducting research in this area, but also address many of the methodological challenges associated with research in this area.

We propose that the following issues may be considered when conducting research with families living with ASD.

- 1. Wording of instructions and questions should suit the processing styles of children and individuals with ASD (e.g. concrete and single-faceted sentences). This may involve including step-by-step, written instructions, rather than complicated verbal instructions.
- 2. Consider using alternative methodologies to verbal conversations, such as drawings or photographs (Ravenette, 1997, 2005) or multimedia (Wyn and Harris, 2004).
- 3. Be aware of the potential for linguistic confusions. Misinterpretations may be from the individual with ASD (e.g. literal interpretations of phrases, misunderstanding words with double meanings or difficulty articulating experiences) or the researcher (e.g. misunderstanding an individual's specific meaning of a particular word). To avoid misinterpretations, researchers can involve participants in interpretation of findings (Dockett et al., 2009).
- 4. Ensure participation of all family members is based on voluntary and informed consent. This may involve asking children and individuals with ASD to describe their understanding of the study's aims and procedures and what they will be asked to do.
- 5. Attempt to prepare participants for the range of personal experiences that may be focused on during the study. This may also involve managing unexpected or negative reactions related to issues focused on during the study.
- 6. Consider using qualitative approaches that are supported by FS approaches. Such approaches provide opportunities to capture subjective experiences and understand complex patterns of relationships between individuals and subsystems (Carrington and Graham, 2001). Furthermore, qualitative approaches have the potential to capture idiographic, multifaceted issues often present in the families by avoiding predetermined and sometimes restrictive response options of quantitative approaches. Furthermore, qualitative approaches are useful for conducting research with children (Dockett et al., 2009; Mishna et al., 2004). Notably, there are justifiable reasons for utilisation of quantitative approaches (i.e. standardised measurements and greater opportunity for generalisation). However, these approaches may benefit from being complemented with qualitative sections (i.e. mixed methods approaches) in FS research.

Statistical analysis recommendations

An array of statistical techniques is available to researchers applying FS approaches to individuals with ASD and their families. A comprehensive review of available strategies is beyond the scope of this article. Instead, we briefly comment on some analytic techniques that can be used in future family-focused ASD research utilising FS approaches.

- It is important to note that FS data are inherently 1. interdependent. For instance, while interested in how a child's characteristics influence his or her behaviour, we may also be interested in how characteristics of a parent influence the child's behaviour. It is appropriate then that the interdependence in dyadic relationships, such as that between parent and child, is modelled and tested using appropriate strategies. Cook and Kenny's (2005) actor-partner interdependence model is an illustration of modelling the concept of interdependence using appropriate techniques. This approach highlights the application of structural equation modelling and multilevel modelling to longitudinal dyadic data (Cook and Kenny, 2005). Campbell and Kashy (2002) provide a more comprehensive review of the actor-partner interdependence model. This approach was used to examine the degree of nonindependence in sense-making and benefit finding between mothers and fathers of children with AS (Samios et al., 2012). Results indicated that overall meaning-making was interrelated between partners (Samios et al., 2012), highlighting the importance of adopting an interpersonal approach to analyse family data.
- 2. Data from FS research have certain characteristics that need to be considered during analysis. Data are usually nested or hierarchical in nature. For instance, children are members of families they are nested within families. Studies may also collect inter-generational data. Multilevel models can account for the interdependence inherent in nested data structures evident in FS approaches. It is recommended that researchers use, where appropriate, analytical techniques that model the characteristics of FS data. Examples of applications of multilevel models in family research include Snijders and Kenny (1999) and Jenkins et al. (2005).
- 3. It is important to consider the ways in which family dynamics may influence the analysis and interpretation of findings. Such considerations may include family size (e.g. number of siblings), sibling ages and genders and blended families.

Conclusion

There remains limited research focusing on families living with ASD (Orsmond and Seltzer, 2007). This is of concern

given the diverse and pervasive impacts these conditions have on families. Of the research that is available, it can be difficult to synthesise findings due to limited use of a common theoretical direction. This article highlights some of the limitations in the existing literature and proposes the efficacy of FS approaches as a guiding framework for future family-focused ASD research. The benefits of FS approaches involve the inclusion of theoretically sound concepts, balanced focus of both positive and negative factors involved in family functioning and inclusion of all family members in research methodologies. If future family-focused ASD research utilises a common framework, such as FS approaches, then the research findings of individual studies may be synthesised and emerging patterns made more salient. Furthermore, reviewing the findings of past research through a FS lens may lead to further insights and alternate interpretations of some existing research findings. Together, this will result in a deeper understanding of research findings, which will potentially inform evidence-based clinical support services for families living with ASD. All these benefits contribute to our overall goal of learning about the best ways to support families living with ASD.

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References

- Adreon D and Stella J (2001) Transition to middle and high school. *Intervention in School and Clinic* 36(5): 266–271.
- Allison S, Stacey K, Dadds V, et al. (2003) What the family brings: gathering evidence for strengths-based work. *Journal* of Family Therapy 25(3): 263–284.
- Altiere MJ and Von Kluge S (2009) Searching for acceptance: challenges encountered while raising a child with autism. *Journal of Intellectual & Developmental Disability* 34(2): 142–152.
- Attwood T (2007) *The Complete Guide to Asperger's Syndrome*. London: Jessica Kingsley Publishers.
- Australian Bureau of Statistics (2011) Autism in Australia. Available at: http://www.abs.gov.au/AUSSTATS/abs@ .nsf/ Latestproducts/4428.0Main%20Features42009?opendocume nt&tabname=Summary&prodno=4428.0&issue=2009&num =&view= (2009, accessed 8 September 2012)
- Bagatell N (2007) Orchestrating voices: autism, identity and the power of discourse. *Disability & Society* 22(4): 413–426.
- Baker JK, Smith LE, Greenberg JS, et al. (2011) Change in maternal criticism and behaviour problems in adolescents and adults with autism across a 7-year period. *Journal of Abnormal Psychology* 120(2): 465–475.
- Bauminger N (2002) The facilitation of social-emotional understanding and social interaction in high-functioning children with autism: intervention outcomes. *Journal of Autism and Developmental Disorders* 32(4): 283–298.
- Bauminger N, Shulman C, Agam G (2003) Peer interaction and loneliness in high-functioning children with autism. *Journal* of Autism and Developmental Disorders 33(5): 489–507.

- Bayat M (2007) Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research* 51(9): 702–714.
- Becvar RJ and Becvar DS (1982) *Systems Theory and Family Therapy: A Primer*. Washington, DC: University Press of America.
- Blackledge JT and Hayes SC (2006) Using acceptance and commitment training in the support of parents of children diagnosed with autism. *Child & Family Behavior Therapy* 28(1): 1–18.
- Boss P (1999) *Ambiguous Loss Learning to Live with Unresolved Grief.* Cambridge, MA: Harvard University Press.
- Boss P (2004) Ambiguous loss research, theory, and practise: reflections after 9/11. *Journal of Marriage and the Family* 66(3): 551–566.
- Bowen M (1995) Clinical view of the family. *Family Systems* 2(2): 153–156.
- Bowen M and Kerr ME (1988) Family Evaluation: An Approach Based on Bowen Theory. New York: W. W. Norton & Co.
- Bradford K (2010) Supporting families dealing with autism and Asperger's disorders. *Journal of Family Psychotherapy* 21(2): 149–156.
- Bray JH and Hetherington EM (1993) Families in transition: introduction and overview. *Journal of Family Psychology* 7(1): 3–8.
- Brewin BJ, Renwick R and Schormans AF (2008) Parental perspectives of the quality of life in school environments for children with Asperger syndrome. *Focus on Autism and Other Developmental Disabilities* 23(4): 242–252.
- Campbell L and Kashy DA (2002) Estimating actor, partner, and interaction effects for dyadic data using PROC MIXED and HLM: a user-friendly guide. *Personal Relationships* 9(3): 327–342.
- Carrington S and Graham L (2001) Perceptions of school by two teenage boys with Asperger syndrome and their mothers: a qualitative study. *Autism* 5(1): 37–48.
- Carroll JS, Olson CD and Buckmiller N (2007) Family boundary ambiguity: a 30-year review of theory, research and measurement. *Family Relations* 56: 210–230.
- Cook WL and Kenny DA (2005) The actor-partner interdependence model: a model of bidirectional effects in developmental studies. *International Journal of Behavioral Development* 29: 101–109.
- Cosden M, Koegel LK, Koegel RL, et al. (2006) Strength-based assessment for children with autism spectrum disorders. *Research and Practice for Persons with Severe Disabilities* 31(2): 134–143.
- Cox MJ and Paley B (1997) Families as systems. *Annual Review* of *Psychology* 48: 243–267.
- Davis K and Gavidia-Payne S (2009) The impact of child, family, and professional support characteristics on the quality of life in families of young children with disabilities. *Journal of Intellectual & Developmental Disability* 34(2): 153–162.
- Dew A, Balandin S and Llewellyn G (2008) The psychosocial impact of siblings of people with lifelong physical disability: a review of the literature. *Journal of Developmental and Physical Disabilities* 20: 485–507.
- Dockett S, Einarsdottir J and Perry B (2009) Researching with children: ethical tensions. *Journal of Early Childhood Research* 7(3): 283–298.

- Early TJ and GlenMaye LF (2000) Valuing families: social work practice with families from a strengths perspective. *Social Work* 45(2): 118–130.
- Edwards JT (2011) *Working with Families: Guidelines and Techniques.* 2nd ed. Hoboken, NJ: John Wiley & Sons, Inc.
- Gerhardt PF and Lainer H (2011) Addressing the needs of adolescents and adults with autism: a crisis on the horizon. *Journal of Contemporary Psychotherapy* 41: 37–45.
- Griffith GM, Totsika V, Nash S, et al. (2011) 'I just don't fit anywhere': support experiences and future support needs of individuals with Asperger syndrome in middle adulthood. *Autism* 16(5): 1–19.
- Guite J, Lobato D, Kao B, et al. (2004) Discordance between sibling and parent reports of the impact of chronic illness and disability on siblings. *Children's Health Care* 33(1): 77–92.
- Hastings RP (2003a) Behavioural adjustment of siblings of children with autism engaged in applied behaviour analysis early intervention programs: the moderating role of social support. *Journal of Autism and Developmental Disorders* 33(2): 141– 149.
- Hastings RP (2003b) Child behaviour problems and partner mental health as correlates of stress in mothers and fathers of children with autism. *Journal of Intellectual Disability Research* 47(4/5): 231–237.
- Hastings RP and Taunt HM (2002) Positive impact of children with developmental disabilities on their families: a preliminary study. *Education and Training in Mental Retardation and Developmental Disabilities* 37(4): 410–420.
- Heiman T and Berger O (2007) Parents of children with Asperger syndrome or with learning disabilities: family environment and social support. *Research in Developmental Disabilities* 29(4): 289–300.
- Jenkins J, Dunn J, O'Connor TG, et al. (2005) Change in maternal perception of sibling negativity: within and between family influences. *Journal of Family Psychology* 19: 533–541.
- Jensen VK and Spannagel SC (2011) The spectrum of autism spectrum disorder: a spectrum of needs, services, and challenges. *Journal of Contemporary Psychotherapy* 4: 1–9.
- Johnson N, Frenn M, Feetham S, et al. (2011) Autism spectrum disorder: parenting stress, family functioning and healthrelated quality of life. *Families, Systems & Health: The Journal of Collaborative Family Healthcare* 29(3): 232–252.
- Klein DM and White JM (1996) *Family Theories: An Introduction*. Thousand Oaks, CA: SAGE.
- Lecavalier L, Leone S and Wiltz J (2006) The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research* 50(3): 172–183.
- Levy A and Perry A (2011) Outcomes in adolescents and adults with autism: a review of the literature. *Research in Autism Spectrum Disorders* 5(4): 1271–1282.
- Luther EH, Canham DL and Cureton VY (2005) Coping and social support for parents of children with autism. *The Journal of School Nursing* 21(1): 40–47.
- McGuire JE (2009) A Strengths-Based Approach to Building Social Competence in Adolescents with Asperger's Syndrome. Irvine, CA: Alliant University Irvine.
- Macks RJ and Reeve RE (2007) The adjustment of non-disabled siblings of children with autism. *Journal of Autism and Developmental Disorders* 37: 1060–1067.

- Markoulakis R, Fletcher P and Bryden P (2012) Seeing the glass half full benefits to the lived experiences of female primary caregivers of children with autism *Clinical Nurse Specialist* 26(1): 48–56.
- Mascha K and Boucher J (2006) Preliminary investigation of a qualitative method of examining siblings' experiences of living with a child with ASD. *British Journal of Developmental Disabilities* 52(102): 19–28.
- Meadon H and Stoner JB (2010) Review of literature related to social, emotional and behavioural adjustment of siblings with autism spectrum disorder. *Journal of Developmental and Physical Disabilities* 22: 83–100.
- Miodrag N and Hodapp RM (2010) Chronic stress and health among parents of children with intellectual and developmental disabilities. *Mental Retardation and Developmental Disorders* 23: 407–411.
- Mishna F, Antle BJ and Regehr C (2004) Tapping the perspectives of children. *Qualitative Social Work* 3(4): 449–468.
- Morgan SB (1988) The autistic child and family functioning: A developmental-family systems perspective. *Journal of Autism* and Developmental Disorders 18(2): 263–280.
- Müller E, Schuler A and Yates GB (2008) Social challenges and supports from the perspective of individuals with Asperger syndrome and other autism spectrum disabilities. *Autism* 12(2): 173–190.
- Neely-Barnes SL, Hall HR, Roberts RJ, et al. (2011) Parenting a child with an autism spectrum disorder: public perceptions and parental conceptualizations. *Journal of Family Social Work* 14(3): 208–225.
- O'Brien M (2007) Ambiguous loss in families of children with autism spectrum disorders. *Family Relations* 56: 135–146.
- Orsmond GI and Seltzer MM (2007) Siblings of individuals with autism spectrum disorders across the life course. *Mental Retardation and Developmental Disabilities Research Reviews* 13: 313–320.
- Pakenham KI, Samios C and Sofronoff K (2005) Adjustment in mothers of children with Asperger syndrome. *Autism* 9(2): 191–212.
- Pakenham KI, Sofronoff K and Samios C (2011) Finding meaning in parenting a child with Asperger syndrome: correlates of sense making and benefit finding. *Research in Developmental Disabilities* 25(3): 245–264.
- Phelps KW, Hodgson JL, McCammon SL, et al. (2009a) Caring for an individual with autism disorder: a qualitative analysis. *Journal of Intellectual & Developmental Disability* 34(1): 27–35.
- Phelps KW, McCammon SL, Wuensch KL, et al. (2009b) Enrichment, stress, and growth from parenting an individual with autism spectrum disorder. *Journal of Intellectual & Developmental Disability* 34(2): 133–141.
- Pinkerton J and Dolan P (2007) Family support, social capital, resilience and adolescent coping. *Child & Family Social Work* 12(3): 219–228.
- Rao PA and Beidel DC (2009) The impact of children with highfunctioning autism on parental stress, sibling adjustment, and family functioning. *Behavior Modification* 33(4): 437–451.
- Ravenette T (1997) Tom Ravenette: Selected Papers. Personal Construct Psychology and the Practice of an Educational Psychologist. Farnborough: European Personal Construct Association.

Ravenette T (2005) Constructive intervention with children when presented as problems. In: Fransella F (ed.) *The Essential Practitioner's Handbook of Personal Construct Psychology*. Chichester: John Wiley & Sons, Inc., pp. 133–144.

Reichman NE, Corman H and Noonan K (2008) Impact of child disability on the family. *Maternal and Child Health Journal* 12(6): 679–683.

Ross P and Cuskelly M (2006) Adjustment, sibling problems and coping strategies of brothers and sisters of children with autistic spectrum disorder. *Journal of Intellectual & Developmental Disability* 31(2): 77–86.

Russo RJ (1999) Applying a strengths-based practice approach in working with people with developmental disabilities and their families. *Families in Society* 80(1): 25–33.

Samios C, Pakenham KI and Sofronoff K (2012) Sense making and benefit finding in couples with Asperger syndrome: an application of the actor-partner interdependence model. *Autism* 16(3): 275–292.

Sargent J (1991) Adolescents and family therapy: beyond control to strengthening relationships. *Journal of Family Psychology* 4(3): 354–360.

Seligman M and Darling RB (2007) Ordinary Families, Special Children: A Systems Approach to Childhood Disability. New York: Guilford Press

Siegel LS (1988) Definitional and theoretical issues and research on learning disabilities. *Journal of Learning Disabilities* 21(5): 264–266.

Smith LE, Hong J, Seltzer MM, et al. (2010) Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders* 40: 167–178.

Smith TL (2000) Siblings of children with autism: Psychosocial adjustment and the evaluation of group intervention. Toronto: University of Toronto.

Snijders TAB and Kenny DA (1999) The social relations model for family data: a multilevel approach. *Personal Relationships* 6: 471–486.

Stoddart K (1999) Adolescents with Asperger syndrome – case studies of individual and family therapy. Autism 3: 255–271.

Stoneman Z (2005) Siblings of children with disabilities: research themes. *Mental Retardation* 43(5): 339–350. Swanson HL (1988) Toward a metatheory of learning disabilities. Journal of Learning Disabilities 21(4): 196–209.

Trute B and Hauch C (1988) Building on family strength: a study of families with positive adjustment to the birth of a developmentally disabled child. *Journal of Marital and Family Therapy* 14(2): 185–193.

Turnbull AP, Summers JA and Brotherson MJ (1984) Working with Families with Disabled Members: A Family Systems Approach. Lawrence, KS: Research & Training Center on Independent Living, University of Kansas.

Turnbull AP, Summers JA and Brotherson MJ (1986) Family life cycle. In: Gallagher JJ and Vietz PM (eds) Families of Handicapped Persons. Baltimore: Brookes Publishers, pp. 45–65.

Von Bertalanffy L (1950) An outline of general system theory. British Journal for the Philosophy of Science 1(2): 134–165.

Von Bertalanffy L (1974) *Perspectives on General System Theory*. New York: George Braziller.

Vliem SJ (2009) Adolescent Coping and Family Functioning in the Family of a Child with Autism. Michigan: The University of Michigan.

Waterhouse L (2008) Autism overflows: increasing prevalence and proliferating theories. *Neuropsychology Review* 18: 273– 286.

Wetherby A and Woods J (2006) Effectiveness of early intervention for children with autism spectrum disorders beginning in the second year of life. *Topics in Early Childhood Special Education* 26: 67–82.

Whitchurch GG and Constantine LL (1993) Systems theory. In: Boss PG, Doherty WJ, LaRossa R, et al. (eds) Sourcebook of Family Theories and Methods: A Contextual Approach. New York: Plenum Press, pp. 325–355.

Woods JJ and Brown JA (2011) Integrating family capacitybuilding and child outcomes to support social communication development in young children with autism spectrum disorder. *Topics in Language Disorders* 31(3): 235–246.

World Health Organization (2005) Child and Adolescent Mental Health Policies and Plans. Geneva: World Health Organization.

Wyn J and Harris A (2004) Youth research in Australia and New Zealand. *Young* 12(3): 271–289.Table 1. Definitions of FS concepts.