

Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder

Daryl J. Higgins, Susan R. Bailey and Julian C. Pearce

Autism 2005 9: 125

DOI: 10.1177/1362361305051403

The online version of this article can be found at:

<http://aut.sagepub.com/content/9/2/125>

Published by:



<http://www.sagepublications.com>

On behalf of:



[The National Autistic Society](http://www.nas.org.uk)

Additional services and information for *Autism* can be found at:

Email Alerts: <http://aut.sagepub.com/cgi/alerts>

Subscriptions: <http://aut.sagepub.com/subscriptions>

Reprints: <http://www.sagepub.com/journalsReprints.nav>

Permissions: <http://www.sagepub.com/journalsPermissions.nav>

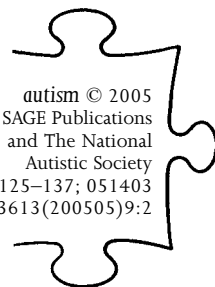
Citations: <http://aut.sagepub.com/content/9/2/125.refs.html>

>> [Version of Record](#) - Apr 27, 2005

[What is This?](#)

Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder

autism © 2005
SAGE Publications
and The National
Autistic Society
Vol 9(2) 125-137; 051403
1362-3613(200505)9:2



DARYL J. HIGGINS *Deakin University, Australia*

SUSAN R. BAILEY *Deakin University, Australia*

JULIAN C. PEARCE *Deakin University, Australia*

ABSTRACT A survey of parents/caregivers of a child with an autism spectrum disorder (ASD) was conducted to examine the relationship between ASD characteristics, family functioning and coping strategies. Having a child with ASD places considerable stress on the family. Primary caregivers of a child with ASD from a regional and rural area in Victoria, Australia ($N = 53$) were surveyed concerning their child with ASD, family functioning (adaptability and cohesion), marital satisfaction, self-esteem and coping strategies. Results suggest that these caregivers had healthy self-esteem, although they reported somewhat lower marital happiness, family cohesion and family adaptability than did norm groups. Coping strategies were not significant predictors of these outcome variables. Results highlight the need for support programmes to target family and relationship variables as well as ASD children and their behaviours, in order to sustain the family unit and improve quality of life for parents and caregivers as well as those children.

KEYWORDS
ASD; Asperger
syndrome;
autism;
coping; family
support;
respite

ADDRESS Correspondence should be addressed to: DR DARYL J. HIGGINS, Senior Research Fellow (Manager, National Child Protection Clearinghouse), Australian Institute of Family Studies (AIFS), 300 Queen Street, Melbourne, Victoria 3000, Australia. e-mail: daryl.higgins@aifs.gov.au

The social impact upon families of having a child with an autism spectrum disorder (ASD) has received little attention in the research literature. However, there is growing body of evidence to suggest that chronic illness and disability negatively impact on families and family functioning (Williams and Bond, 2002). The current study was designed to survey

parents/caregivers of a child with ASD to examine the level of family stress and the coping strategies they employ.

A child diagnosed with ASD may represent a constant source of stress on the family unit, as not only are the caregivers affected, but also siblings and relationships among family members (Sanders and Morgan, 1997). The stress results mainly from the extremely antisocial, disruptive behaviours associated with ASD, such as self-injurious, tantrum and obsessive/compulsive behaviours, which may preclude a normal family life (Gray and Holden, 1992). Having to cope with the physical and emotional demands of caring for a child with ASD poses a threat to the psychosocial wellbeing of parents/caregivers. Their self-confidence and self-esteem can be eroded in the face of totally unfamiliar child behaviour and unique demands (Gray and Holden, 1992; Holroyd and McArthur, 1976; Powers, 1989). Caregivers of a child with ASD often experience helplessness; feelings of inadequacy and failure; anger; shock; guilt; frustration; and resentment (Jones, 1997; Powers, 1989; Tommasone and Tommasone, 1989). They may be reluctant to medicate their child, even when the family's ability to function effectively is threatened by the child's severe behavioural problems (Konstantareas et al., 1995). Stress is particularly related to the issues of ongoing dependency, and the limits imposed on family activity (Koegel et al., 1992).

Other researchers have demonstrated that the emotional upheaval experienced by the caregivers of a child with ASD can result in a variety of psychological problems including depression and anxiety (Bristol and Schopler, 1984; Hoppes and Harris, 1990). In addition, it has been shown that a high level of stress experienced by mothers of children with autism has an inverse relationship with the educational progress of the child (Robbins et al., 1991).

Researchers have largely focused on the stress experienced by families with a child with ASD, but little work has been conducted looking at the particular impact on family functioning and marital satisfaction. Sharpley et al. (1997) reported that the three most stressful factors arising from parenting a child with ASD were: (1) the permanency of the condition; (2) the lack of acceptance of autistic behaviour by society and family members; and (3) the low levels of support provided by health care services and other social services. They noted that services and the provision of short-term breaks (respite) – which can be of real help – are infrequent and insufficient to meet caregivers' needs.

Research on marital relationships in families who have a child with a disability is inconclusive regarding the impact of the child with a disability on the marriage. Some research suggests a higher divorce rate among these families, while other research has shown no difference in these rates when

compared with other families (Hayes, 1997; Hecimovic et al., 1999). Nevertheless, Rodrigue et al. (1990) found that mothers of a child with ASD reported less marital satisfaction than did mothers of a child with Down syndrome or mothers of developmentally normal children. Some caregivers of a child with ASD experience a sense of social isolation. This could be due to the time and energy demands placed on caregivers by the child with ASD, which severely limits their free time and ability to engage in social activities. Also, the disruptive nature of autistic behaviour, and the lack of public understanding of the disorder, results in limited availability of child-minding services and respite care, which furthers the stresses and demands on caregivers (Gray and Holden, 1992; Sanders and Morgan, 1997).

Senel and Akkok (1996) reported that children with a disability have special needs that require more attention, greater vigilance and effort from parents than non-disabled children. Thus, parents of children with disabilities have less time to spare for other family members. The addition of a child with ASD to a family challenges existing roles, and may lead to a restructuring of roles within the family to cope with the special needs of the disabled child, and the financial difficulties encountered.

Various authors report that the stress on families who have a child with ASD may be exacerbated because this disability is generally not identifiable by physical appearance (Gray and Holden, 1992; Sanders and Morgan, 1997). There appears to be a lack of understanding from the wider community of behaviours associated with ASD. Consequently, people are often insensitive regarding the public behaviour of children with ASD. Research has also shown that the stress associated with ASD impacts on most aspects of families' lives, including recreation activities, housekeeping, finances, emotional and mental health of caregivers, marital relationships, physical health of family members, sibling relations and relationships with extended family, friends and neighbours (Lilly, 1977; Rodrigue et al., 1990; Roeyers and Mycke, 1995; Senel and Akkok, 1996).

The aims of this study were critically to examine the perceptions and experiences of families of which one child (or more) was diagnosed with ASD and to assess the behaviour and characteristics of children with ASD and the impact of ASD on families. The research expands upon existing studies of the stressors faced by families caring for a chronically ill or disabled child, and also considers the potential exacerbating problem of living in a non-metropolitan area. It was hypothesized that:

- 1 Primary caregivers of a child with ASD will report low marital happiness, family adaptability, family cohesion and self-esteem.
- 2 Coping style would add to prediction of adjustment (marital happiness, family adaptability, family cohesion and self-esteem).

Method

Participants and procedure

A total of 134 surveys was sent to the caregivers of children with ASD in a regional and rural area of south-west Victoria, Australia, requesting that the primary care provider of the child with ASD complete and return the survey. Caregivers were recruited through the databases of local organizations providing specialized ASD services. These service providers conducted the mail-out on behalf of the researchers, with an explanatory cover letter, so that all caregivers of a child with ASD would remain anonymous to the researchers. Of the 134 surveys sent out, 53 were completed and returned (a response rate of 40 percent). Of the returned surveys, one was incomplete and could not be used in the data analysis. The primary care providers of the children with ASD in this study were mothers (97 percent) and fathers (3 percent). The respondents came mostly from intact marriages: 40 (75.5 percent) had never separated/divorced; one (1.9 percent) was widowed pre-diagnosis; two (3.8 percent) divorced before the birth of the child with ASD; and 10 (17.2 percent) divorced after the birth of the child with ASD.

Measures

This article represents a section of a larger study that also investigated perceptions about support services available for children with ASD and their families. The questionnaire contained items assessing general demographic characteristics and behavioural characteristics of the children with ASD and support services available for children with ASD and their families. Parents were also asked to indicate whether or not their child exhibited each of the following behaviours, and to rate on a three-point scale their degree of concern about each behaviour ('not at all', 'somewhat' or 'greatly'): misbehaviour and temper tantrums in public places; self-injurious behaviour (e.g. head banging); aggressive behaviour towards others; destructive behaviour; repetitive behaviours; lack of interpersonal responsiveness/withdrawal; self-stimulation behaviours/masturbation; and/or any other behaviour about which they were concerned.

The following domains were also assessed.

Family functioning Family life was measured with the Family Adaptability and Cohesion Evaluation Scales (FACES II) developed by Olson et al. (1982). The scales measure family adaptability and cohesion on a five-point Likert scale (1 = almost never to 5 = almost always). Sample items measuring family adaptability included: 'In our family it is easy for everyone to express his/her opinion' and 'Children have a say in their discipline'.

Sample items measuring family cohesion included: 'Family members are supportive of each other during difficult times' and 'Family members share interests and hobbies with each other'. The range of scores for adaptability and for cohesion was 15–70 and 15–80, respectively. Higher scores on the adaptability scale indicated more flexible families and higher scores on the cohesion scale indicated more connected families.

Marital quality and marital happiness The Quality Marriage Index (QMI) was used to assess overall marital quality and marital happiness (Norton, 1983). The scale consists of a total of six items. Five items measured different aspects of marital quality using a seven-point Likert scale (1 = very strong disagreement to 7 = very strong agreement). Items included: 'We have a good marriage/partnership' and 'I feel like part of a team with my partner'. Scores measuring overall marital quality ranged from 5 to 35, with higher scores indicating enhanced marital quality. Overall marital happiness was measured with a single item, using a 10-point scale (1 = very unhappy, 5 = happy, 10 = perfectly happy).

Self-esteem The Rosenberg Self-Esteem Scale was used to measure self-esteem (Rosenberg, 1965). The scale consists of 10 items. Respondents were asked to indicate their level of agreement or disagreement with each statement, using a five-point Likert scale (1 = strongly agree to 5 = strongly disagree). Sample items included: 'I feel that I have a number of good qualities' and 'I certainly feel useless at times'. Scores ranged from 10 to 50, with higher scores reflecting greater levels of self-esteem.

Coping strategies The Coping Health Inventory for Patients (CHIP) developed by McCubbin et al. (1983) was adapted to measure the coping strategies used by the primary care provider of a child with ASD. The adapted scale consisted of 41 items. Respondents were asked to rate each statement according to how helpful they considered the statement to be in their role of primary care provider to a child with ASD. Ratings were made on a four-point Likert scale (0 = not helpful to 3 = extremely helpful). The range of scores for each coping factor were 0–51 (self-esteem), 0–27 (optimism), and 0–18 (spousal support), with higher scores indicating more helpful coping strategies.

Results

Behaviour and characteristics of children with ASD

From the 52 completed surveys, a total of 58 children with ASD were identified, as some families had more than one child with ASD. Of the

Table 1 Gender, age and birth order of children with autism spectrum disorder (N = 58)

Birth order	Gender						Mean age (years:months)
	Male		Female		Unidentified		
	n	%	n	%	n	%	
1st born	21	36	3	5	3	5	12:00
2nd born	18	31	3	5	1	2	10:01
3rd born	7	12	0		0		9:08
6th born	2	3	0		0		6:08
Total	48	83	6	10	4	7	10:10

children with ASD, caregivers reported that 34 (59 percent) had been diagnosed via prior psychometric testing as high-functioning ASD (including Asperger syndrome) and 17 (29 percent) had been diagnosed via prior psychometric testing as low-functioning ASD; the form of autism for seven (12 percent) of the children was not identified. The mean age at which the child was diagnosed with ASD was 5 years and 10 months, and their mean age at the time of the survey was 10 years and 10 months. In addition, 29 percent of the children with ASD had also been diagnosed as having an intellectual disorder, 13.8 percent had asthma and 12.1 percent had been diagnosed with attention deficit hyperactivity disorder (ADHD). More than half of the children with ASD in this sample (54 percent) received disability funding from the local government educational authority, with 77 percent of these receiving the funding for a school integration aide (a person who provides scholastic and social assistance to a child with a disability, in order to foster integration into a mainstream classroom). Table 1 shows the gender, mean age and birth order of the children with ASD. Most of the children with ASD were the first or second born (collectively 84 percent), and most were males.

Most of the children with ASD in this study attended school (93 percent), with 50 percent of these children attending a public primary or secondary school and 28 percent attending a dedicated school for children with disabilities. Of the 54 percent of children who received disability funding, 96 percent used the funding for an integration aide at a mainstream school.

Caregivers indicated that their child with ASD most commonly displayed the following characteristics: (1) fascination with topics, people or objects (76 percent); (2) repetitive behaviour (69 percent); (3) temper

Table 2 Concern of primary caregiver regarding behaviours commonly exhibited by children with autism spectrum disorder (*N* = 58)

<i>Behaviour type</i>	<i>Exhibiting behaviour (%)</i>	<i>Concern (somewhat or great) (%)</i>
Repetitive behaviour	76	67
Misbehaviour in public	67	95
Withdrawal behaviour	64	86
Aggressive behaviour	62	100

tantrums (66 percent); (4) repetitive talking about a topic (62 percent); and (5) lack of eye contact in communication (61 percent). Table 2 shows particular behaviours exhibited by this group of children with ASD and a rating of the degree to which the primary care provider was concerned by the behaviour.

The greatest concern caregivers had regarding commonly exhibited behaviours was the aggressive behaviour exhibited by 36 (62 percent) of the children with ASD, which appeared to be more prevalent in the older rather than the younger children. Misbehaviour in public was also of great concern to the primary care providers. It is possible that the notion of being judged as a parent by the community and perhaps being viewed as not being able to manage one's children was related to concern over these two types of behaviour. Although repetitive behaviour was exhibited by 76 percent of this group of children with ASD (*N* = 44), it was of less concern to the primary care providers, possibly because this type of behaviour has minimal effect on others.

Impact of ASD on family functioning

A total of 87 percent of the primary care providers of the children with ASD in this study indicated that they were in a stable relationship, with 83 percent of their partners being the other parent of the child with ASD. Seventy-six percent of the primary care providers indicated that they had never been separated or divorced. Table 3 shows the mean scores obtained by this group of primary caregivers on the various scales assessing marital quality, family life, self-esteem and coping strategies. The overall marital happiness rating for this group of primary caregivers (mean = 6.1, *SD* = 2.3) was somewhat lower than the mean rating of 7.7 (*SD* = 1.8) obtained by the norm group of 407 married couples from four different states across America in the Norton (1983) study. The overall family adaptability and family cohesion scores (mean = 46.4, *SD* = 6.5; and mean = 59.2, *SD* = 9.5 respectively) were also below those of the norm group of 2082

Table 3 Mean scores obtained by primary caregivers of children with autism spectrum disorder on scales assessing marital quality, family life, self-esteem and coping strategies

Scale	Score range	Mean	SD
Quality Marriage Index (QMI)	5–35	26.5	8.8
QMI (global happiness)	1–10	6.1	2.3
Family functioning (FACES II):			
Adaptability	15–70	46.4	6.5
Cohesion	15–80	59.2	9.5
Self-esteem	10–50	40.2	5.6
Coping (CHIP):			
Self-esteem	0–51	33.0	9.7
Optimism	0–27	18.3	5.1
Spousal support	0–18	13.0	4.4

caregivers surveyed in the USA, who obtained scores of 49.9 (SD = 6.6) for adaptability and 64.9 (SD = 8.4) for cohesion. The adapted scale was factor analysed to determine the primary coping strategies utilized by the primary care providers. Three coping factors were identified and were interpreted as self-esteem, optimism and spousal support. Sample items from the self-esteem coping factor included: 'Developing myself as a person' and 'Becoming more self-reliant and independent'. Sample items from the optimism coping factor included: 'Believing that things will always work out' and 'Investing myself in my child(ren)'. Sample items from the spousal support coping factor included: 'Talking over personal feelings and concerns with my spouse' and 'Going out with my spouse on a regular basis'. In addition, the results obtained on the coping subscales suggest that most of the coping strategies employed by caregivers in their role as primary care provider to a child with ASD were at least moderately helpful.

Caregivers acknowledged the high level of stress on families, with 41 percent reporting some form of physical, emotional, financial or marital relationship stress. Some caregivers (25 percent) described a negative effect on family life. Normal, spontaneous outings were difficult, and rarely was the family able to all go out together because of the stressful effect on the child with ASD. There also appeared to be a lack of understanding about ASD from the wider community, with 22 percent of caregivers stating that family, friends, teachers and the community did not understand the behavioural characteristics of children with ASD.

Coping strategies

Four hierarchical multiple regression analyses were used to determine if addition of scores on the coping scale (CHIP) improved prediction of marital happiness, family cohesion, family adaptability and self-esteem beyond that afforded by total satisfaction and total availability of services. Results from the four regressions were not significant ($p > 0.05$).

Discussion

The purpose of the study was to examine the impact upon families of having a child with ASD. As hypothesized, primary caregivers of a child with ASD reported lower marital happiness, family adaptability and family cohesion than normative data; however, there was no evidence of lower self-esteem. The hypothesis that coping style would add to prediction of adjustment (marital happiness, family adaptability, family cohesion and self-esteem) was not supported.

The sample of children with ASD in this study appeared consistent with the children with ASD described in previous research (e.g. Klin and Volkmar, 1997; Schreibman, 1988; Wing, 1997). Most of the children were first- or second-born males; they commonly engaged in repetitive behaviours, had a particular fascination with topics, and avoided eye contact during communication. Of note, however, was that a large proportion of this sample of children (59 percent) had been diagnosed as high-functioning ASD. However, researchers have noted that most children with ASD are diagnosed as low functioning (Schreibman, 1988), and diagnosed children with high-functioning ASD exhibited particular behavioural problems (Tonge et al., 1999). The high proportion of children with high-functioning ASD in the current study suggests a bias in the respondents to this survey, and/or a high detection rate for high-functioning ASD in the region that was surveyed. It must also be recognized that there was a lack of independent verification of the child's diagnosis, and therefore it is possible that respondents may exhibit bias when documenting their child's level of functioning.

Family functioning

Data supported our hypothesis that the sample of caregivers of a child with ASD would report lower marital happiness, family adaptability and family cohesion than normative data. Using the criteria devised by Olson et al. (1982), mean scores for family adaptability and family cohesion indicate that the average family in the sample falls outside the healthy family functioning range, with families demonstrating less flexibility and a lack of warmth and connection compared with normative data.

The low overall marital happiness rating reported by the caregivers of children with ASD in the present study was consistent with the findings of Rodrigue et al. (1990), who also found that mothers of children with ASD reported low levels of marital satisfaction. In families dealing with a child with a chronic illness or disability, parents focus a lot of attention on the child, and risk ignoring their own relationship needs and the needs of their partner.

The overall family cohesion and adaptability scores obtained in the present study were inconsistent with the findings of Rodrigue et al. (1990). They compared mothers of children with ASD, children with Down syndrome, and normally developing children. They found that mothers of children with ASD reported higher levels of family cohesion and lower levels of family adaptability than did the mothers in the other two groups, although the mean cohesion and adaptability scores for all three groups fell within the healthy family functioning range. It should be noted that in many models of family functioning, high levels of family cohesion can be interpreted as evidence of enmeshment, a maladaptive and extreme form of family cohesion (Olson et al., 1982). Although the direction was different, the data reported by Rodrigue and our data suggest the levels of family cohesion and family adaptability in families with a child with ASD may be at risk of falling outside the healthy family functioning range.

There are some obvious and practical explanations for the risk of family dysfunction in families with a child with ASD. Characteristics of children with ASD (such as low social competency and persistency) and the behavioural manifestation of these tendencies make social outings for families with a child with ASD difficult (Kraijer, 2000). This is likely to place additional stress on families, and create conflict within the family system. If families are not able to engage in joint activities with both the child with ASD and other siblings, they will tend to score low on the measure of family functioning used here, indicating a risk of the family being disconnected, or unable to be responsive to all members' needs.

Coping strategies

Coping strategies did not appear to be related to marital or family adjustment. This was surprising, given that the use of positive coping strategies is associated with adjustment to a range of chronic illnesses (McCubbin et al., 1983). However, it may be that the measure we used was not specific enough to assess the particular stresses and coping strategies associated with caring for a child with ASD, or that the reality of living with a child with ASD is not mediated by the coping strategies employed by caregivers. In this regard, it may not be coping strategies *per se*, but the cognitive appraisal of the situation that mediates the relationship. Milgram and Atzil (1988)

found that life satisfaction in parents of children with ASD was related not to objective evaluations of the child's behaviour (by teachers, principals and psychologists), but to their ratings of parenting behaviours (e.g. level of parenting difficulty, proportion of parenting tasks and fairness of this).

In addition, the lack of significant findings with regard to coping strategies may be due to the relative homogeneity of the sample, reflecting those who are coping well with their child's disability. Further research with caregivers who are experiencing difficulties may show that particular coping strategies – as well as cognitive perceptions of the parenting task (Milgram and Atzil, 1988) – are differentially associated with adjustment.

An obvious limitation to this study is the low response rate, which may have resulted in response bias. Although the low response rate may be reasonable, given the length of the survey and the high levels of time and energy demands placed on these caregivers, it is possible that a group of caregivers who are not coping with their situation did not have the time or inclination to respond. If this is so, it is reasonable to assume that our results are positively skewed.

Similarly, selection bias may have resulted from the recruitment method, which used the databases of local organizations providing specialized services for children with ASD and their families. All of the families in the present study have had access to some form of government-funded service. The caregivers who are coping on their own, who do not use these services or who may not be aware of the services have not been included. Finally, social desirability may have led some participants to respond to items as they felt they 'should', rather than as they actually believed. Due to the negativity that often appears to surround ASD, some caregivers may have felt pressure to present a socially desirable image of themselves and their families.

This study supports the need for the provision of services aimed to enhance marital and family functioning for families in which there is a child with ASD. This study provides an overview of the negative effects of having a child with ASD on family functioning and marital satisfaction. It supports previous studies that indicate that caring for a child with ASD is stressful, and sheds new light on the effects a child with ASD has on family functioning and marital satisfaction.

Acknowledgements

We are grateful to Arlene Walker and Nicolette Young for their assistance with identifying and reviewing relevant literature, and to Arlene Walker and Kate Ferris for conducting data entry and analysis.

References

- BRISTOL, M.M. & SCHOPLER, E. (1984) 'A Developmental Perspective on Stress and Coping in Families of Autistic Children', in E. SCHOPLER & G. MESIBOV (eds) *Autism in Adolescents and Adults*, pp. 251–78. New York: Plenum.
- GRAY, D.E. & HOLDEN, W.J. (1992) 'Psychosocial Well-Being among the Caregivers of Children with Autism', *Australia and New Zealand Journal of Developmental Disabilities* 18: 83–93.
- HAYES, V.E. (1997) 'Families and Children's Chronic Conditions: Knowledge Development and Methodological Considerations', *Scholarly Inquiry for Nursing Practice* 11: 259–84.
- HECIMOVIĆ, A., POWELL, T.H. & CHRISTENSEN, L. (1999) 'Supporting Families in Meeting Their Needs', in D.B. ZAGER (ed.) *Autism: Identification, Education, and Treatment*, 2nd edn, pp. 261–99. Mahwah, NJ: Erlbaum.
- HOLROYD, J. & MCARTHUR, D. (1976) 'Mental Retardation and Stress on the Parents: A Contrast between Down's Syndrome and Childhood Autism', *American Journal of Mental Deficiency* 80: 431–8.
- HOPPE, K. & HARRIS, S.L. (1990) 'Perceptions of Child Attachment and Maternal Gratification in Mothers of Children with Autism and Down Syndrome', *Journal of Clinical Child Psychology* 19: 365–70.
- JONES, G. (1997) 'Disabling Children: Autism, the Effect on Families and Professionals', *Educational and Child Psychology* 14 (3): 71–6.
- KLIN, A. & VOLKMAR, F.R. (1997) 'The Pervasive Developmental Disorders: Nosology and Profiles of Development', in S.S. LUTHAR (ed.) *Development Psychopathology: Perspectives on Adjustment, Risk, and Disorder*, pp. 208–26. New York: Cambridge University Press.
- KOEGEL, R.L., SCHREIBMAN, L., LOOS, L.M., DIRLICH-WILHELM, H., DUNLAP, G., ROBBINS, F.R. & PLIENIS, A.J. (1992) 'Consistent Stress Profiles in Mothers of Children with Autism', *Journal of Autism and Developmental Disorders* 22: 205–16.
- KONSTANTAREAS, M., HOMATIDIS, S. & CESARONI, L. (1995) 'Brief Report: Variables Related to Parental Choice to Medicate Their Autistic Children', *Journal of Autism and Developmental Disorders* 25: 443–52.
- KRAIJER, D. (2000) 'Review of Adaptive Behaviour Studies in Mentally Retarded Persons with Autism/Pervasive Developmental Disorder', *Journal of Autism and Developmental Disorders* 30: 39–47.
- LILLY, H. (1977) 'Autistic Children's Families', *Australian Autism Review* 1: 27–34.
- MCCUBBIN, H.I., MCCUBBIN, M.A., PATTERSON, J.M., CAUBLE, A.E., WILSON, L.R. & WARWICK, W. (1983) 'CHIP – Coping Health Inventory for Caregivers: An Assessment of Parental Coping Patterns in the Care of the Chronically Ill Child', *Journal of Marriage and the Family* 45: 359–70.
- MILGRAM, N.A. & ATZIL, M. (1988) 'Parenting Stress in Raising Autistic Children', *Journal of Autism and Developmental Disorders* 18: 415–24.
- NORTON, R. (1983) 'Measuring Marital Quality: A Critical Look at the Dependent Variable', *Journal of Marriage and the Family* 45: 141–51.
- OLSON, D.H., BELL, R.Q. & PORTNER, J. (1982) *FACES II: Family Adaptability and Cohesion Evaluations Scales*. St Paul, MN: Family Social Science.
- POWERS, M.D. (1989) 'Children with Autism and Their Families', in M.D. POWERS (ed.) *Children with Autism: A Parent's Guide*, pp. 105–39. Bethesda, MD: Woodbine House.
- ROBBINS, F.R., DUNLAP, G. & PLIENIS, A.J. (1991) 'Family Characteristics, Family

- Training and the Progress of Young Children with Autism', *Journal of Early Intervention* 15: 173–84.
- RODRIGUE, J.R., MORGAN, S.B. & GEFKEN, G. (1990) 'Families of Autistic Children: Psychological Functioning of Mothers', *Journal of Clinical Psychology* 19: 371–9.
- ROEYERS, H. & MYCKE, K. (1995) 'Siblings of a Child with Autism, with Mental Retardation and with a Normal Development', *Child: Care, Health and Development* 21: 305–19.
- ROSENBERG, M. (1965) *Society and the Adolescent Self-Image*. Princeton, NJ: Princeton University Press.
- SANDERS, J.L. & MORGAN, S.B. (1997) 'Family Stress and Adjustment as Perceived by Caregivers of Children with Autism or Down Syndrome: Implications for Intervention', *Child and Family Behaviour Therapy* 19 (4): 15–32.
- SCHREIBMAN, L. (1988) *Autism*, vol. 17. Newbury Park, CA: Sage.
- SENEL, H.G. & AKKOK, F. (1996) 'Stress Levels and Attitudes of Normal Siblings of Children with Disabilities', *International Journal for the Advancement of Counselling* 18: 61–8.
- SHARPLEY, C., BITSIKA, V. & EFREMIDIS, B. (1997) 'Influence of Gender, Parental Health, and Perceived Expertise of Assistance upon Stress, Anxiety, and Depression among Parents of Children with Autism', *Journal of Intellectual and Developmental Disability* 22: 19–28.
- TOMMASONE, L. & TOMMASONE, J. (1989) 'Adjusting to Your Child's Diagnosis', in M.D. POWERS (ed.) *Children with Autism: A Parent's Guide*, pp. 31–54. Bethesda, MD: Woodbine House.
- TONGE, B.J., BRERETON, A.V., GRAY, K.M. & EINFELD, S.L. (1999) 'Behavioural and Emotional Disturbance in High-Functioning Autism and Asperger Syndrome', *Autism* 3: 117–30.
- WILLIAMS, K.E. & BOND, M.J. (2002) 'The Roles of Self-Efficacy, Outcome Expectancies and Social Support in the Self-Care Behaviours of Diabetics', *Psychology, Health and Medicine* 7: 127–41.
- WING, L. (1997) 'The Autistic Spectrum', *The Lancet* 350: 1761–7.