Stress in Parenting Autistic Children :

The Daily Hassles Approach to Conceptualising Stress

and

Research Portfolio

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CHAPTER 1

Major Research Project Literature Review

(written for submission to the Journal of Child Psychology and Psychiatry – appendix 1.1 for notes for Contributors).

Stresses in Parenting Autistic Children

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Stresses in Parenting Autistic Children

Summary

This paper reviews studies on stress in parenting autistic children. Previous studies have identified a number of sources of stress including the condition itself, its associated social and behavioural features, and parents' uncertainty about their child's development, related to the diverse nature of autism. Parent and child characteristics and family factors are discussed in relation to their contribution to stress in parenting. In addition, these factors are discussed within a normal developmental framework and relative to other disabilities. The theoretical and empirical basis for the need for future research to conceptualise stress in parenting autistic children from the daily hassles perspective is presented.

Key Words

Stress in parenting autistic children

Daily hassles

Sources of stress

Stresses in Parenting Autistic Children

General Introduction

Parents of autistic children have been reported as experiencing particularly high levels of stress in parenting relative to parents of children with other disabilities and not surprisingly, those of normal development (Bouma and Schweitzer, 1990; Wolf and Fisman, 1989; 1991; Dumas et al, 1991; Moes, 1992; Rodrigue et al, 1990).

It has been documented that stress in parenting contributes to the psychological wellbeing of parents of children with disabilities (Holroyd and McArthur, 1976; Fisman and Wolf, 1991). Wolf, Noh, Fisman and Speechley (1989) in a comprehensive study of psychological effects of parenting stress on parents of autistic children, Downs Syndrome children and normally developing children found elevated depression in the autistic group due to increased levels of parenting stress.

In light of the well documented association between psychological wellbeing, effective parenting and optimal child functioning (see Cox, 1988, Abidin, 1990, Belsky, 1984) it is necessary to try to identify sources of increased stress in autism with a view to developing interventions and aid preventative planning to limit the risk of secondary damage in the autistic child.

This paper reviews recent research findings to identify factors associated with stress of parenting an autistic child. Implications for research are discussed.

Stress in Parenting and Autism

The type of disability on parenting stress has revealed fairly consistent findings across studies with significantly elevated parenting stress reported by parents of autistic children. This result has been

consistent despite different studies using different measures of stress and different sample characteristics. However, few studies have systematically investigated and reported on the sources of increased stress in parenting an autistic child relative to other disorders and to normal development. From the available studies, some contradictory findings have been documented, for example, in relation to effects of gender of the parent, parental age and age of the child on parenting stress. Some of these parent and child characteristics will be discussed for their contribution to parenting stress. Some factors such as social support have consistently been found to influence stress in parents of autistic children. The contribution of social support to stress will be discussed in more detail later in this paper.

The nature of Autism

A source of stress in parenting autistic children is perhaps the condition itself and its associated features. The central features of autism are impairments in communication, responsiveness to others, and deficits in social understanding and social relationships (DSM-IV, Sigman, and Capps, 1997; Norton and Drew, 1994)). Children with autism may also have a range of behavioural difficulties including ritualistic or obsessive behaviour, and difficulties adapting to change (DSM-IV, Sigman and Capps, 1997; Aaron and Gittens, 1994).

Some authors have attributed increased levels of stress in parents of autistic children to uncertainty about the child's development, related to the diverse nature of autism. Autistic children show inconsistencies in different areas of development unlike other disabilities like Downs Syndrome, where there are relatively consistent deficits in all aspects of development (Rodrigue et al, 1992).

Specific behavioural and social features of autism are thought to contribute to stress in parenting (Norton and Drew, 1994; Rodrigue et al, 1992). In a study by Liwag (1989) investigating stress in mothers and fathers of autistic children, parents were found to be particularly stressed by features associated with autism including, lack of speech, hyperactivity and tantrum behaviour. Similar results have been found in other studies (Konstantareas and Homatidis ,1989).

There is evidence to suggest that features associated with autism make daily demands of normal parenting, referred to by Crnic and Greenberg (1990) as 'parenting daily hassles', more challenging (Aarons and Gittens, 1994; Norton and Drew, 1994). The following sections outline the daily hassles approach to conceptualising stress and discusses the contribution of the general demands of normal parenting to stress in parenting autistic children.

The Daily Hassles approach to conceptualising stress

The daily hassles approach to conceptualising stress is relatively new. This approach conceptualises stress as a product of stressful daily events (or daily hassles) and the individuals cognitive appraisal of the personal significance of these events (Chamberlain et al, 1990; Lazarus and colleagues, 1985; 1984). The emphasis on the persons cognitive appraisal of the event as a central factor in the stress experienced has important methodological implications for research studies.

Daily hassles specifically associated with parenting have been identified as sources of stress in parenting young children of normal development (Crnic and Greenberg, 1990). Parenting daily hassles refer to the normal everyday events characteristic of parenting (Crnic et al, 1990). They include, for example, meal time and bedtime difficulties, difficulties with friends, sibling arguments, difficulties in managing the child's behaviour in public, difficulties in dressing the child to go out, as well as other everyday events of a similar nature.

The validity of daily hassles as an independent measure of stress has been documented (Caspi et al, 1987; Chamberlain et al, 1990; Crnic and Greenberg, 1990; Lazarus et al, 1985). Daily hassles have been found to be better predictors of psychological wellbeing than the more traditional major life events approach to stress (Crnic et al, 1990; Chamberlain et al, 1990).

Parenting Daily Hassles and Autism

Little is known about the stress parents of autistic children experience as a result of the normal stressful demands of parenting relative to normal development and to other disabilities. There is some evidence to

suggest parenting daily hassles are sources of stress in parenting autistic children. However there appears to be no systematic study investigating the stress associated with normative parenting daily hassles or identifying specific daily events of parenting that differentiate mothers of autistic children from other groups.

Some studies have identified areas of difficulty for parents of autistic children including obtaining child care arrangements, taking the child out in public places, restrictions on family travel, disrupted planning of activities, and difficulties in establishing sleeping and eating patterns (Haefele and Heriggeler, 1983; Rodrigue et al, 1990, 1992; Factor et al, 1990; Norton and Drew, 1994; Konstnatareas and Homatidis, 1989).

It is likely that child characteristics and features of autism contribute to the challenge of parenting daily hassles.

Despite the potential risk of stress for parents of autistic children in relation to normal demands of parenting, and the validity of parenting daily hassles as a measure of stress, to date this area remains under-researched. The issue of the cumulative effects of parenting daily hassles on parents of autistic children has still to be addressed.

Parent and Child Characteristics

Studies have tended to report on the general stress level experienced by parents. Fisman and Wolf (1991) however from their study using the Parenting Stress Index (PSI - Llyod and Abidin, 1985) identified child characteristics as sources of stress in parenting which differentiated parents of autistic children from parents of Downs syndrome children. Increased levels of parenting stress for parents of autistic children related to sources of stress associated with the adaptability (difficulty in adjusting to change in environment), acceptability (less attractive, intelligent or appropriate than desired) and demanding (for example, need for attention and assistance) of the child, that made parenting difficult. In contrast only the acceptability of the child was identified as a source of stress by parents of Downs syndrome children.

Similar findings of child characteristics as sources of stress for parents of autistic children have been found by Konstantareas et al (1989) and Liwag (1989).

For mothers of both autistic and Downs Syndrome children additional sources of stress were found in the Parent domain of the PSI where mothers reported dysphoria, feelings of poor health and a sense of a lack of competence in parenting (also reported by DeMyer; 1979; Rodrigue et 1990). These findings were not found by Fisman et al (1991) for fathers who only reported stress associated with child characteristics.

This finding is consistent with other studies that have found mothers of autistic children to report higher levels of general stress and parenting stress than fathers (Reddon, 1992; Rodrigue et al, 1990; Gray and Holden, 1992; Milgram and Atzil, 1988). However, contrary to these findings some studies have not found mothers to be more stressed than fathers (Factor et al, 1990; Konstantareas and Homatidis, 1989). These contradictory findings are likely to be a result of the different measures of stress adopted in the studies.

The general trend for mothers to experience more stress is perhaps to do with a combination of mothers being more susceptible to psychological distress than fathers and to mothers assuming a larger share of the daily tasks in caring for a child with autism (Milgram and Atzil, 1988; Reddon, 1992). On the other hand perhaps fathers may report less stress due to social desirability. However, fathers as well as mothers experience high levels of stress (Rodrigue, Morgan and Geffken, 1992) which must be addressed at a practical level.

The combined effect of parent and child characteristics rather than one in isolation may for mothers in particular, help explain increased stress in parenting autistic children. The combined effect may assist in helping identify mothers of children most at risk of stress (Barnett, Hall and Bramlett, 1990).
A comparison across studies suggests that mothers continue to take more responsibility in relation to caring for their autistic child through childhood and into adulthood (Holmes and Carr, 1991). Significant levels of stress in parents have been documented at all stages of the child's development, when the child is in infancy, middle childhood, adolescence, and adulthood (Factor et al, 1990; Konstatntareas and Homatidis, 1989; Fong, 1991; Holmes and Carr, 1991). However, there appears to be a lack of research

comparing levels of parenting stress in autism as a function of the child's chronological age and in comparison with other disabilities and normal development. The next section discusses the effects of age of the child in more detail.

Child's chronological age and stress

Some studies have found age effects on stress and psychological wellbeing of parents of autistic children while others report no age effects (Gill and Harris, 1991). Of those reporting effects of age the results have been contradictory and the issue of age remains unclear. The findings of some studies suggest greater stress for parents with increasing age of the child (Bristol, 1984; Harris, 1984; Holmes and Carr, 1991) while others suggest perhaps greater stress when the child is younger (Gray and Holden, 1992). Differences in age ranges of the samples in these studies may account for the differences in results.

Focusing on the autistic child from infancy to middle childhood and considering their development within a normal developmental framework suggests continuity in social difficulties for the autistic child, irrespective of intellectual ability (Sigman and Capps, 1997). Social relationships for the normal child become increasingly important with age and it is during middle childhood that friendships become more evident, they become more interested in and consider other peoples points of view, and are more aware of social norms. It is perhaps in middle childhood that the autistic child's difficulties become more apparent as they remain less inclined to share others interests, and engage in social interactions. Prior to middle childhood the autistic child's development is similar in many respects to that of normal children and features associated with autism are perhaps not considered so out of the ordinary at this young age. This suggests that with increasing age of the child specific parenting daily hassles such as dealing with problems with friends becomes more difficult for parents and an additional source of stress in parenting an older autistic child. In contrast it has been documented that although sleeping and eating difficulties can be extreme in infancy they tend to abate with increasing age and may no longer be a source of stress in parenting (Aarons and Gittens, 1994).

These findings suggest there is perhaps an interaction between specific parenting daily hassles and age contributing to increased stress in parents of autistic children in comparison with normal development.

When older children with autism have still not achieved the developmental tasks expected of a child at a much younger age this is likely to be a source of stress for parents (McCallion et al, 1993, for a review of developmental transition research).

Comparative studies on stress in autism have tended to use normal groups matched on mental age or adaptive behaviour in their research design which results in chronological age of the normal group being significantly younger than the autistic group. Difficulties may arise in untangling whether the source of group differences is a result of the normal child being younger or to do with the child being autistic. Also, the selection of normal subjects becomes problematic. A discussion of this is beyond the scope of this paper and has been discussed elsewhere (Hobson, 1991). In comparative studies investigating the effects of age and stress in parenting it would seem more appropriate for the normal group to be matched on chronological age.

Further work is needed on the effects of the autistic child's age on stress experienced in parenting. By identifying sources of stress in parenting which differentiate parents of younger and older autistic children this can aid preventative planning.

Family Variables

A number of family variables including family composition, family size, social support within the family and interactions between the family and the community, and socioeconomic status (see Fisman and Wolf, 1991 for a review) may influence stress experienced in parenting an autistic child. In summary, smaller families, single parents, families of middle or upper socioeconomic status and less social support are more likely to experience higher levels of stress in parenting. The next section looks at the role of social support in stress.

Social Support and Stress

Conceptualisation of Social Support

The social support literature consistently reports beneficial effects of social support on mental health (Ganster and Victor, 1987; Cohen and Willis, 1985). It would therefore seem reasonable to assume that a socially supportive environment will function to reduce stress experienced by parents of autistic children. Of the few studies on stress in parenting autistic children that have included a measure of social support the findings suggest an inverse relation between social support and stress. Parents of autistic children tend to report lower stress with greater perceived support (Reddon et al, 1992; Gray et al, 1992; Fisman et al, 1989; Factor et al, 1990; Gill and Harris, 1991; Konstantareas et al, 1989).

By adopting some of the social support theories from social support literature (Ganster and Victor, 1987) it may help explain the finding that social support reduces stress in parenting autistic children. Social support may function to increase parents self esteem and sense of control perhaps increasing confidence in their parenting competence. Changes in parents' behaviour may be encouraged through receiving information and guidance from others. This may help the parent to deal more effectively with the stress generated in parenting an autistic child and therefore enhance coping ability (Kessler et al, 1985; Cohen and Syme, 1985, Gottlieb, 1983; Lazarus and Folkman, 1984). This may have an effect on parents cognitive appraisals of stressful daily events, reducing stress experienced in relation to parenting daily hassles. The other person may provide direct support such as help with household chores, daily tasks associated with parenting, and providing transport and financial assistance (Willis, 1985), relieving some of the burden of parenting.

Social support theories suggest perceptions of support are the most essential aspect of support (Cohen and Symes 1985; House and Khan, 1985). It is likely that it is the parents' perceptions of support that is the crucial factor in determining the effects of social support on parenting stress in autism. It does not necessarily follow that someone who receives a lot of support across a number of areas will automatically perceive this as favourable. In support of this notion, Gill and Harris (1991) in a study investigating social support effects on the psychological wellbeing of mothers of children with autism found a

significant relationship between perceived availability of support and stress while no significant relationship was found for actual receipt of support and stress (also see Cohen and Willis, 1985) .

However, there seems to be no general agreement on how to define social support and different studies have conceptualised it differently. Based on social support theories and research findings it seems social support can be best conceptualised as multidimensional with structural aspects and functional aspects. Cognitive appraisals of support along these dimensions are perhaps the most accurate measure of social support. Structural support can be defined as the existence or availability of people on whom you can rely (Sarason et al, 1983; Berkman, 1985; Sherbourne and Stewart,1991). Functional support can be defined as ' the degree to which interpersonal relationships serve particular functions" Sherbourne et al, (1991). Functions of support can generally be categorised as emotional and practical. There is evidence to suggest structural and functional support measure two separate constructs of social support (Sherbourne et al, 1991; Sarason et al, 1987; Cohen and Syme , 1985). There is a need to identify the effects of each on stress within the one study using the same measures.

Social Support, Stress and Autism

With regard to structural social support for parents of children with autism it has been found that there is no difference in social support from mothers of Downs Syndrome children. However in a comparison with mothers of children of normal development they reported fewer people in their social network (Rodrigue et al, 1990). In contrast to this Konstantareas and Homatidis (1988) reported mothers of autistic and normal children to have equal numbers of supports. The most likely reason for these contradictory findings is that the studies used different measures of support and a different conceptualisation of structural social support.

In Rodrigue et al (1990) mothers of autistic children reported the people in their social network to have multiple functions while mothers of normal children reported more specialised functions for the people in their social network. On a practical level support from professionals, respite care and other formal support services have been identified as playing a role in reducing stress in parents of autistic children (Bristol, 1984; Bristol et al, 1983). Konstantareas et al, (1988; 1989) found mothers of autistic children to be

satisfied with emotional support from their husbands but were not satisfied with the quality of instrumental (or practical) support from their husbands in relation to daily chores and disciplining the child.

These studies highlight the need to measure the effects of social support on stress from a multidimensional perspective of social support. Determining support needs of parents of autistic children has potential for planning intervention strategies. The issue remains unclear and further work is needed to identify support needs in relation to other disabilities and normal development in an attempt to clarify the issue.

Conclusions and Future Research

Parents of autistic children have consistently been found to report greater stress in parenting relative to other disabilities and to normal development. A general tendency is indicated in the literature for mothers to report higher levels of stress than fathers, however there are some inconsistent results. A number of sources of stress in parenting autistic children have been suggested by the literature, including features of autism, the diverse nature of autism, parent characteristics, family variables, child characteristics and the normal demands of parenting.

However, the research is limited and some areas remain under researched. In particular an area in need of systematic research is stress in relation to the normal demands of parenting. The theoretical basis for such a study can be found in adopting the Daily Hassles approach to conceptualising stress. Factors, suggested by the literature to influence stress should either be included as a variable, or the design of the research should control for the effects of such factors, for example, parent characteristics, social support, and family variables.

In addition, there is also a need for research in areas where results documented are contradictory to help resolve the issues. Future studies should take into account in their design the methodological limitations of previous studies. For example, inclusion of a normal control group matched on chronological age and inclusion of a disability control group.

References

Aarons, M. and Gittens, T. (1994). The Handbook of Autism. Routledge. London.

Abidin, R. (1990) Parenting Stress Index - Short Form. Test Manual. University of Washington.

American Psychiatric Association 1994. *Diagnostic and Statistical manual of mental disorders* (4th Edition).

Barnett, D.W., Hall, J.D. , and Bramlett, R.K. (1990). Family factors in preschool assessment and intervention; A validity study of parenting stress and coping measures. *Journal of School Psychology*, 28, 1, 13-20.

Belsky, J. (1984). The Determinants of Parenting: A Process Model. Child Development, 55, 83-96.

Berkman, L.F. (1985). The relationship of social networks and social support to morbidity and mortality. In S. Cohen and L. Syme (Eds), *Social Support and Health*, 241-259, New York, Academic Press.

Bouma, R., and Schweitzer, R. (1990). The impact of chronic childhood illness on family stress : A comparison between autism and cystic fibrosis. *Journal of Clinical Psychology*, 46, 6, 722-730.

Bristol, M. M. and Schopler, E. (1983). Stress and coping in families of autistic adolescents. In E. Schopler and G.B. Mesibov (Eds), Autism in adolescents and adults, 251-278. New York: Plenum.

Bristol, M.M. (1984). Family resources and successful adaptation to autistic children. In E. Schopler and G.B. Mesibor (Eds.), *The effects of autism on the family*, 289-310. New York : Plenum Press.

Caspi, A., Bolger, N. and Eckenrode, J., (1987). Linking Person and Context in the Daily Stress Process. *Journal of Personality and Social Psychology*, 52, 1, 184-195.

Chamberlain, K., and Zika, S. (1990). The minor events Approach to Stress : Support for the use of daily hassles. *British Journal of Psychology*, 81, 469-481.

Cohen, S., and Syme, S.L. (1985a). Issues in the study and application of social support. In S. Cohen and S.L. Syme (Eds)., *Social Support and Health*, New York, Academic Press.

Cohen, S., and Wills, T.A. (1985). Stress, Social Support, and the Buffering Hypothesis. *Psychological Bulletin*, 98, 2, 310-357.

Cox, A.D. (1988) Maternal Depression and impact on children's development. *Archives of Disease in Childhood*, 63, 90-95.

Crnic, K.A., and Greenberg, M.T. (1990). Minor Parenting stresses with young children. *Child Development*, 61, 1628-1637.

Demyer, M.K. (1979). *Parents and Children in autism.* Toronto : John Wiley and sons.

Dumas,, J.E., Wolf, L.C., Fisman, S.N., and Culligan, A. (1991). Exceptionality, 2, 2, 97-110.

Factor, D.C., Perry, A., and Freeman, N. (1990). Brief report: Stress, Social support and respite care use in families with autistic children. *Journal of Autism and Developmental Disorders*, 20, 1, 139-146.

Fisman, S.N., Wolf, L.C., (1991). The handicapped child : Psychological effects of parental, marital, and sibling relationships. *Psychiatric Clinics of North America*, 14, 1, 199-217.

Fisman, S.N., Wolf, L.C., and Noh, S. (1989). Marital Intimacy in parents of exceptional children. *Canadian Journal of Psychiatry*, 34, 6, 519-525.

Fong, P.L., (1991). Cognitive appraisals in high and low stress mothers of adolescents with autism. *Journal of Consulting and Clinical Psychology*, 59, 3, 471-474.

Ganster, D.C. and Victor, B. (1988). The impact of social support on mental and physical health. *British Journal of Medical Psychology*, 61, 17-36.

Gill, M.J., and Harris, S.L. (1991). Hardness and social support as predictors of psychological discomfort in mothers of children with autism. *Journal of Autism and Developmental Disorders*, 21, 4, 407-416.

Gottlieb, B.H. (1983). *Social Support Strategies*, Beverly Hills, CS : Sage.

Gray, D.E., and Holden, W.J. (1992). Psycho-social well-being among the parents of children with autism. Australia and New Zealand *Journal of Developmental Disabilities*, 18, 2, 83-93.

Haefele, W.F., and Heriggeler, S.W. (1983). Autism : a family-ecological systems perspective. Meeting Their Needs : *Provisions of Services to the Severely Emotionally Disturbed and Autistic Conference proceedings*, 62-75, Memphis.

Harris, S.L. (1984). The family and the autistic child : A behavioural perspective. *Family Relations*, 33, 127-134.

Hobson, P.R. (1991). Methodological Issues for Experiments on Autistic Individuals, Perception and Understanding of Emotion. *Journal of Child Psychology and Psychiatry*, 32, 7, 1135-1158.

Holmes, N., and Carr, J. (1991), The Pattern of Care in Families of Adults with a Mental Handicap : A Comparison Between Families of Autistic Adults and Downs Syndrome Adults. *Journal of Autism and Developmental Disorders*, 21, 2, 159-176.

Holroyd,J., and McArthur,D. (1976). Mental retardation and stress on the parents: a contrast between Downs Syndrome and childhood autism. *American Journal of Mental Deficiency*, 80, 431-436.

House, J.S., and Kahn, R.L. (1985), Measures and Concepts of Social Support. In S. Cohen and S.L. Syme (Eds)., *Social Support and Health*, 83-108, New York : Academic Press.

Kessler, R.C., and McLeod, J.D. (1985). Social Support and Mental Health in community samples. In S. Choen and S.L. Syme (Eds)., *Social Support and Health*, 219-240, New York : Academic Press.

Konstantareas, M.M. and Homatidis, S. (1989). Assessing Child Symptom Severity and Stress in parents of Autistic Children. *Journal of Child Psychology and Psychiatry*, 30, 3, 459-470.

Konstantareas, M.M., and Homatidis, S. (1988). Stress and differential parental involvement in families of autistic and learning disabled children. In E. Hibbs (Ed.), *Children and Families : Studies in prevention and intervention.* 321-336, New York : International Universities Press.

Lazarus, R.S., and Folkman, S. (1984). Stress, Appraisal and Coping, New York, Springer.

Lazarus, R.S., DeLongis, A, Folkman, S., and Gruen, R. (1985). Stress and adaptational outcomes: The problem of confounded measures. *American Psychologist*, 40, 770-779.

Liwag, M.E. (1989). Mothers and Fathers of autistic children : An exploratory study of family stress and coping. *Philippine Journal of Psychology*, 22, 3-16.

Lloyd, B.H., and Abidin R.A. (1985). Revision of the Parenting Stress Index., *Journal of Pediatric Psychology*, 10, 169-177.

McCallion, P., and Toseland, R. W. (1993). Empowering Families of Adolescents and Adults with Developmental Disabilities. Families in Society*; Journal of Contemporary Human services*

Milgram, N.A., and Atzil, M. (1988). Parenting stress in raising autistic children. *Journal of Autism and Developmental Disorders*, 18, 3, 415-424

Moes, D., Koegel, R.L., Shreibman, L., and Loos, L.M. (1992). Stress profiles for mothers and fathers of children with autism. *Psychological Reports*, 71, 3, 2, 1272-1274.

Norton, P., and Drew, C. (1994). Autism and Potential Family Stressors. *The American Journal of Family Therapy*, 22, 1, 67-76.

Reddon, J.E., McDonald, L. and Kysela, G.M. (1992). Parental Coping and Family Stress 1 : Resources for and functioning of families with a pre-school child having a developmental Disability. *Early Child Development and Care*, 83, 1-26.

Rodrigue, J.R., Morgan, S.B, and Geffken,G. (1990). Families of autistic children: Psychological functioning of mothers. Special Issue: The stresses of parenting. *Journal of Clinical Child Psychology*.

Rodrigue, J.R., Morgan, S.B., and Geffken,G.R. (1992). Psychosocial adaptation of fathers of children with autism, Downs Syndrome, and normal development. *Journal of Autism and Developmental Disorders*, 22, 2, 249-263.

Sarason, B.R., Shearin, E.N., Pierce, G.R., and Sarason, I.G. (1987). Interrelations of social support measures : The critical and practical implications. *Journal of Personality and Social Psychology*, 813-832

Sarason, I.G., Levine, H.M., Basham, R.B. and Sarason, B.R. (1983), Assessing Social Support : The Social Support Questionnaire. *Journal of Personality and Social Psychology*, 44, 127-139.

Sherbourne, C.D., and Stewart, A.L., (1991). The MOS Social Support Survey. *Soc. Sci. Med.* 32, 6, 705-714.

Sigman, M., and Capps, L. (1997). Children with Autism : A Developmental Perspective. Bruner, J., Cole, M., and Karmiloff-Smith, A. (Eds). Harvard University Press.

Willis, T.A. (1985), Supportive Functions of Interpersonal relationships. In S. Cohen and S.L. Syme (Eds). *Social Support and Health*, 61-82, New York : Academic Press.

Wolf, L.C., Noh, S., Fisman, S.N., and Speechley, M. (1989). Brief Report : Psychological Effects of parenting stress on parents of autistic children. *Journal of Autism and Developmental Disorders*, 19, 1, 157-166.

CHAPTER 2

Major Research Proposal

Stresses in Parenting Autistic Children : A Research Proposal

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Maternal Perceptions of Stress with Routine Tasks of Parenting

Summary

The proposed research aims to investigate stress associated with parenting daily hassles for mothers of autistic children, and to identify specific parenting daily hassles differentiating between mothers of autistic children, Downs Syndrome children, and normally developing children, all in the age range 3 to 8 years. The study aims to investigate effects of age of the children and social support on stress. Mothers will be interviewed by the author to gather information for matching groups. Following this they will complete the Parenting Stress Index, Preschool behaviour checklist, Parenting Daily Hassle Scale and a measure of social support. The participants will be recruited through the Strathclyde Autistic Society, the Downs Syndrome Association and mainstream schools and nurseries. Ethical permission will be obtained from the National Autistic Society and Downs Syndrome Association. Permission has been granted to various mainstream schools and nurseries. The study has important practical implications and is of tremendous clinical relevance. Identifying variables altering stress levels and types of parenting daily hassles most stressful will have implications for developing special provisions to help parents of children with disabilities manage the problems they face in parenting. By being aware of the potential problems faced by parents when a child is at a certain age can aid preventative planning and help to reduce stress in parents to prevent secondary damage in the autistic child.

Key Words

Parenting Daily Hassles

Autism

Children

Preventing stress

Stresses in Parenting Autistic Children : A Research Proposal

Introduction

A review of existing literature indicates increased levels of stress in parenting autistic children, relative to other disabilities and to normal development (Fisman and Wolf, 1991, Rodrigue et al 1990). Research findings suggest stress in parenting contributes to psychological wellbeing which is associated with effective parenting and optimal child development (Belsky, 1984; Abidin, 1990, Fisman and Wolf, 1991). There is therefore a need to identify sources of stress in parenting autistic children to help develop interventions to reduce stress in parents and prevent secondary damage in the autistic child resulting from high levels of stress in parents.

An area of potential stress in parenting autistic children is the normal everyday demands of parenting which are challenging for any parent. These have been referred to as 'parenting daily hassles' by Crnic and Greenberg (1990) and include mealtime difficulties, child care difficulties, difficulties with friends, among others. This is an area that seems to be largely neglected in the field of autism. Despite evidence to suggest these events are a source of stress for parents of autistic children (Haefele and Herrigeler, 1983, Norton and Drew, 1994, Aarrons and Gittens, 1994) and the validity of the daily hassles approach to stress (Caspi et al 1987; Crnic and Greenberg 1990, Lazarus et al 1984, 1985), there appears to be no systematic study investigating stress of parenting daily hassles in autism, relative to other disabilities and to normal development.

This paper outlines a proposal for a research study addressing this issue and related issues including, effects of age of the child and the role of social support in stress.

Aims

The primary aim of the proposed research is to investigate stress in parenting daily hassles for mothers of autistic children. An associated aim is to identify specific parenting daily hassles differentiating mothers of autistic children from mothers of Downs Syndrome and normal children. The issue of parenting stress as a function of the child's age is to be addressed. In addition, the role of support in stress is to be investigated.

Hypotheses

The following hypotheses are to be explored.

Hypothesis 1:

Mothers of children with a disability (Autistic or Downs Syndrome) were expected to report greater stress than mothers of normal children, with the autistic group reporting most stress. In addition, it was predicted that mothers of older children with a disability would report greater stress than mothers of younger children and all would report greater stress than mothers of normal children.

Hypothesis 2:

7 items of the PDH in particular (items 5, 14, 15, 16, 18, 19, and 20) were expected to differentiate between groups of mothers in terms of frequency of the event and stress in relation to the event..

Hypothesis 3:

Mothers who report greater perceived satisfaction with emotional and practical support were expected to report less stress in parenting, irrespective of type of disability (autistic or Downs Syndrome) or normal development and age of the child.

Plan of Investigation

Methodology

The following procedures are planned for this research study.

Sample

There will be 3 groups of mothers in this study : one of 40 mothers of autistic children, one of 40 mothers of children with Downs Syndrome, and one of 40 mothers of children of normal development. Each group will comprise 20 mothers of pre-school aged children (3-5 years) and 20 mothers of school-aged children (6-8 years).

Mothers in the autistic group will be recruited from local branches of the National Autistic Society and The Downs Syndrome group will be recruited from the local Downs Syndrome Association. Children whose mothers are included in the normal development group will attend local mainstream schools and nurseries. These children will have no diagnosis of disabilities and will be functioning at an expected developmental level for their chronological age, as assessed by their parents and teachers.

Design

To maximise experimental control groups will be matched as closely as possible, for example on sex of child, age of mother, number of siblings. Autistic and Downs Syndrome groups will be matched on the basis of language and more general ability as assessed by the Vineland Adaptive Behaviour Scales (Sparrow, Bella and Cicchetti, 1984) and from additional information provided by mothers.

Measures

Data will be collected through the following self-report questionnaires completed by mothers. The child's nursery teacher or nursery nurse will be asked to complete a questionnaire regarding behaviour to provide an objective measure of the child's behaviour. This will help to validate perceptions.

Parent Measures

1. Parenting Stress Index - short form (Abidin, 1990) – Appendix 1.2.7

2. Parenting Daily Hassle Scale (Crnic and Greenberg, 1990) – Appendix 1.2.6

3. Social Support Measure (devised for the purposes of this study - Appendix 1.2.5)

4. Preschool Child Behaviour Checklist (McGuire and Richman, 1988)

Teacher rating of child behaviour

1. Preschool Child Behaviour Checklist (McGuire and Richman, 1988)

All measures have been selected for their reliability and validity and are all quick instruments to complete. Previous research has shown these measures have been well accepted by parents. The support measure has been devised as no existing measure was found to include all the relevant measures of support needed for investigation in this study.

Measures of Stress Associated with Parenting

(a) *Parenting Stress Index-short form (PSI/SF)*

The PSI/SF, a self report questionnaire, gives a measure of overall perceived stress as experienced by the mother in relation to her role as a parent. Overall stress is measured as a function of parental distress, child behavioural status and of the parent - child interaction.

(b) *Parenting Daily Hassle Scale (PDH)*

This measure assesses stresses experienced in relation to daily events of parenting. This self report questionnaire has 20 items rated on 2 dimensions - the frequency of occurrence of the event and how hassled the parent felt by the event. Scoring the measures produces a frequency score and intensity score. Preceived stress will be measured on the intensity dimension

Measures of Perceived Support

(a) *Social Support Questionnaire (SSQ)*

The SSQ has been devised specifically for the purposes of this study. The construction of the questionnaire was guided by the findings of social support literature. The questionnaire is in 2 parts. Part 1 consists of 3 general questions indicating the amount of support available, the source of this support and a rating of satisfaction on a scale from 0 to 10. Part 2 consists of 12 items covering the function of support. Items include emotional and practical functions of support such as respite, help with routine tasks,

provision of information and advice, aspects of the marital relationship, and aspects of friendships. On each item mothers are required to record the number of people from whom they receive the support described, the source of this support and if they are satisfied with that particular aspect of support. Pilot work will be undertaken to enhance the validity of the SSQ.

Measure of Child's behaviour

(a) *Pre-school Behaviour Checklist (PBCL)*

The PBCL is to be completed by mothers to indicate their perceptions of their child's behaviour and by the child's teacher, nursery teacher or nursery nurse. This measure was selected for its reliability, validity and quick administration, only taking approximately 5 minutes to complete.

A preschool measure has been selected as the behaviours listed are likely to be problematic in older children with handicaps. It is expected that older children of normal development will reach ceiling level on this measure.

Procedure

Interviews with mother

After obtaining written consent from mothers they will be interviewed in a convenient location in a friendly, comfortable and relaxed atmosphere (Appendix 1.2).

Interviews will be semi-structured. The interview will begin with reassuring mothers of anonymity and confidentiality. This will be followed by collecting information on age of mother, marital status, number and age of other children in the family, occupation, physical health of mother and family. In the case of mothers of autistic children they will be asked about the history of their child's disorder, including when they first thought something was wrong, and how long ago the diagnosis was made. Mothers of children with Downs Syndrome will be asked about the history of the handicap. A brief interview schedule has been devised by the author to record this information (Appendix 1.2.3). Additional information will be

recorded on the Vineland Adaptive Behaviour Scale (Sparrow et al, 1984). Information given will be used for matching groups.

Mothers will then be asked to complete the self report questionnaires.

On completion of the questionnaires mothers will be given an information sheet explaining in more detail the purposes of the study (Appendix 1.2.4).

The entire interview will take approximately 30 minutes.

After obtaining written consent from the child's mother their teacher, or nursery nurse will be contacted and asked to complete the PBCL. This will take between three and five minutes to complete.

In order to match the correct form with the questionnaires the child's mother completes, a number will be attached to each form which corresponds with the number attached to his/her mothers self report questionnaires. The form will be attached to the appropriate questionnaires once completed and the numbers removed. This will allow anonymity to be maintained.

Mothers will be offered the opportunity to attend a group session run by the author and Consultant Clinical Psychologist, to deal with any stress resulting from this research.

Setting

Once ethical permission has been given, parents and children registered with the Strathclyde Autistic Society and Downs Syndrome Association will be asked to participate. Head teachers at a mainstream nursery and primary school have granted permission to carry out this research within their schools. Another nursery and school have been contacted incase there are difficulties in obtaining the numbers needed within the normal development group. Head teachers and nursery heads in special educational

facilities where autistic and Downs Syndrome children attend will be contacted once ethical permission has been granted for this study.

Data Analysis

The responses on the questionnaires will be scored according to the scoring criteria as laid out in the manuals of the appropriate questionnaire. Scores will be transferred and stored on a data file on computer in the format required for use with the statistical programme SPSSPC+.

Descriptive statistics (means and standard deviations) will be computed and appropriate statistical tests will compare groups to determine if differences exist between the age groups and autistic, Downs Syndrome and normal groups on stress. Regression analysis will help to indicate the contribution of social support variables to stress.

The results of this study will be discussed in relation to previous research findings and for their contribution to the existing literature. The practical and research implications will be discussed.

Practical Implications

The implications of this study are numerous and of tremendous clinical relevance. By identifying specific daily parenting tasks perceived by mothers as stressful may help us understand more fully how parents of autistic children in comparison with parents of Downs Syndrome children and children of normal development are affected on a daily basis . Identifying alterations in stress levels and in types of stress will have implications for developing special provisions to help parents manage the problems they face in parenting. Being aware of the potential problems faced by parents when their child is of a certain age can aid preventative planning.

*Timescale

Data collection will take place from January 1996 until April 1996.

* Completion of Data Collection was extended to December 1997 following a break in collection of data, due to personal circumstances of the author. Data analysis was planned to be carried out from January 1998 to May 1998

Ethical Approval

It is necessary to gain ethical approval from the National Autistic. A proposal has been sent to be considered at their next meeting. At present the Downs Syndrome Association are considering whether or not ethical approval needs to be granted prior to recruiting their mothers.

References

Aarons, M. and Gittens, T. (1994). The Handbook of Autism. Routledge. London.

Abidin, R. (1990) Parenting Stress Index - Short Form. Test Manual. University of Washington.

Belsky, J. (1984). The Determinants of Parenting: A Process Model. Child Development, 55, 83-96.

Caspi, A., Bolger, N. and Eckenrode, J. (1987). Linking Person and Context in the Daily Stress Process. *Journal of Personality and Social Psychology*, 52, 1, 184-195.

Crnic, K.A., and Greenberg, M.T. (1990). Minor Parenting stresses with young children. Child Development, 61, 1628-1637.

Fisman, S.N., Wolf, L.C., (1991). The handicapped child : Psychological effects of parental, marital, and sibling relationships. *Psychiatric Clinics of North America*, 14, 1, 199-217.

Haefele, W.F., and Heriggeler, S.W. (1983). Autism : a family-ecological systems perspective.

Meeting Their Needs : *Provisions of Services to the Severely Emotionally Disturbed and Autistic Conference proceedings*, 62-75, Memphis.

Lazarus, R.S., and Folkman, S. (1984). Stress, Appraisal and Coping, New York, Springer.

Lazarus, R.S., DeLongis, A, Folkman, S., and Gruen, R. (1985). Stress and adaptational outcomes: The problem of confounded measures. American Psychologist, 40, 770-779.

McGuire, and Richman, (1988). Preschool Behaviour Checklist.

Norton, P., and Drew, C. (1994). Autism and Potential Family Stressors. *The American Journal of Family Therapy*, 22, 1, 67-76.

Rodrigue, J.R., Morgan, S.B, and Geffken,G. (1990). Families of autistic children: Psychological functioning of mothers. Special Issue: The stresses of parenting. Journal of Clinical Child Psychology.

Sparrow, S.S., Bella, D.A., and Cicchetti, D.V. (1984). The Vineland Adaptive Behavioural Scales : Interview Edition Survey Form. American Guidance Service, Circle Pines, Minnesota.

CHAPTER 3

Major Research Project Paper

(written for submission to the Journal of Child Psychology and Psychiatry – appendix 1.1 for notes for Contributors).

Stresses in Parenting Autistic Children : The Daily Hassles Approach to Conceptualising Stress

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Stress in Parenting Autistic Children: The Daily Hassles approach to conceptualising stress

Summary

The study investigated stress associated with the normal everyday demands of parenting (parenting daily hassles, pdh) in mothers of pre-school and school aged autistic children. Comparisons were made between age groups and mothers of Downs Syndrome children and mothers of normally developing children. Consistent with previous research findings and as predicted, results indicated a trend for greater general stress in parenting autistic children. However, overall, pdh were less stressful in the autistic group than in the Downs Syndrome group, and of similar stress to normal development. Specific pdh were found to differentiate between disability groups on stress and frequency of the pdh. Hassles found to be less stressful for the autistic group were those in more practical areas of parenting. This maybe explained by the finding that these mothers reported greater satisfaction with practical support than mothers of Downs Syndrome children. However, practical support may not be enough to buffer against the stress of pdh related to the social difficulties of the autistic child. This was found to be a particular source of stress in parenting autistic children. Surprisingly, emotional support was not found to contribute to stress in this study. Age of the child offered little explanation for stress differences between the groups. Generally, across the groups, greater stress was reported by mothers of older children. Research and practical implications are discussed.

Key Words

Stress associated with everyday demands of parenting

Parenting Daily Hassles

Practical Support

Emotional Support

Age

Children

Autism

Stress in Parenting Autistic Children: The Daily Hassles approach to conceptualising stress

Introduction

The importance of studying stress in parents of autistic children is highlighted in previous research findings suggesting (1) increased levels of stress in parents of autistic children relative to other disabilities and to normal development (Bouma and Schweitzer, 1990, Fisman and Wolf; , 1989; 1991; Dumas et al, 1991; Moes, 1992, Rodrigue et al, 1990), (2) stress in parenting contributes to psychological wellbeing (Holroyd and McArthur, 1976; Fisman and Wolf, 1991) and (3) an association between psychological wellbeing, effective parenting and optimal child development (Cox, 1988; Belsky, 1984; Abidin, 1990).

Identifying sources of stress in autism is important in developing interventions to reduce stress and the risk of secondary damage in the autistic child. Sources of stress in autism have been reviewed elsewhere (Haldane, 1998). In summary, elevated levels of stress in autism have been attributed to the unique social and behavioural features of autism, parent and child characteristics, family variables and social support (Fisman and Wolf, 1991; Gill and Harris, 1991; Rodrigue et al, 1992; Norton and Drew, 1994).

However, an area of potential stress in parenting autistic children that seems largely neglected in the literature is the normal everyday demands of parenting, referred to by Crnic and Greenberg (1990) as 'parenting daily hassles'. Examples include, mealtime and bedtime difficulties, difficulties with friends and managing the child's behaviour in public and have been identified as sources of stress in normal development (Crnic and Greenberg, 1990). It is likely that child characteristics and features of autism, in particular, make parenting daily hassles more challenging for parents of autistic children (Aarrons and Gittens, 1994; Norton and Drew, 1994).

The dearth of research in this area in the field of autism is perhaps largely attributed to the daily hassles approach to conceptualising stress being a relatively new concept. Stress is conceptualised as a product of stressful daily events (or daily hassles) and the individuals cognitive appraisal of the personal significance of these events (Chamberlain et al, 1990; Lazarus and colleagues, 1985; 1984).

There is some evidence to suggest parenting daily hassles are sources of stress in autism (Haefele and Herrigeler, 1983; Rodrigue et al, 1990, 1992; Factor et al, 1990, Norton and Drew, 1994; Konstantareas and Homatidis, 1989; Aarrons and Gittens, 1994). However, despite these findings and the validity of parenting daily hassles as an independent measure of stress (Caspi et al, 1989; Chamberlain et al, 1990; Crnic and Greenberg, 1990; Lazarus et al, 1984; 1985) , to date, there appears to be no systematic study investigating the stress associated with parenting daily hassles in parents of autistic children relative to normal development and other disabilities.

The primary aim of this study was to investigate stress in parenting daily hassles for mothers of autistic children. Mothers were selected in view of a general trend for greater stress in mothers than in fathers and a tendency for them to assume more responsibility for the daily tasks of child-rearing (Reddon,et al 1992, Rodrigue et al,1990, Milgram and Atzil, 1988; Gray and Holden, 1992). In addition, an associated aim was to identify specific parenting daily hassles differentiating mothers of autistic children from mothers of Downs Syndrome and normal children. Downs Syndrome was selected as a good control for disability as it is a recognised disability.

Given the conflicting results of the few studies available on the effects of the child's age on stress (Haldane, 1998), further research appears warranted in this area. In this study the issue of parenting stress as a function of the child's age was addressed. The role of support in stress was also investigated in light of previous findings suggesting beneficial effects of social support (Cohen and Willis, 1985; Ganster and Victor, 1987; Reddon et al, 1992; Gill and Harris, 1991).

The following hypotheses were explored, based upon previous findings and theoretical considerations discussed above.

Hypothesis 1:

Mothers of children with a disability (Autistic or Downs Syndrome) were expected to report greater stress than mothers of normal children, with the autistic group reporting most stress. In addition, it was

predicted that mothers of older children with a disability would report greater stress than mothers of younger children and all would report greater stress than mothers of normal children.

Hypothesis 2:

7 items of the PDH in particular (items 5, 14, 15, 16, 18, 19, and 20) were expected to differentiate between groups of mothers in terms of frequency of the event and stress in relation to the event..

Hypothesis 3:

Mothers who report greater perceived satisfaction with emotional and practical support were expected to report less stress in parenting, irrespective of type of disability (autistic or Downs Syndrome) or normal development and age of the child.

Method

Sample

Three groups of mothers participated in this research; one of mothers of autistic children (A group), one of mothers of Downs Syndrome children (DS group) and one of mothers of normally developing children (N group). Each group comprised 10mothers of pre-school aged children (3-5 years) and 10 mothers of school-aged children (6-8 years).

Sample size was reduced from that proposed due to difficulties in recruiting mothers in A and DS groups. The smaller number of mothers in these groups perhaps indicates the high levels of stress these mothers are experiencing. As the N group was interviewed while recruitment of the other groups was underway, forty mothers were interviewed as proposed. To achieve equal sized groups for analyses, 10 mothers of pre-school children and 10 of school aged children were randomly selected from those interviewed.

Diagnosis of autism was made previously by clinicians not affiliated with this study. Mothers in the A group were recruited through local branches of the National Autistic Society, from whom ethical

permission was granted. The DS group was from the local Downs Syndrome Association. Children were diagnosed with Downs Syndrome at birth. The N group was from local mainstream schools and nurseries.

Design

Given individual differences in families, in order to maximise experimental control groups were matched as closely as possible on sex of child, age of mother, number of siblings. None of the mothers had a psychiatric history or were currently receiving psychological treatment, the majority had no medical problems, had no further education, were married or living with the child's father, and reported no recent major life events.

In order to reduce the risk of differences between A and DS groups being accounted for by different levels of ability, groups were matched, as closely as possible given the small sample size, and the different nature of disabilities, on the basis of language and more general ability. The developmental and personal history of the children included in the disability groups and their raw scores on the Daily Living Skills (DLSD) and Communication Domains (CD) of the Vineland Adaptive Behaviour Scale (VABS), suggested the children included were likely to have moderate to severe learning disabilities. For inclusion in the disability groups the child had a history indicating delayed language acquisition and continuing speech difficulties with the child predominantly using only single words. All of the children included had raw scores on the VABS within the ranges of 0-1 for Domestic and Community skills, 0-24 for personal skills (as measured on the DLSD), and 0 for written skills, 0-6 for expressive and 0-12 for receptive skills (as measured on the CD).

Children in the normal group were considered by their mothers and teachers to be of average ability. They were not matched with the other groups on language and general ability in order to provide a framework of normal development from which to compare the A and DS groups.

Procedures

Mothers took part in a brief semi-structured interview (approx. 15 minutes) to gather information for matching groups. A brief interview schedule was devised (appendix 1.2.3) to gather demographic information, information on the child's ability, and other relevant parent, child and family characteristics

to facilitate the matching of groups as described above. Also for matching purposes additional information gathered in this interview was recorded on The Vineland Adaptive Behaviour Scales (Sparrow et al, 1984) by the author. Following this the remainder of the interview was structured for measure completion (a further 15 minutes approximately).

A handout was then given describing the study (appendix 1.2.4). A group session run by the author and a Consultant Clinical Psychologist was planned to deal with stress resulting from this research, however all mothers declined the offer.

Measures

1. Measures of Stress associated with Parenting

(a) Parenting Stress Index – short form (PSI/SF) – Appendix 1.2.7

The PSI/SF (Abidin, 1990), is a 36 item questionnaire used as a general measure of stress mothers perceive. Only the total stress score was used in analysis (Cut off raw score for clinically significant levels of stress = 90+). Raw scores on the sub-scales (parental distress, child behaviour and parent-child interaction) for 80 data sets are available from the author.

(b) Parenting Daily Hassles (PDH) – Appendix 1.2.6

The PDH (Crnic and Greenberg, 1990) is a 20item questionnaire, measuring stress perceived in relation to daily events of parenting. Perceived stress was measured on the intensity dimension of the PDH which required mothers to report the hassle they experienced by the event in each item (Intensity Dimension, (PDI), score range = 20 to 100, higher scores indicate greater stress).

The PDH also provided a measure of perceived frequency of the event (PDF), to be used in analysis (frequency score range = 0 to 80).

2. Measure of Mother's Perceived Support

Social Support Questionnaire (SSQ) - Appendix 1.2.5

The SSQ, designed by the author, consists of 12 items designed to measure the respondent's perceptions of the support they receive. It consists of 2 dimensions – practical support and emotional support. Each

dimension has 6 items. The construction of the questionnaire was guided by findings of social support literature (Cohen and Willis, 1985; Ganster and Victor, 1987) and studies incorporating support measures in autism (Reddon et al, 1992; Gill and Harris, 1991).

Pilot work: Pilot work was undertaken to enhance the validity of the SSQ. Parents known to the author and colleagues were asked to classify the 12 items to be included in terms of their function (either under practical or emotional support). There was 100% respondent agreement. All respondents in the pilot work agreed the SSQ was comprehensive and easy to complete.

Coding of SSQ: For the purposes of analyses only perceived satisfaction with support was coded. For each item of the SSQ mothers were asked to state if they were satisfied with the support they received as stated in the item. 2 dimension scores – satisfaction with emotional support (SES) and satisfaction with practical support (SPS) were obtained.. For each item on which satisfaction was reported the item was scored 1. Dimension scores were obtained by summing the scores across items in the dimension. The range of scores for each dimension was 0-6 with higher scores indicating greater satisfaction with support received, as measured on that dimension. The SSQ therefore provided a measure of perceived satisfaction with emotional and practical support in this research.

3. Measure of Child's behaviour

Pre-school Behaviour Checklist (PBCL)

The PBCL (McGuire and Richman, 1988) is a checklist of children's behaviour. However it was not used for matching groups or in the analyses, as proposed. It had been intended for teachers to complete this measure, as well as mothers, to help validate mothers perceptions of the child's behaviour. However, following a poor response rate from teachers in the DS group (15% returned completed forms) teachers in the A group were not contacted. The response rate in the N group was 100%.

Results

Preliminary Analysis and Rationale for Analysis

Data were screened for accuracy of data entry. Histograms and normal probability plots (pplots) on the measures (appendix 1.3) indicated no extreme cases which may influence or distort results.

Examination of the data permitted parametric analysis. The data on the PSI/SF, PDH, and SPS dimension of the SSQ seemed to be reasonably normally distributed as indicated by, similar means and medians, the majority of Kurtosis and Skewness values around zero, and indicated graphically by no major deviations of scores from the diagonal on pplots and from histograms indicating the majority of scores to be central in the distribution (appendix 1.3). Formal tests for equal variance were not performed on the data as they are considered too strict. Instead analysis proceeded on the assumption that variances were equal. Where it was felt assumptions for parametric analyses were close to being violated alpha levels were altered from 0.05 to 0.01 in order to reduce type 1 error.

Although the measures could perhaps be considered to be more ordinal scaling than interval by summing across items within the measure it was considered a more continuous variable was being produced for use in analysis, allowing parametric analysis to be performed.

The results are organised according to the hypotheses of the study. Where clear predictions were made one-tailed tests were applied.

Hypothesis 1: Effects of type of disability (group) and age of the child on perceived stress

Effects of type of disability: One way ANOVA to statistically compare the mean values for the A, DS and Ngroups, on both the PSI/SF and the PDI (intensity dimension of the PDH) were performed on the data (see table 1-1). ANOVA yielded significant effects of type of disability on both measures of stress.

Table 1-1 Anova : Effects of Type of Disability (A, DS, N) on Stress

Stress Measure	**A** *N=20*	**DS** *N=20*	**N** *N=20*	**F**	**P**	**Scheffe** ($p < 0.01$) *Groups*	*Mean difference*
PS1 Mean	105.4	100.3	72.9	18.2	P<0.001**	A from N	32.55*
SD	(8.0)	(26.4)	(15.7)			DS from N	27.40*
PD1 Mean	37.5	47.2	37.4	5.8	P < 0.01*	A from DS	-9.75*
SD	(5.3)	(15.7)	(7.5)			DS from N	9.8*

* significant results at $p < 0.01$ ** significant results at $p < 0.001$

PSI/SF: Mothers of normally developing children reported significantly lower stress on the PSI/SF than mothers of both Autistic children and Downs Syndrome children, as confirmed by post hoc testing. Although there was no significant difference indicated between A and DS groups mean values suggest a trend for greater stress in the A group.

Results indicate mothers of autistic and downs children both report clinically significant levels of stress in parenting (cut off score = 90).

PDI: Mothers of autistic children reported significantly less stress than the DS group and similar levels to the N group.

In sum, results on the PSI/SF allow us to accept the hypothesis that mothers of children with a disability (A or DS) report greater stress than mothers of normal children. A trend is indicated for greater stress in A group than in the DS group. However, on the PDI while mothers of DS children still report greater stress than the N group, mothers of autistic children report similar levels of stress to the normal group.

Effects of age of the child: To test if mothers of older children report more stress than mothers of younger children, t-tests were performed (see table 1-2 below for results).

Table 1-2 Independent T-tests : Effects of Age of Child on Stress

Stress Measure		Age group 3-5	Age group 6-8	t value	p
PS1 Autistic	Mean	100.3	110.5	3.67	P<0.001**
	SD	(7.6)	(4.4)		
Downs Syndrome	Mean	89.3	111.2	1.99	P < 0.05
	SD	(18.3)	(29.5)		
Normal	Mean	72.7	73.0	0.04	P > 0.05
	SD	(14.6)	(17.6)		
PD1 Autistic	Mean	35.0	39.9	2.27	P > 0.01
	SD	(5.6)	(4.0)		
Downs Syndrome	Mean	44.9	49.5	0.64	P < 0.05
	SD	(17.4)	(14.4)		
Normal	Mean	32.7	42.7	3.45	P < 0.01*
	SD	(6.0)	(5.8)		

*significant results at $p < 0.01$ ** significant results at $p < 0.001$

As predicted, mothers of older autistic children reported significantly greater stress than mothers of younger children on the PSI/SF. On the PDI the difference in stress was significant at p=0.02, however more conservative alpha levels of 0.01 had been set for this measure. Therefore the hypothesis of greater stress with older children for this measure on the basis of significance levels has to be rejected., However, mean values indicate a general trend of greater stress for mothers of older children.

The hypothesis has to be rejected in the DS group as differences between age groups on stress measure were not significant at 0.01. However mean values indicate a general trend for greater stress when the child is older.

Interestingly, mothers of normal children reported greater stress on the PDI as children got older. This was not evident on the PSI/SF where mean values were similar.

Effects of Interaction of type of disability and age of the child: A factorial 3 x 2 model was adopted to investigate if some of the variance in stress experienced by mothers can be attributed to the combined effects of age and disability. 2 way ANOVA performed on the data revealed no significant interaction effects of these variables on either the PSI/SF ($F=1.944$, $p<0.05$) or PDI ($F=0.34$, $p>0.05$).

Hypothesis 2: Specific daily events of parenting and stress

ANOVA on the data were restricted to the 7 questions of the PDH for which it had been predicted would differentiate the groups. The results are summarised in tables 2-1 and 2-2 below.

Table 2-1 Anova : Specific Daily Events of Parenting : Frequency and stress by group

PDH Item	Mean A	Mean DS	Mean N	f value	Significance	Scheffe ($p < 0.01$) Groups	Mean difference
Q. 5 : Baby-sitters are difficult to find							
Freq.	1.95	2.55	1.30	8.15	P < 0.001**	A from DS	1.25*
Stress	2.35	2.7	1.35	5.80	P < 0.01*	A from DS	1.35*
Q. 14 : The child gets dirty several times a day requiring changes of clothes							
Freq.	1.05	2.0	1.75	10.31	P < 0.001**	A from N A from DS	-0.70* -0.95*
Stress	1.05	2.15	1.65	12.09	P < 0.001**	A from DS	-1.10*
Q. 15 : Difficulties getting privacy (e.g. in the bathroom)							
Freq.	1.5	2.7	2.45	17.5	P < 0.001**	A from N A from DS	-1.40* -1.65*
Stress	1.0	2.55	2.35	16.76	P < 0.001**	A from N A from DS	-1.35* -1.55*
Q. 16 : The child is hard to manage in public (grocery store, shopping centre, restaurant)							
Freq.	1.5	2.7	1.55	3.98	P < 0.05	A from DS DS from N	-1.20* -1.15*
Stress	1.9	2.65	1.95	2.07	P > 0.05	NONE	
Q. 18 : Difficulties in leaving the child for a night out or at school or daycare							
Freq.	1.6	1.6	1.25	2.77	P > 0.05	NONE	
Stress	1.7	2.2	1.2	4.96	P < 0.01*	NONE	
Q. 19 : The child having difficulties with friends (e.g. fighting, trouble getting along, or no friends available)							
Freq.	3.6	1.75	1.35	105.14	P < 0.001**	A from DS A from N	1.85* 2.25*
Stress	4.15	2.1	1.8	29.2	P < 0.001**	A from DS A from N	2.05* 2.35*
Q. 20 : Having to run extra errands to meet the child's needs							
Freq.	1.8	2.15	1.5	5.63	P < 0.01*	DS from N	0.65*
Stress	1.2	2.2	1.2	15.39	P < 0.001**	A from DS A from DS	-1.00* 1.00*

*significant results at $p < 0.01$ ** significant results at $p < 0.001$

As seen from table 2-1 stress associated with 5 parenting events significantly differentiated A and DS groups. On 4 of the 5 questions (qus. 5, 14, 15, 20), mothers of DS children reported significantly greater stress in comparison to mothers of autistic children. On all 4 of these questions the DS group also

reported significantly higher frequency of the event than the A group. In addition greater frequency was also reported by the DS group on question 16.

On only 1 of the 7 questions the autistic group reported significantly greater stress than the DS group (question 19). Significantly higher frequency of the event was also reported by the A group.

There were no questions where the N group differed significantly from both mothers of autistic and Downs Syndrome children.

Table 2-2 below summarises the results of t- tests on the data for age differences.

Table 2-2 T-tests : Specific Daily Events of Parenting : Frequency and stress by age

Frequency : Means						Intensity : Means					
PDH Item	Grp	age 3-5	age 6-8	t	p	PDH Item	Grp	age 3-5	Age 6-8	t	p
	A	1.2	1.4	0.76	P > 0.05	Q. 5I	A	1.1	1.6	2.1	P < 0.05
Q. 5F	DS	2.0	3.1	2.01	P > 0.05		DS	2.6	2.8	0.3	P > 0.05
	N	1.9	2.0	0.22	P > 0.05		N	2.2	2.5	0.45	P > 0.05
	A	1.0	1.1	1.0	P > 0.05	Q. 14I	A	1.0	1.1	1.0	P > 0.05
Q. 14F	DS	1.4	2.6	3.18	P < 0.01*		DS	1.5	2.8	3.07	P < 0.01*
	N	1.7	1.8	0.28	P > 0.05		N	1.5	1.8	0.9	P > 0.05
	A	1.1	1.0	1.0	P > 0.05	Q. 15I	A	1.0	1.0	-	-
Q. 15F	DS	2.5	2.9	0.78	P > 0.05		DS	2.7	2.4	0.55	P > 0.05
	N	2.3	2.6	0.58	P > 0.05		N	2.1	2.6	1.0	P > 0.05
	A	1.5	1.5	-	-	Q. 16I	A	1.7	2.1	0.71	P > 0.05
Q. 16F	DS	2.2	3.2	2.61	P < 0.05		DS	2.8	2.5	0.45	P > 0.05
	N	1.6	1.5	0.36	P > 0.05		N	1.6	2.3	1.30	P > 0.05
	A	1.3	1.9	2.55	P < 0.05	Q. 18I	A	1.2	2.2	2.84	P < 0.01*
Q. 18F	DS	1.2	2.0	2.75	P < 0.01*		DS	1.8	2.6	1.23	P > 0.05
	N	1.1	1.4	1.57	P > 0.05		N	1.2	1.2	0	P > 0.05
	A	3.3	3.9	3.29	P<0.001**	Q. 19I	A	4.1	4.2	0.29	P > 0.05
Q. 19F	DS	1.3	2.2	3.08	P > 0.01*		DS	1.8	2.4	1.21	P > 0.05
	N	1.2	1.5	1.41	P > 0.05		N	1.2	2.4	2.15	P < 0.05
	A	1.9	1.7	0.85	P > 0.05	Q. 20I	A	1.0	1.4	2.45	P < 0.05
Q. 20F	DS	1.6	2.7	3.58	P < 0.01*		DS	1.8	2.6	1.9	P > 0.05
	N	1.4	1.6	0.73	P > 0.05		N	1.1	1.3	0.85	P > 0.05

* significant results at $p < 0.01$ ** significant results at $p < 0.001$

Mothers of older children in the DS group were generally found to report greater frequency of events than mothers of younger children (significant results on questions 14, 18, 19, 20, table 2-2). Interestingly, although frequency of events increased as the child got older stress reported only increased significantly

on one item (question 14) with increasing age of the child. There was less effect of age of the child in the A group, where significant results were found on items 18 stress and 19 frequency only(table2-2).

There were no significant age effects within the normal group on either frequency or stress.

There were no significant combined effects of age of the child and group on any of the variables.

Hypothesis 3: The role of support mechanisms in stress

A regression model of analysis was adopted to investigate the role of SPS and SES in stress (table 3).

Table 3 Results of Multiple Regression Analysis : Contribution of SPS and SES to stress on the PD1

Overall Equation	**R^2=0.225** Adjusted **R^2=0.198**		**F=8.285** P=0.0007
Variables Entered	**Beta**	**t**	**significance of t**
SPS	-0.383	-3.286	0.0017
Age	0.276	2.371	0.0211
Group	0.105	0.872	0.387
SES	-0.142	-0.962	0.340

From table 3 it can be seen that the overall equation was significant with an adjusted R^2 value of 0.198. This indicates there was some predictive power in the equation. The stepwise model indicated SPS and age were significant variables with Beta Weightings of -0.383 and 0.276 respectively. For SPS the Beta Weighting was inversely significant (Beta = -0.383, significance level = 0.0017) as predicted, indicating less satisfaction with practical support was associated with greater stress on the PDI. Beta Weightings for group and SES were not of sufficient magnitude for these variables to be included in the equation. The result for SES was surprising and contradictory to predictions.

A comparison of descriptive statistics and histograms of the distributions of the data on SES and SPS suggested differences in the distributions with SES negatively skewed. The majority of scores on SES being 6. The data for SES was re-coded into 2 groups (group 1 included scores from 0 to 5 and group 2 included scores of 6) to improve the distribution of the data. The regression analysis was performed on this new variable (SESGRP). However, it still was not found to contribute significantly to stress.

Although group was not found to contribute significantly, an ANOVA of group (A, DS, N) on SPS indicated the mothers of autistic children reported greater satisfaction with practical support than mothers in the DS group where greater stress was reported ($F=6.77$, $p<.01$).

Discussion

Consistent with previous research findings, mothers of children with a disability experienced greater stress in parenting relative to normal development. A general trend for greater stress in mothers of autistic children was indicated, supporting previous findings. However, interestingly this pattern of stress was only found in relation to more general parenting stress and not in relation to the more specific everyday parenting events. Overall, parenting daily hassles were less stressful for mothers of autistic children than for mothers of downs children and of similar stress to mothers of normal children.

The results suggest parenting daily hassles are likely to be most stressful for mothers who report lower perceived satisfaction with practical support. This may help explain the difference in stress in relation to parenting daily hassles between the disability groups as mothers of autistic children report greater satisfaction with support than mothers of Downs Syndrome children. This is perhaps reflected in the nature of specific hassles less stressful for mothers of autistic children. These were in more practical areas of parenting including, finding babysitters, running extra errands to meet the child's needs and getting privacy.

The nature of these less stressful hassles suggests that practical support may function to reduce stress by others providing direct support, relieving some of the burden of parenting (Willis, 1985). However, given that this study did not measure actual support received it may be that mothers who perceive practical support to be available should they need it are more likely to experience less stress. Further research is needed to clarify how practical support functions to reduce stress in parenting daily hassles. The findings of an inverse relationship between practical support and stress in this study are consistent with previous research.

In view of previous findings suggesting beneficial effects of emotional support on stress it was surprising that satisfaction with emotional support was not found to make a significant contribution to stress in this study. It seems most likely that this finding is an indication of the difficulty in assessing emotional support. While mothers reported a range of scores on practical support, very little range was found on emotional support, perhaps suggesting a greater reluctance to admit they were not satisfied with emotional support than with practical support. This raises important methodological considerations for future research aiming to clarify the role of emotional support in stress. Social support measures used in future studies should aim to address this issue, perhaps by including a measure of social desirability.

There remains, however, the possibility that practical and emotional support do have different relationships with stress, at least stress associated with parenting daily hassles. Such a finding highlights the need to assess social support from a multidimensional perspective.

The findings suggest that satisfaction with practical support is perhaps not enough to buffer against the stress of parenting daily hassles related to the social difficulties of the autistic child. This was found to be a particular source of stress in parenting autistic children, where perhaps more support is needed. Higher frequency and greater stress for mothers of autistic children in relation to the child having difficulties with friends were found in this study. This suggests that the social features of autism make particular parenting daily hassles more stressful for mothers of autistic children than for mothers of other children. This is consistent with the theory that the unique characteristics of autism make parenting more stressful.

This is perhaps an area of parenting where emotional support would be most beneficial. However, this remains speculative as the association between different kinds of social support and particular parenting daily hassles was not addressed in this study and remains an area in need of research.

Mothers of older children appear to be more at risk of experiencing stress from parenting daily hassles than mothers of younger children, at least within the age range 3 to 8 years. A general trend across groups indicates greater stress for mothers of older children. While across groups age of the child may explain some of the stress difference on the PDH age does not appear to offer much explanation for stress

differences between autistic, Downs Syndrome and normal groups. Furthermore, within these groups there was little effect of age on the particular parenting daily hassles selected for comparisons in this study. In the older autistic and Downs Syndrome groups where greater frequency of hassles were reported in comparison to the younger groups this was generally not accompanied by greater stress in relation to the particular event of parenting. This perhaps suggests that mothers of older children in this study had developed more adaptive coping strategies to deal with the challenges of parenting.
Clearly, there is a need for longitudinal research to trace the progression of stress associated with parenting daily hassles and the relation to the coping strategies of parents.

Specifically in relation to mothers of autistic children the child having difficulties with friends appears to be greater in older children. This is consistent with the theory that in middle childhood the social difficulties of the autistic child become more apparent (Haldane, 1998). However, greater stress in relation to this difficulty was not evident in mothers of older children compared to mothers of younger autistic children. There was perhaps no additional stress in the older group because mothers of older children perhaps understand and recognise the extent of their autistic child's problems while mothers of younger children are still struggling with the diagnosis and understanding the social limitations of autism.

The issue of age of the child and stress in parenting daily hassles remains unclear. There is a need to investigate this further and identify the specific tasks of parenting which generate greater stress in parents of autistic children with increasing age of the child. This is important in designing interventions to prevent stress in parents as the child gets older.

Overall, the foregoing findings have important practical implications for designing interventions to reduce stress in parenting autistic children and in aiding preventative planning. There is a high level of stress in mothers of autistic children therefore interventions must aim to reduce the stress experienced by mothers as well as focusing on the autistic child's development. To help prevent further increases in stress clinicians on diagnosis of autism should aim to fully assess the practical support parents have both in terms of their perceptions of the support and the actual support received. This may lead to referral to appropriate professions to acquire support or perhaps interventions to change cognitions in relation to the

support they do receive. Parents should be educated about the features of autism and guided in management of everyday tasks of parenting before they become a source of great stress.

However, certain methodological considerations must be taken into account in interpreting and generalising the results of this study. The sample size of this study was small, the age range was limited, participants were volunteers, difficulties arose in measuring emotional support and there was a possible difficulty that mothers ratings of the child's level of functioning employed in matching groups, may not be independent of mother's stress.

Nevertheless, this study adds to the available literature by extending the daily hassles conceptualisation of stress in parenting into the field of autism using a systematically controlled study. Furthermore, the study has produced some interesting and valuable results that have important practical implications for planning interventions to reduce stress in parents of autistic children. Additionally, the results of the study provide direction for further research investigating stress associated with parenting daily hassles for mothers of autistic children.

References

Aarons, M. and Gittens, T. (1994). The Handbook of Autism. Routledge. London.

Abidin, R. (1990) Parenting Stress Index - Short Form. Test Manual. University of Washington.

Belsky, J. (1984). The Determinants of Parenting: A Process Model. Child Development, 55, 83-96.

Bouma, R., and Schweitzer, R. (1990). The impact of chronic childhood illness on family stress : A comparison between autism and cystic fibrosis. *Journal of Clinical Psychology*, 46, 6, 722-730.

Caspi, A., Bolger, N. and Eckenrode, J. (1987). Linking Person and Context in the Daily Stress Process. *Journal of Personality and Social Psychology*, 52, 1, 184-195.

Chamberlain, K., and Zika, S. (1990). The minor events Approach to Stress : Support for the use of daily hassles. *British Journal of Psychology*, 81, 469-481.

Cohen, S., and Wills, T.A. (1985). Stress, Social Support, and the Buffering Hypothesis. Psychological Bulletin, 98, (2), 310-357.

Cox, A.D. (1988) Maternal Depression and impact on children's development. Archives of Disease in Childhood, 63, 90-95.

Crnic, K.A., and Greenberg, M.T. (1990). Minor Parenting stresses with young children. Child Development, 61, 1628-1637.

Dumas,, J.E., Wolf, L.C., Fisman, S.N., and Culligan, A. (1991). Exceptionality, 2, (2), 97-110.

Factor, D.C., Perry, A., and Freeman, N. (1990). Brief report: Stress, Social support and respite care use in families with autistic children. Journal of Autism and Developmental Disorders, 20, (1), 139-146.

Fisman, S.N., Wolf, L.C., (1991). The handicapped child : Psychological effects of parental, marital, and sibling relationships. *Psychiatric Clinics of North America*, 14, 1, 199-217.

Fisman, S.N., Wolf, L.C., and Noh, S. (1989). Marital Intimacy in parents of exceptional children. Canadian Journal of Psychiatry, 34, 6, 519-525.

Ganster, D.C. and Victor, B. (1988). The impact of social support on mental and physical health. *British Journal of Medical Psychology*, 61, 17-36.

Gill, M.J., and Harris, S.L. (1991). Hardness and social support as predictors of psychological discomfort in mothers of children with autism. *Journal of Autism and Developmental Disorders*, 21, 4, 407-416.

Gray, D.E., and Holden, W.J. (1992). Psycho-social well-being among the parents of children with autism. Australia and New Zealand Journal of Developmental Disabilities, 18, 2, 83-93.

Haefele, W.F., and Heriggeler, S.W. (1983). Autism : a family-ecological systems perspective. Meeting Their Needs : *Provisions of Services to the Severely Emotionally Disturbed and Autistic Conference proceedings*, 62-75, Memphis.

Haldane, E. (1988). Stresses in Parenting Autistic Children. Unpublished research portfolio, 1.

Holroyd,J., and McArthur,D. (1976). Mental retardation and stress on the parents: a contrast between Downs Syndrome and childhood autism. American Journal of Mental Deficiency, 80, 431-436.

Konstantareas, M.M. and Homatidis, S. (1989). Assessing Child Symptom Severity and Stress in parents of Autistic Children. Journal of Child Psychology and Psychiatry, 30, (3), 459-470.

Lazarus, R.S., and Folkman, S. (1984). Stress, Appraisal and Coping, New York, Springer.

Lazarus, R.S., DeLongis, A, Folkman, S., and Gruen, R. (1985). Stress and adaptational outcomes: The problem of confounded measures. American Psychologist, 40, 770-779.

McGuire, and Richman, (1988). Preschool Behaviour Checklist.

Milgram, N.A., and Atzil, M. (1988). Parenting stress in raising autistic children. Journal of Autism and Developmental Disorders, 18, 3, 415-424

Moes, D., Koegel, R.L., Shreibman, L., and Loos, L.M. (1992). Stress profiles for mothers and fathers of children with autism. *Psychological Reports*, 71, 3, 1272-1274.

Norton, P., and Drew, C. (1994). Autism and Potential Family Stressors. *The American Journal of Family Therapy*, 22, 1, 67-76.

Reddon, J.E., McDonald, L. and Kysela, G.M. (1992). Parental Coping and Family Stress 1 : Resources for and functioning of families with a pre-school child having a developmental Disability. *Early Child Development and Care*, 83, 1-26.

Rodrigue, J.R., Morgan, S.B, and Geffken,G. (1990). Families of autistic children: Psychological functioning of mothers. Special Issue: The stresses of parenting. Journal of Clinical Child Psychology.

Rodrigue, J.R., Morgan, S.B., and Geffken,G.R. (1992). Psychosocial adaptation of fathers of children with autism, Downs Syndrome, and normal development. *Journal of Autism and Developmental Disorders*, 22, 2, 249-263.

Sparrow, S.S., Bella, D.A., and Cicchetti, D.V. (1984). The Vineland Adaptive Behavioural Scales : Interview Edition Survey Form. American Guidance Service, Circle Pines, Minnesota.

Willis, T.A. (1985), Supportive Functions of Interpersonal relationships. In S. Cohen and S.L. Syme (Eds). *Social Support and Health*, 61-82, New York : Academic Press.

CHAPTER 4

Small Scale Service Evaluation Project

(written for submission to the Clinical Psychology Forum - appendix 2.1 for notes for Contributors).

Evaluating a Clinical Child Psychological Service : Parent Satisfaction and Expectations

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Evaluating a Clinical Child Psychological Service : Parent Satisfaction and Expectations

Summary

The study evaluated a Glasgow based clinical child psychology department through parent expectations and satisfaction with their first visit. The study was designed taking into account a number of problems identified in other satisfaction studies. A questionnaire was designed for the purposes of the study. It was found that parents were generally satisfied. Areas that a number of parents were not satisfied with included receiving an explanation, feeling their problems had been understood and the visit being helpful. Many parents felt their expectations for their visit were not met and the psychologist was not as expected. There was some evidence for an association between expectations and satisfaction, although this conclusion is tentative given the limitations of the study. Recommendations were made based on the findings.

Key Words

Parent expectations and satisfaction

Evaluation of child service

Evaluating a Clinical Child Psychological Service : Parent Satisfaction and Expectations

Introduction

As new clinical psychology services for children evolve within the framework of the Trust system there is an even greater emphasis on increasing service quantity, while maintaining or improving service quality and meeting the standards set by the Trust. There has been gradual recognition of the importance for providers of child services to routinely evaluate their service. The need for services to obtain the opinion of the patient as a means of evaluation is emphasised in Government documents (e.g., The Griffiths Report, Griffiths, 1983; the Health of the Nation ,DoH, 1993 document). Recent service related studies have supported this (e.g., Kerruish et al, 1988; Donabedian, 1988; Carr et al, 1994). In child psychology services the child is the patient. However, it is important to obtain feedback from the parents (e.g., Lobb et al, 1987) who will make the decision to bring the child for further appointments.

In view of the valuable feedback mental health users can provide on the service they receive (Spencer 1995) obtaining feedback from users is important. This helps identify ways of improving the service to more adequately meet the clients needs. However given that there is a relatively small number of clinical child psychologists it may not be possible to implement all changes suggested.

Despite the limited number of psychologists, demand for clinical child psychology services are high. There is therefore a need to make the best use of the resources available to meet this high demand. One possible way to achieve this would be through decreasing the likelihood of non-attendance and non-compliance with therapy. If people attend for appointments and comply with therapy then this should lead to treatment being more effective and more short term. This would help reduce waiting lists by more adequately meeting the demand as psychologists would have more time to see a greater number of people.

One way of increasing the likelihood of compliance and attending future appointments would seem to be through ensuring users of the service are satisfied with the service they are receiving. This is supported by research findings indicating an association between user satisfaction and increased likelihood of

compliance and of attending future appointments (Fitzpatrick, 1991). This suggests iis important to assess the factors of the service with which users are and are not satisfied. This would allow changes t to be taken on board by the provider of the service, with the aim of improving satisfaction.

Research identifies a number of variables that may affect satisfaction with a service being received. For the purposes of this paper the focus is on the results of several recent studies suggest patient satisfaction may be determined in part by expectations (e.g., Spector, 1988; Webster, 1982). The results of such studies suggest that some patients may have inaccurate expectations of therapy. In view of research findings suggesting an association between inaccurate expectations and early termination (Hughes, 1995) it is important to investigate if the patients expectations are inaccurate. One method of looking at this is to investigate if the service is meeting with the users' expectations. If it is not, there is the potential danger of people dropping out of therapy as they are not receiving what they are expecting to receive and are not satisfied.

Previous studies incorporating patient expectations suggest patients' expectations may not be met by the service in a number of areas. For example, discrepancies in what a patient expected the psychologist to do and what actually happened in sessions have been found (e.g. Heine et al , 1960, Hughes, 1995). Discrepancies between the patient and therapist in the duration of therapy have also been found (e.g., Kupst et al, 1979). It may be that the patient is looking for a 'one-off' consultation session while the therapist assumes the patient wants several therapy sessions (Hughes, 1995). Some people are perhaps passive and want specific advice or medication (e.g. Heine et al, 1960) rather than taking an active role in therapy. Some may expect quick solutions to their problems (e.g. Kupst et al, 1979) when in reality it may take many months.

A commitment of professionals is to find ways to improve their service. Routine service evaluation should help them to achieve this. It seems that an important element in the overall evaluation of the service should be evaluating user satisfaction and variables perhaps affecting satisfaction, for example, whether or not the service meets with patient expectations. Evaluating parent satisfaction and expectations was the focus of the present study that aimed to evaluate the existing quality of service by a Glasgow based clinical child psychology service.

Research Questions

The specific study questions were

1. What was satisfying for parents on their first visit to the psychology clinic and what was not satisfying?
2. Were parents' expectations and aspirations met or not met in their first visit?
3. Is there a relation or not between parent satisfaction and expectations and aspirations?

Method

Methodological Issues

Careful consideration was given to the design of this study in view of the number of methodological problems evident from existing service related studies. For example had a postal survey been used there was the potential danger of few people returning the survey. Generally low return rates of 30 to 40% have been found for postal surveys (e.g.Lebow et al, 1982; Cookson et al, 1995). There was also the need design the study in a way which would limit the influence of social desirability and acquiescence on patients' responses (for example, Stallard and Chadwick, 1991). The timing of completion of the questionnaire was decided based on the research questions. As the study is asking about satisfaction with first visits to a clinic it was most appropriate to ask parents to complete it at the end of their first visit and not three to twelve months after discharge as in a study by Skaife and Spall (1995). Satisfaction with first visits in this study may have been confounded by memory and perceived outcome of therapy.

Sample

Parents of children attending for the first time at the psychology clinics of a number of pshologists in the department were asked to participate in this study. Where both parents attended with the child the parent most likely to bring the child for further appointments was asked to participate. In total 3030 parents took

part over a six week period. This included parents of children attending community based psychologists and parents of children attending hospital based psychologists.

Measure: Parent Satisfaction and Expectation Questionnaire (PSEQ) - (appendix 2.2)

Structure of the PSEQ

The *PSEQ* was developed for the purposes of this study as there was found to be no existing appropriate measure. The *PSEQ* is a questionnaire designed to be completed by parents of children attending psychology for the first time to assess satisfaction and expectations. It is divided into 2 sections. The first of these comprises 5 questions about parents satisfaction with their visit. The second section focuses on whether or not parents felt their expectations and aspirations had been met by the service. This section comprises 3 questions. The questionnaire involves parents indicating their satisfaction and whether or not their expectations were met by marking their response in one of five categories (no, not at all; no, not very much; not sure; yes, a little; yes, a lot) for each question. To obtain more information about expectations each of the three expectation questions was followed by an open ended question. For example, the expectation question 'Did the psychologist go about the job the way you expected?' was followed by the question 'If not, how was it different?'

Development of the PSEQ

The questions on the PSEQ were generated from discussions with staff members, research literature and clinical experience. Satisfaction questions included in the questionnaire were intended to reflect the approach adopted by psychologists in the department in the first interview. This approach involves the psychologists obtaining a full and comprehensive assessment of the presenting problems through obtaining the necessary information from the parents while at the same time being receptive to the parents concern. The psychologist should be encouraging parents to talk about their concerns rather then bombarding them with a series of questions. The aim is to make the parents feel they are being listened to and understood. Thus questions in the PSEQ focusing on measuring satisfaction with the first visit included 'Do you feel the psychologist listened to the problems?' and 'Do you feel the problems were understood?'. Expectation questions were based on previous research findings.

Staff members of the department and clinical psychologists in other departments were asked to comment on the questions. The questionnaire was piloted on a small group of parents. This was to help identify any

potential problems in understanding the questions and rating of responses. Parents reported finding the questionnaire understandable and easy to complete. It was well received and took approximately 5 minutes to complete.

Procedure

At the end of the first interview the parent most likely to bring the child for further appointments was asked by the psychologist they had seen to complete the PSEQ in private in the waiting area. They were asked to put the questionnaire in the envelope and hand it into reception before leaving. These instructions were also given at the top of the PSEQ. This method was to ensure the whole process was confidential and anonymous and to help control for social desirability and acquiescence. There was a better return rate than would have been expected from a postal survey with the majority of parents returning the completed questionnaire.

Scoring and analysis of the PSEQ

Each question on the PSEQ was considered separately. For the questions focusing on satisfaction if the categories 'yes a little' and 'yes a lot ' were marked this indicated satisfaction . For expectation questions this indicated the service had met their expectations. If the categories, 'no not at all' or 'no not very much' were marked on satisfaction questions this indicated dissatisfaction. For each question the number of people falling into each of the five categories for that question was totalled.

It was not possible to use the chi-square statistical test to investigate the association between satisfaction and expectations as numbers in the cells were too small, often being zero. Instead, the questionnaires were looked at individually to see if the parents who did not express satisfaction were the same parents who felt their expectations had not been met. Frequency scores were recorded.

Results

The results are presented in three sections in line with the research questions being asked.

(1) Satisfaction Issues

All parents expressed satisfaction to some degree with the service they had received, as measured by the PSEQ (see table 1).

Table 1: Frequency scores for parent satisfaction with their first visit to the psychology clinic (N=30)

	RESPONSE CATEGORIES				
	no not at all	**no not very much**	**not sure**	**yes a little**	**yes a lot**
1 : Was the psychologist pleasant?	0	0	0	1	29
2 : Do you feel the psychologist listened to the problem?	0	0	1	0	29
3 : Do you feel the problems were understood?	0	0	3	3	24
4 : Were you given an explanation for the problems?	1	1	4	10	14
5 : Did you find the visit helpful?	1	0	4	4	21

What was satisfying for parents on their first visit to the psychology clinic and what was not?

Eighteen out of 30 parents expressed satisfaction on all 5 questions. Twelve parents did not express satisfaction on at least one question.

Table 1 shows all parents reported the psychologist was pleasant and 29/30 reported the psychologist had listened to their problems. One was unsure. The main areas parents did not find satisfactory were in feeling their problems had been understood, feeling they had been given an explanation for their problems and finding their visit helpful.

Of the 5 parents who reported their visit was either unhelpful or expressed uncertainty about how helpful it had been 2 parents were also not satisfied they had received an explanation. One of them also felt unsure if their problems were understood. The other people who were not satisfied or uncertain expressed satisfaction on all the other satisfaction questions.

(2) Expectation Issues

There was a lot of uncertainty as to whether the visit had met parents expectations and aspirations (see table 2).

Were parents' expectations and aspirations met or not met in their first visit?

Fourteen of 30 parents expectations were not met on at least one of the areas indicated from the expectation questions. 16/30 parents felt their expectations had been met on all three areas indicated in the expectation questions.

Five of the 9 parents who were unsure if the session had achieved what they hoped reported their expectations were met on questions 6 and 8. Three reported their expectations were met on question 8 but were unsure if the psychologist was as they had expected. One parent reported the psychologist was not at all as they expected and they were unsure if the psychologist had gone about the job as they had expected.

Of the other 3 of the 4 parents who were uncertain if the psychologist had gone about the job as expected, 2 reported their expectations had been met on questions 6 and 7. One parent reported that although the session had achieved what they had hoped they were uncertain if the psychologist was as they expected. The other 2 of the 3 parents reporting the psychologist was not at all as expected reported their expectations were met on questions 7 and 8.

Table 2 : Parents Expectations

	RESPONSE CATEGORIES				
	no not at all	**no not very much**	**not sure**	**yes a little**	**yes a lot**
6 : Was the psychologist what you expected?	3	0	4	8	15
7 : Did the session achieve what you hoped it would?	0	0	9	8	13
8 : Did the psychologist go about the job the way you expected?	0	0	4	7	19

(3) Satisfaction and Expectations -- ***Is there a relation or not between parent satisfaction and expectations and aspirations?***

Are the parents who did not express satisfaction the same parents who felt their expectations and aspirations had not been met?

Seven of the 12 parents who did not express satisfaction on all 5 satisfaction questions reported their expectations had not been met on at least one of the expectation questions, compared with 7 of 18 expressing satisfaction on all five questions who felt their expectations had not been met on at least one of the expectation questions.

The results indicate that only 1 of 6 parents who were not satisfied they had received an explanation reported their expectations had not been met. While all 3 of those who were unsure if their problems had been understood were unsure if the psychologist was as expected and if the session had achieved what they hoped it would.

4/5 parents who did not say their visit had been helpful felt not all of their expectations had been met. Three of the 4 reported the psychologist was not as they had expected. One of these 3 parents also reported the session had not achieved what they had hoped it would. One parent reported their expectations had not been met on question 6 only.

Discussion

The study highlights the importance of evaluating a child psychology service by investigating parent satisfaction and supports the view that users can provide valuable feedback on the service (Spencer, 1995).

Assessing satisfaction with the service has identified a number of areas where parents are satisfied and a number of areas where changes may be made with the aim of improving satisfaction. The importance of making these changes to achieve the aim of improved satisfaction is crucial in view of the association between user satisfaction and the increased likelihood of compliance and attending future appointments.

Overall parents expressed satisfaction to some degree with the service they received on their first visit to the psychology clinics. Parents reported feeling satisfied that the psychologist was pleasant and listened to their problems that suggests the aims of the psychologist to be attentive and pleasant are being achieved.

However, a number of parents did not feel satisfied that the problems were understood. It is perhaps not that the psychologist did not understand the problems being reported to them but rather that parents were not reporting all of their worries. This may prevent the psychologist from being able to understand everything. Another area where a number of parents were not satisfied was in feeling they had been given a clear explanation for their problems. Perhaps for these parents a further session for assessment of the problems was needed before the psychologist could begin to offer a fuller explanation.

The results of the study suggest that many parents do hold inaccurate expectations. This is an important issue to address in view of the literature suggesting an association between inaccurate expectations and early termination of therapy. Expectations least often met were the session achieving what parents hoped for and the psychologist being as expected. Since the majority of parents failed to complete the open ended questions on the PSEQ about their expectations it is only possible to speculate as to the reasons why their expectations were not met by the service. Perhaps, as Hughes (1995) reports, parents only expected a 'one off' consultation and a quick solution to the problems while the psychologist offered further sessions for assessment and intervention. Perhaps they preferred to be more passive and were looking for specific advice or medication while further sessions offered would involve them taking a more active role in helping improving their child's problems.

In view of the small numbers being talked about it is necessary to be tentative in making conclusions. However the findings do suggest a possible association between expectations and satisfaction. Parents who were not satisfied were more likely to report the service had not met with their expectations. The results implied the visit was most likely to be not considered helpful where the session had not achieved what the parent had hoped and for some where the psychologist was not as expected. This perhaps suggests that satisfaction with the visit was determined in part by the expectations parents held prior to

their visit. This perhaps suggests that by altering expectations it may be possible to improve satisfaction with the service.

Usefulness of The PSEQ;

The study suggests that the PSEQ is a useful questionnaire for investigating parents expectations and satisfaction with the service received on their first visit to the psychology clinic. However this study suggests a number of possible changes need to be made to increase its usefulness.

Firstly, a measure of direction of expectations held by parents should perhaps be included in the PSEQ. It had been intended that the open ended questions would give this information for example, whether or not the psychologist was better or worse than expected. However, few people completed these questions. Those that did suggested the service was more positive than expected for example, 'much more beneficial and practical'. Perhaps because of the format of the questionnaire they did not see them. This suggests the format could perhaps change in the following way:

For example, Question 8 on the PSEQ:

Did the psychologist go about the job the way you expected?

If not, how was it different?

may become

Question 8: Did the psychologist go about the job the way you expected?

Question 9 :If the psychologist did not go about the job the way you expected , how was it different?

Perhaps a better way to measure direction would be to ask parents directly to indicate if the service was more positive or more negative than they had expected. Future studies may compare different ways of improving the PSEQ to include direction.

Secondly, question 7 of the PSEQ may need to be altered. It was intended that this question referred to characteristics of the psychologist, e.g. age, sex, did they expect the psychologist to be dressed in a white coat like a doctor. From those who did complete the open ended part of question 7 it seemed that this question may not have been properly understood. It may be necessary to ask these questions more directly.

Limitations of the study;

There were some methodological problems highlighted in this study which future studies should address. Firstly, the sample may not have been representative of all parents. The sample size was small and it was not known if all the different problems dealt with in the department were included in the study. Secondly, the study did not differentiate between hospital based and community services. Thirdly, limitations in the questionnaire meant it would have only been possible to hypothesise about direction of expectations held by parents based on the small amount of qualitative data provided by parents. However it should be noted that for the present study direction was not crucial information given the main focus was on whether or not expectations had been met.

Approaches to overcoming these methodological problems would include using larger sample sizes, separating problems into different groups, separating community and hospital based patients and altering the PSEQ as suggested above.

A number of parents gave negative feedback suggesting the methodology allowed parents to feel they could be direct, providing valuable information to improve the service.

Conclusions and Recommendations for practice

In conclusion, the study has demonstrated the importance of evaluating opinions of service users, endorsing previous findings of research (e.g., Lobb et al, 1987; Carr et al, 1994) and government reports. Considering the results a number of recommendations to improve service quality have been made to staff at the department for consideration.

Implementing the recommendations will help the service to more adequately meet the needs of the parents. It may also help to decrease non-attendance and non-compliance with therapy through meeting parents expectations and increasing parent satisfaction (e.g., Fitzpatrick, 1991; Hughes, 1995).

Recommendations following from results were:

There is a need for giving parents information prior to their visit. A leaflet of relevant information about the first visit to the department should be sent to parents. This should give details of psychologists, what

happens in the first visit, possible outcomes of the first visit and details of how psychologists go about their job.

Psychologists should ask parents in the initial interview what they hope will be achieved by coming to see the psychologist. This will help the psychologist to understand if the parent is looking for advice, an explanation of their problems and will help determine whether or not the parent is looking for treatment.

Given a number of parents were not satisfied they had received an explanation the psychologist should give more thorough explanations of the problems. If further assessment is needed before this can be achieved this should be made clear to parents.

To make parents feel their problems have been understood the psychologist should in the session summarise their understanding of the problems as presented by the parent. They should ask them what they feel has not been understood clearly.

It should be routine practice for psychologists to encourage parents to tell them if they are not receiving what they expected, and if they feel they have not been understood. This would allow parents' opinions to be continually evaluated and the service can be changed accordingly.

Psychologists in evaluating their service must be prepared to deal with negative evaluation and take on board suggestions to improve the service if these changes can be made within the aims set by the Trust.

References

CARR, A., McDONNELL, D., and OWEN, P. (1994) Audit and family systems consultation; evaluation of practice at a child and family centre. Journal of Family Therapy, 16, 143-157

COOKSON, D., and FULLER, G. (1995) Referrer appraisal of a child and family service. Clinical Psychology Forum, 77, 19-21

DEPARTMENT of HEALTH (1993) Health of the Nation ; Key Area Handbook, Mental Health. London; HMSO

DONABEDIAN, A. (1988) The quality of care; how can it be assessed? Journal of the American Medical Association, 260, 1743-8

FITZPATRICK, R. (1991) Surveys of patient satisfaction; I important general considerations. British Medical Journal, 302, 887-9

GRIFFITHS, E. T. (1983) NHS Management Inquiry. London;Department of Health and Social Security

HEINE, R. A., and TROSMAN, H. (1960) Initial expectations of the doctor - patient interaction as a factor in continuance in psychotherapy. Psychiatry, 23, 275-8

HUGHES, I. (1995) Why do they stop coming? Reasons for therapy termination by adult clinical psychology clients. Clinical Psychology Forum, 81, 7-11

KERRUISH, A., WICKINGS, I., and TARRANT, P. (1988) Information from patients as a management tool; empowering managers to improve the quality of care. Hospitals and Health Service Review, April, 64-7

KUPST, M. J., and SCHULMAN, J. L. (1979) Comparing professional and lay expectations of psychotherapy. Psychotherapy; Theory, Research and Practice, 16, 237-43

LEBOW, J. (1982) Consumer satisfaction with mental health treatment. Psychological Bulletin, 91, 224-59

LOBB, C. D., TRIGG, L. J., and CASSELS, C. (1987) An evaluation of consumer satisfaction in a child psychiatric service; viewpoints of patients and parents. American Journal of Orthopsychiatry, 57, 132-4

McAULIFFE, E., and MacLACHLAN, M. (1992) Clinicians' resistance to Consumer Satisfaction Surveys; What they never tell you. Journal of Management in Medicine, 6, 3, 47-51

SKAIFE, K., and SPALL, B. (1995) An independent approach to auditing psychology services for adult mental health clients. Clinical Psychology Forum, 77, 14-18

SPECTOR, K. (1988) Increasing take-up rates of clinical psychology services. Clinical Psychology Forum, 13, 11-13.

SPENCER, A. (1995) Staff Attitudes towards Consumer Satisfaction Surveys. Clinical Psychology Forum, 86, 25-27

STALLARD, P., and CHADWICK, R. (1991) Consumer evaluation; a cautionary note. Clinical Psychology Forum, 34, 2-4

WEBSTER, A. (1992) The effect of pre-assessment information on clients satisfaction, expectations and attendance at a mental health day centre. British Journal Of Medical Psychology, 65, 89-93

CHAPTER 5

Abstracts of Clinical Case Research Studies

(papers written for submission to the Journal of Child Psychology and Psychiatry and to The British Journal of Learning Disabilities – appendix 1 for notes for Contributors in Research Portfolio Supplement).

A Multi-component approach to Treatment of Childhood Depression : A Single Case Study

Behavioural Treatment of a needle phobia in a man with learning disabilities and complex emotional and behavioural difficulties

Treatment of Sleep Problems in a 9 year old girl : A parent managed behavioural programme with minimal therapist intervention.

Dr E.R. Haldane

Dept. of Psychological Medicine
University of Glasgow
Gartnavel Royal Hospital

A Multi-component Approach to Treatment of Childhood Depression : A Single Case Study

Author

Haldane, Elizabeth, R.

Institution

University of Glasgow, Dept. of Psychological Medicine, Gartnavel Royal Hospital, Glasgow

Title

A Multi-component Approach to Treatment of Childhood Depression : A Single Case Study

Abstract

A multi-component approach to outpatient treatment of depression in an eleven year old girl is described. This involves individual cognitive behaviour treatment for depression and family intervention. Family intervention was from a cognitive perspective, based on the constructivist approach to family intervention and focused on the use of therapeutic conversations. The Children's Depression Scale (Lang and Tisher, 1983) was used as a pre-treatment and post-treatment measure. Results indicated support for the effectiveness of multi-component interventions in treating depression.

Key Phrases

Multi-component treatment of depression

Children

Family intervention

Cognitive behaviour treatment

(written for submission to The Journal of Child Psychology and Psychiatry – see appendix 3.1.2 for notes for contributers).

Behavioural Treatment of a needle phobia in a man with learning disabilities and complex emotional and behavioural difficulties

Author

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Institution

University of Glasgow, Dept. of Psychological Medicine, Gartnavel Royal Hospital, Glasgow

Title

Behavioural Treatment of a needle phobia in a man with learning disabilities and complex emotional and behavioural difficulties

Abstract

This paper discusses the implementation and effectiveness of a behavioural programme for treatment of a needle phobia in a complex case, where the man has learning disabilities, manic depression and related behaviour difficulties. Problems potentially affecting the effectiveness of treatment of the phobia, arising from his other difficulties, were identified at assessment and treatment modified accordingly. Treatment was exposure based. Components of the intervention included a graded hierarchy, modelling and relaxation training. Treatment was presented at an appropriate level and close monitoring of his mood allowed treatment to focus as relapse prevention when his mood was low. In addition, his CPN was trained as co-therapist. The behaviour programme was effective in treating his phobia. Results are discussed in relation to previous research findings and for their contribution to existing literature. Research and practical implications are also discussed.

Key Phrases

Behavioural Treatment

Learning disabilities

Outcome study

Complex case

Phobias

Learning Disabilities

Complex Case

(written for submission to The British Journal of Learning Disabilities – see appendix 1.1 : Research Portfolio Suppliment for notes for contributers).

Treatment of Sleep Problems in a 9 year old girl : A parent managed behavioural programme with minimal therapist intervention.

Author

Haldane, Elizabeth, R.

Institution

University of Glasgow, Dept. of Psychological Medicine, Gartnavel Royal Hospital, Glasgow

Title

Treatment of Sleep Problems in a 9 year old girl : A parent managed behavioural programme with minimal therapist intervention.

Abstract

A parent managed behavioural programme with minimal therapist intervention for treatment of sleep problems in a 9 year old girl is described. Assessment procedures are also described. Sleep problems included behaviour problems on going to bed and symptoms indicative of anxiety at bedtime. Treatment strategies included cueing (establishing a regular positive bedtime routine), positive reinforcement by her parents for appropriate behaviour and graduated extinction to reduce inappropriate behaviour. Relaxation based training for anxiety management at bedtime was also incorporated into the programme. Treatment was successful within one week and maintained at follow up after 6 weeks and at 3 months. The study highlights the important role parents can play in both the maintenance and treatment of sleep problems in children. Of particular importance for clinical practice are the findings that treatment was successful within a short time and with minimal therapist contact. Variables predicting successful response to treatment of this nature are identified. The study provides a package of multiple behavioural strategies which may serve as a basis for a treatment package for similar cases.

Key Phrases

Treatment of sleep problems

Parent managed behavioural programme

Minimal therapist intervention

(written for submission to The Journal of Child Psychology and Psychiatry – see appendix 1.1 : Research Portfolio Suppliment for notes for contributers).

Appendix 1 :
Major Research Project

Stress in Parenting Autistic Children :
The Daily Hassles Approach to Conceptualising Stress

Appendix 1.1

Notes for Contributors :

The Journal of Child Psychology and Psychiatry

Dr E.R. Haldane

Dept. of Psychological Medicine
University of Glasgow
Gartnavel Royal Hospital

Notes for Contributors

GENERAL

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The abstract should not exceed three hundred words and should be typed **double spaced**. (In addition, a longer summary may, if desired, be included at the end of the main article.)

Original articles and research reports should, in general, follow the conventional form: Introduction and review of the literature, Materials and Methods, Results and Discussion. To conserve space, less important portions of the paper, such as description of methods, should be marked for printing in smaller type. Descriptions of techniques and methods should be given in detail only when they are unfamiliar. In order to aid readers of the Journal, we encourage authors who are using acronyms for tests or abbreviations not in common usage to provide a list of them which will be printed to follow on from the Abstract.

6. *Acknowledgements*

These should appear on a separate sheet, **double spaced**, at the end of the body of the paper, before the References.

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References in running text should be quoted as follows: Smith and Brown (1990), or (Smith 1990), or (Smith, 1980, 1981a,b), or (Smith & Brown, 1982), or (Smith, 1982; Brown & Green, 1983).

For up to five authors, all surnames should be cited the first time the reference occurs, e.g. Smith, Brown, Green, Rosen, and Jones (1981) or (Smith, Brown, & Jones, 1981). Subsequent citations should use "et al." (not underlined and with no period after the "et"), e.g. Smith et al. (1981) or (Smith et al. 1981).

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References to unpublished material should be avoided.

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Full references should be given at the end of the article in alphabetical order, and not in footnotes. **Double spacing** must be used.

References to journals should include the authors' surnames and initials, the full title of the paper, the full name of the journal, the year of publication, the volume number, and inclusive page numbers. Titles of journals must not be abbreviated and should be underlined.

References to books should include the authors' surnames and initials, the full title of the book, the place of publication, the publisher's name and the year of publication.

References to articles, chapters and symposia contributions should be cited as per the examples below:

Kiernan, C. (1981). Sign language in autistic children. *Journal of Child Psychology and Psychiatry, 22,* 215–220.

Jacob, G. (1983a). Development of coordination in children. *Developmental Studies, 6,* 219–230.

Jacob, G. (1983b). Disorders of communication. *Journal of Clinical Studies, 20,* 60–65.

Thompson, A. (1981). *Early experiences: the new evidence.* Oxford: Pergamon Press.

Jones, C. C., & Brown, A. (1981). Disorders of perception. In K. Thompson (Ed.), *Problems in early childhood* (pp. 23–84). Oxford: Pergamon Press.

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Appendix 1.2

Materials Used in the Research Study

Dr E.R. Haldane

Dept. of Psychological Medicine
University of Glasgow
Gartnavel Royal Hospital

Appendix 1.2.1

Materials Used in the Research Study

Letter to Parents

Dr E.R. Haldane

Dept. of Psychological Medicine
University of Glasgow
Gartnavel Royal Hospital

Stress in Parenting Autistic Children : The Daily Hassles Approach to Conceptualising Stress

Dr. Elizabeth Haldane
Post Graduate Clinical Psychologist
Department of Clinical Child Psychology
Yorkhill NHS Trust
Royal Hospital for Sick Children
Yorkhill
Glasgow

....

Dear .....

I am carrying out a research study looking at the daily stresses faced by mothers when bringing up young children. As part of this study I am interviewing mothers of children in the age range 3 to 8 years old.

I am writing to ask you for your help with this research. If you agree to participate we can arrange a meeting at a time and place suitable for you.

We can have a chat and you will be asked to fill in some short questionnaires over coffee and biscuits. This will only take around 30 minutes of your time.

Your child's nursery teacher or school teacher would be contacted with your permission. They will be asked some questions about your child's behaviour to give me some idea of the things your child has achieved.

All the information I collect will be completely confidential and anonymous.

Please could you fill in and return the enclosed forms in the envelope provided by .....

If you have any questions please phone me on 0141 201 0644 or write to me at the above address.

I hope you agree to take part as your help would be very valuable. I look forward to meeting with you.

Yours sincerely

Dr. Elizabeth Haldane
Post Graduate Clinical Psychologist

Appendix 1.2.2

Materials Used in the Research Study

Consent Form

Dr E.R. Haldane

Dept. of Psychological Medicine
University of Glasgow
Gartnavel Royal Hospital

Parental Consent Form

Stress in Parenting Autistic Children : The Daily Hassles Approach to Conceptualising Stress

Please delete as appropriate

I **agree / do not agree** to take part in this research study. Please **contact / do not contact** me to arrange a meeting.

If you have agreed to take part **please tick** which of the following places would be most suitable for us to meet

Balvicar Child Development Centre in Queens Park	.....
Your childs nursery / school	.....
Yorkhill Children's Hospital	.....
Hawkhead Hospital	.....
Any of the above	.....
None of the above	.....

I understand all information will be completely confidential and anonymous.

Signature of mother ..... **Date** .....

Parental Consent Form

Stress in Parenting Autistic Children : The Daily Hassles Approach to Conceptualising Stress

Please delete as appropriate.

I **agree / do not agree** for my child's nursery / school teacher to be contacted to ask questions about what my child has achieved. I **agree / do not agree** for this information to be used in the above research study.

I understand all information will be completely confidential and anonymous.

Signature of mother ..... **Date** .....

Appendix 1.2.3

Materials Used in the Research Study

Interview Schedule

Dr E.R. Haldane

Dept. of Psychological Medicine
University of Glasgow
Gartnavel Royal Hospital

Interview Schedule

Stress in Parenting Autistic Children : The Daily Hassles Approach to Conceptualising Stress

Date:

identification:

autistic / down syndrome / normal group 3-5yrs / 6-8yr group

name of nursery/school child attending (abbreviation): .....

Mother's Details

age of mother: <16years 16 -19years 20-24years 25-29years 30-34years >=35 years
marital status: are you married / single / living with someone / separated / divorced
occupation: are you working partime / fulltime / training course / unemployed / housewife / other
general health: Do you keep in good health / poor health
If poor health list health problems - list here

medication: are you on any medication yes / no

education: did you leave school with any qualifications? yes / no
If so, list qualifications

did you attend college / university / other
If so, list qualifications

Child details

sex of child boy / girl
age of child 3 4 5 6 7 8
education How long has your child attended nursery school?
Did your child attend nursery school before school? yes / no
position of child in the family
general health of child
developmental history When did your child start to sit by him/herself?
(with parents of autistic / down syndrome children crawl?
first ask if the child is able to do this yet) walk?
talk?
Main worries what main worries do you have regarding your child?

History of autism (for mothers of autistic children only)

When did you first feel something was wrong?

Who did you see about your worries?

When were you told your child had autism?

Does anyone else in your family have autism or any other problems?

History of Down Syndrome (for mothers of children with Down Syndrome)

When were you told your child had Down syndrome?

Were you considered at risk of having a Down Syndrome baby?

Does anyone else in your family have Down syndrome or any other problems?

Family Details

Partner Details
age of partner/husband <16years 16 -19years 20-24years 25-29years 30-34years >=35 years

number of years partner and mother have been together

partner's occupation

health of partner

Children
number of other children

ages of other children

health of other children

any worries about other children

Appendix 1.2.4

Materials Used in the Research Study

Parent Information Sheet

Dr E.R. Haldane

Dept. of Psychological Medicine
University of Glasgow
Gartnavel Royal Hospital

PARENT INFORMATION SHEET

Maternal Perceptions of Stress with Routine Tasks of Parenting

Thankyou for agreeing to take part in this research study. The information you and your child's nursery/school teacher have given me will remain confidential and anonymous. All information from all mothers and teachers will be gathered together.

Within any family parents face challenges by the demands placed on them in bringing up a young child and by children's behaviour which can sometimes be frustrating and annoying for parents. These things sometimes make life difficult, for example, difficulties in kids making friends, having to clean up after the kids and having to keep a constant eye on your child. When children have a handicap life for parents can be even more stressful.

By completing the questionnaires today you have provided valuable information which will help to identify specific tasks of parenting which mothers find most stressful. This will help us to understand more fully the daily stresses parents face in bringing up a child. By looking at this it will help in developing special services in the future to help parents manage the problems they face in parenting. This is very important for all parents but it is particularly important for parents who have a child with a handicap.

I stress again that all information you have given will remain confidential and anonymous. There is no way anyone will be able to tell which questionnaires you completed.

If you have any further questions about this research please do not hesitate to contact me at the Department of Clinical Child Psychology, Yorkhill NHS Trust, Royal Hospital for Sick Children, Yorkhill, Glasgow.

Thankyou once again for your cooperation.

Dr. Elizabeth Haldane
Post Graduate Clinical Psychologist

Appendix 1.2.5

Materials Used in the Research Study

Social Support Questionnaire

Dr E.R. Haldane

Dept. of Psychological Medicine
University of Glasgow
Gartnavel Royal Hospital

Social Support Questionnaire - SSQ

Part 1

Please answer the following questions about the support that is available to you

1. Roughly how many people do you get support from? ☐

2. Who gives you support? *(please tick)*
   - spouse / partner ☐
   - family ☐
   - friends ☐
   - professionals ☐
   - any other ☐ please state who this may be .....

3. Please rate how satisfied you are with the support you receive on a scale of 0-10 where 0 = not at all satisfied and 10 = completely satisfied ☐

Part 2

Please answer all questions found on the following page

Social Support Questionnaire - SSQ

Part 2

Please answer the following questions

Type of Support	Number of people	Source	Satisfaction
	How many people do you get this kind of support from? Please write the number in the box if none write 0.	Please write down those who give you this support (eg friends, doctor, spouse, DSS, family, psychologist etc). You may list more than one. If no- one write no-one.	Are you satisfied with this support? Yes / No / Don't Know (please delete)
EXAMPLE Someone to listen to your problems, fears and worries	2	Psychologist Friends	~~Yes~~/No/~~Dont Know~~
1. Someone to show you love and affection and make you feel good.	☐		Yes/No/Dont Know
2. Someone to go out with socially.	☐		Yes/No/Dont Know
3. Someone to give you information on services and benefits that maybe available for you.	☐		Yes/No/Dont Know
4. Someone to relax with	☐		Yes/No/Dont Know
5. Someone to help you with feeding, dressing, bedtimes for your child.	☐		Yes/No/Dont Know
6. Someone to give you information to help you understand things.	☐		Yes/No/Dont Know
7. Someone for you to love and to make you feel needed.	☐		Yes/No/Dont Know
8. Financial Assistance in the form of benefits, free nappies etc.	☐		Yes/No/Dont Know
9. Someone to do things with to help you forget your worries.	☐		Yes/No/Dont Know
10. Someone to give you advice on how to manage things which are worrying you.	☐		Yes/No/Dont Know
11. Someone to listen to your problems, fears and worries.	☐		Yes/No/Dont Know
12. Someone to look after your child to give you a rest eg. babysitters, respite services etc.	☐		Yes/No/Dont Know

Appendix 1.2.6

Materials Used in the Research Study

Parenting Daily Hassle Scale

Dr E.R. Haldane

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University of Glasgow
Gartnavel Royal Hospital

Parenting Daily Hassle Scale

PARENTING DAILY HASSLES - Crnic and Greenberg (1990)

The statements below describe lots of events that routinely occur in families with young children. These events sometimes make life difficult.

Please read each item and circle how often it happens to you (rarely, sometimes, a lot, or constantly), and then circle how much of a 'hassle' you feel that has been for you FOR THE PAST SIX MONTHS.

Events	How often it happens	Hassle (low-high)
1. Continually cleaning up messes of toys or food.	rarely sometimes a lot constantly	1 2 3 4 5
2. Being nagged, whined at, complained to.	rarely sometimes a lot constantly	1 2 3 4 5
3. Meal-time difficulties, picky eater, complaining etc.	rarely sometimes a lot constantly	1 2 3 4 5
4. The child doesn't listen or won't do as he/she is asked without being nagged.	rarely sometimes a lot constantly	1 2 3 4 5
5. Baby-sitters are difficult to find	rarely sometimes a lot constantly	1 2 3 4 5
6. The child's schedules (e.g. pre-school, other activities) interfere with meeting your own or household needs.	rarely sometimes a lot constantly	1 2 3 4 5
7. Sibling arguments or fights which require a 'referee'	rarely sometimes a lot constantly	1 2 3 4 5
8. The child demands that you entertain or play with him/her.	rarely sometimes a lot constantly	1 2 3 4 5
9. The child resists or struggles over bedtime with you.	rarely sometimes a lot constantly	1 2 3 4 5
10. The child is constantly under foot, interfering with other chores.	rarely sometimes a lot constantly	1 2 3 4 5
11. The need to keep a constant eye on where the child is and what he/she is doing.	rarely sometimes a lot constantly	1 2 3 4 5
12. The child interrupts adult conversations or interactions.	rarely sometimes a lot constantly	1 2 3 4 5
13. Having to change your plans because of unprecedented child needs.	rarely sometimes a lot constantly	1 2 3 4 5
14. The child gets dirty several times a day requiring changes of clothes.	rarely sometimes a lot constantly	1 2 3 4 5
15. Difficulties getting privacy (e.g. in the bathroom).	rarely sometimes a lot constantly	1 2 3 4 5
16. The child is hard to manage in public (grocery store, shopping centre, restaurant).	rarely sometimes a lot constantly	1 2 3 4 5
17. Difficulties in getting the child ready for outings and leaving on time.	rarely sometimes a lot constantly	1 2 3 4 5
18. Difficulties in leaving the child for a night out or at school or day-care	rarely sometimes a lot constantly	1 2 3 4 5
19. The child having difficulties with friends (e.g. fighting, trouble getting along, or no friends available)	rarely sometimes a lot constantly	1 2 3 4 5
20. Having to run extra errands to meet the child's needs.	rarely sometimes a lot constantly	1 2 3 4 5

Appendix 1.2.7

Materials Used in the Research Study

Parenting Stress Index – Short Form

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PARENTING STRESS INDEX

(Short Form)

Richard R. Abidin
University of Virginia

Directions:

In answering the following questions, please think about the child you are most concerned about.

The questions on the following pages ask you to mark an answer which best describes your feelings. While you may not find an answer which exactly states your feelings, please mark the answer which comes closest to describing how you feel.

YOUR FIRST REACTION TO EACH QUESTION SHOULD BE YOUR ANSWER.

Please mark the degree to which you agree or disagree with the following statements by circling the number which best matches how you feel. If you are not sure, please circle #3.

1	2	3	4	5
Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree

Example:

I enjoy going to the movies. (If you sometimes enjoy going to the movies, you would circle #2.)

1 (2) 3 4 5

---

1 Strongly Agree	2 Agree	3 Not Sure	4 Disagree	5 Strongly Disagree

1. I often have the feeling that I cannot handle things very well.	1	2	3	4	5	
2. I find myself giving up more of my life to meet my children's needs than I ever expected.	1	2	3	4	5	
3. I feel trapped by my responsibilities as a parent.	1	2	3	4	5	
4. Since having this child I have been unable to do new and different things.	1	2	3	4	5	
5. Since having a child I feel that I am almost never able to do things that I like to do.	1	2	3	4	5	
6. I am unhappy with the last purchase of clothing I made for myself.	1	2	3	4	5	
7. There are quite a few things that bother me about my life.	1	2	3	4	5	
8. Having a child has caused more problems than I expected in my relationship with my spouse (male/female friend).	1	2	3	4	5	
9. I feel alone and without friends.	1	2	3	4	5	
10. When I go to a party I usually expect not to enjoy myself.	1	2	3	4	5	
11. I am not as interested in people as I used to be.	1	2	3	4	5	
12. I don't enjoy things as I used to.	1	2	3	4	5	
			PD			
13. My child rarely does things for me that make me feel good.	1	2	3	4	5	
14. Most times I feel that my child does not like me and does not want to be close to me.	1	2	3	4	5	*
15. My child smiles at me much less than I expected.	1	2	3	4	5	
16. When I do things for my child I get the feeling that my efforts are not appreciated very much.	1	2	3	4	5	
17. When playing, my child doesn't often giggle or laugh.	1	2	3	4	5	
18. My child doesn't seem to learn as quickly as most children.	1	2	3	4	5	
19. My child doesn't seem to smile as much as most children.	1	2	3	4	5	
20. My child is not able to do as much as I expected.	1	2	3	4	5	
21. It takes a long time and it is very hard for my child to get used to new things.	1	2	3	4	5	

1 Strongly Agree	2 Agree	3 Not Sure	4 Disagree	5 Strongly Disagree

22. I feel that I am:
    1. not very good at being a parent,
    2. a person who has some trouble being a parent,
    3. an average parent,
    4. a better than average parent,
    5. a very good parent.

    1 2 3 4 5 *

23. I expected to have closer and warmer feelings for my child than I do and this bothers me. 1 2 3 4 5

24. Sometimes my child does things that bother me just to be mean. 1 2 3 4 5

P-C DI ☐

25. My child seems to cry or fuss more often than most children. 1 2 3 4 5

26. My child generally wakes up in a bad mood. 1 2 3 4 5

27. I feel that my child is very moody and easily upset. 1 2 3 4 5

28. My child does a few things which bother me a great deal. 1 2 3 4 5

29. My child reacts very strongly when something happens that my child doesn't like. 1 2 3 4 5

30. My child gets upset easily over the smallest thing. 1 2 3 4 5

31. My child's sleeping or eating schedule was much harder to establish than I expected. 1 2 3 4 5

32. I have found that getting my child to do something or stop doing something is:
    1. much harder than I expected,
    2. somewhat harder than I expected,
    3. about as hard as I expected,
    4. somewhat easier than I expected,
    5. much easier than I expected.

    1 2 3 4 5

33. Think carefully and count the number of things which your child does that bother you. For example: dawdles, refuses to listen, overactive, cries, interrupts, fights, whines, etc. Please circle the number which includes the number of things you counted.

    1. 10+ 2. 8-9 3. 6-7 4. 4-5 5. 1-3 1 2 3 4 5 *

34. There are some things my child does that really bother me a lot. 1 2 3 4 5

35. My child turned out to be more of a problem than I had expected. 1 2 3 4 5

36. My child makes more demands on me than most children. 1 2 3 4 5

D.C. ☐

Total Score ☐

Parenting Stress Index (Short Form)

Profile Sheet and Norms

R. R. Abidin - University of Virginia

Parents Name_____ Parents Sex_____ Parents Date of Birth_____

Childs Name_____ Childs Sex_____ Childs Date of Birth_____ Date_____

Percentile Ranks — N=800

	Raw Score	1	5	10	15	20	25	30	35	40	45	50	55	60	65	70	75	80	85	90	95	99+	$\bar{x}$	SD
STRESS Σ of PD +P-C DI +DC		39	46	51	55	59	61	63	65	66	67	69	71	73	75	76	79	82	86	91	99	112	71.0	15.4
PARENTAL D.		12	14	17	19	20	21	22	23	24		25	26	27	28	29	30	31	33	36	39	49	26.4	7.2
PARENT - CHILD D.I.			12	13		14		15	16	17	18	19	20	21	22	23	24	25	26	27	30	35	18.7	4.8
D. CHILD		14	15	17	18	19	21	22	23	24		25	26	27	28	29	30	31	33	36	39	49	26.0	6.7
D. RESPONDING*		7	9	10	11		12				13			14		15		16	17	18	19	24	13.9	5.2
		1	5	10	15	20	25	30	35	40	45	50	55	60	65	70	75	80	85	90	95	99+		

*Score equals the sum of items: 1,2,3,7,8,9,11 - critical score less than 11.

Scoring: Reverse weights for all items.

Appendix 1.3

Statistics : Tables and Graphs

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Appendix 1.3.1

Statistics : Tables and Graphs

Descriptive Statistics

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Gartnavel Royal Hospital

Descriptive Statistics

Table 1.3.1 : Descriptive Statistics (N=20 for each group)

Measure	Group	Mean	Std Deviation	Skewness	Kurtosis
PSI	N	72.85	15.73	0.39	-0.69
	DS	100.25	26.40	-0.34	-0.94
	A	105.40	8.00	-0.67	-0.49
DHI	N	37.40	7.53	-0.28	-0.01
	DS	47.2	15.73	0.51	-0.26
	A	37.45	5.34	0.49	-0.96
SPS	N	3.75	1.48	0.04	-0.94
	DS	2.95	2.19	0.004	-1.59
	A	4.85	1.04	-0.29	-1.14
SES	N	4.95	1.10	-0.42	-1.32
	DS	4.35	1.76	-1.31	0.90
	A	5.55	0.76	-1.39	0.41
DHF	N	36.95	5.74	0.13	-0.86
	DS	45.05	12.84	-0.07	-1.49
	A	40.65	3.86	-0.16	-0.67

Appendix 1.3.2

Statistics : Tables and Graphs

P-P Plots

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Gartnavel Royal Hospital

P-P Plots

Table 1.3.2-1 : Normal P-P Plot of Parenting Stress (N=60)

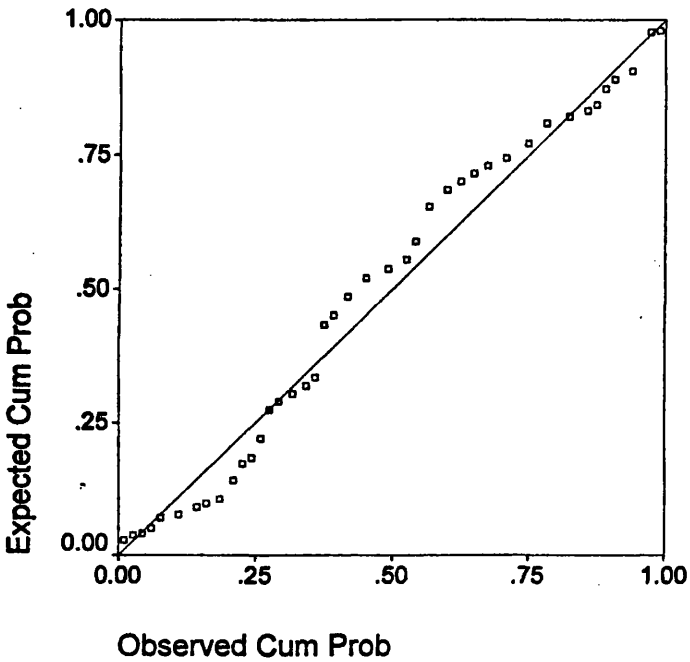


Table 1.3.2-2 : Normal P-P Plot of Daily Hassle Frequency (N=60)

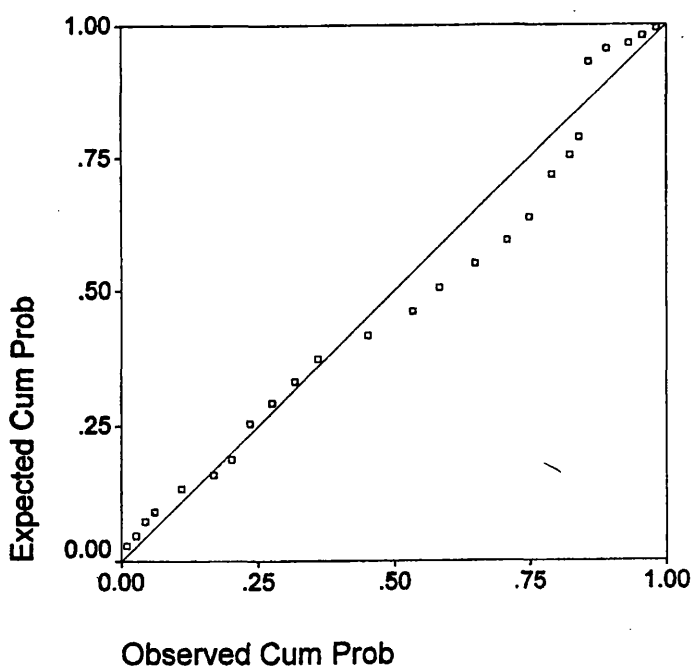


Table 1.3.2-3 : Normal P-P Plot of Daily Hassle Intensity (N=60)

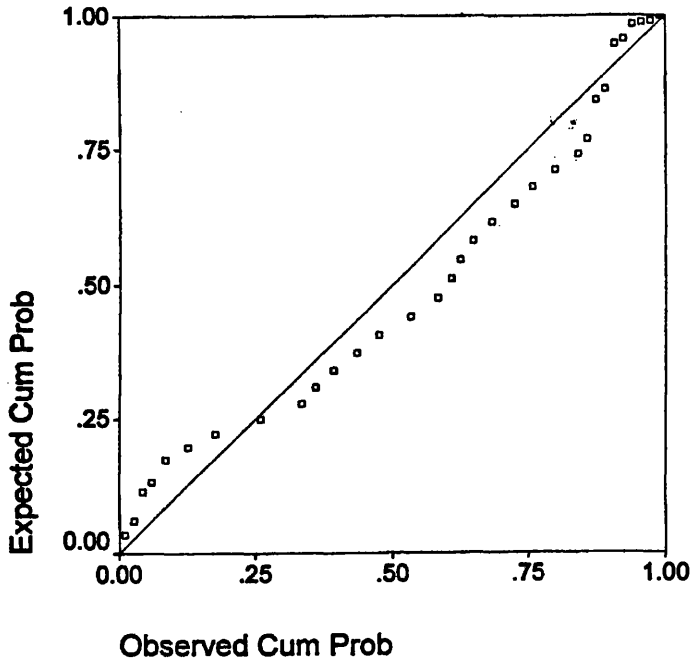


Table 1.3.2-4 : Normal P-P Plot of SES (N=60)

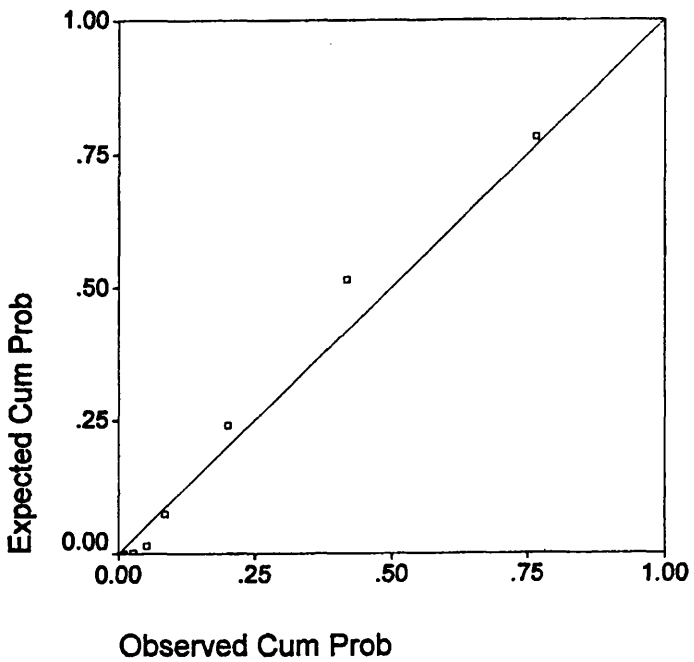


Table 1.3.2-5 : Normal P-P Plot of SPS (N=60)

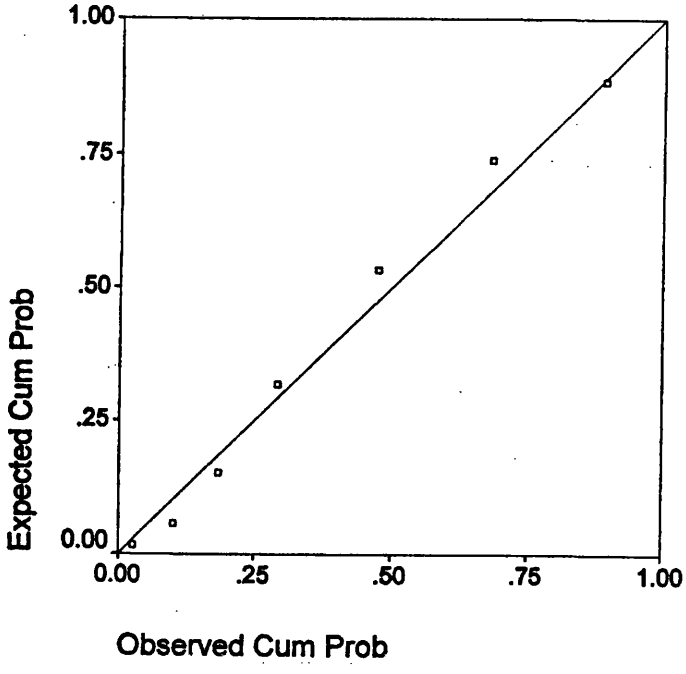


Table 1.3.2-6 : Normal P-P Plot of Parenting Stress : Normal Group (N=20)

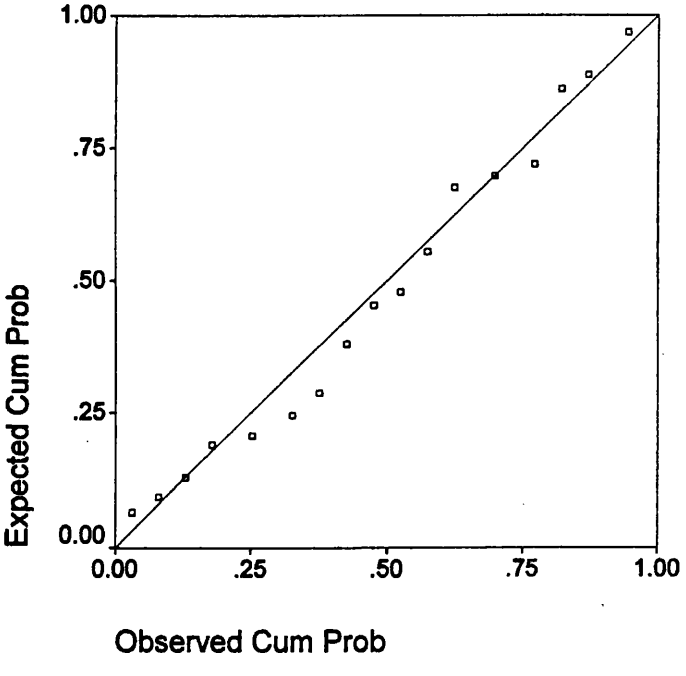


Table 1.3.2-7 : Normal P-P Plot of Daily Hassle Frequency : Normal Group (N=20)

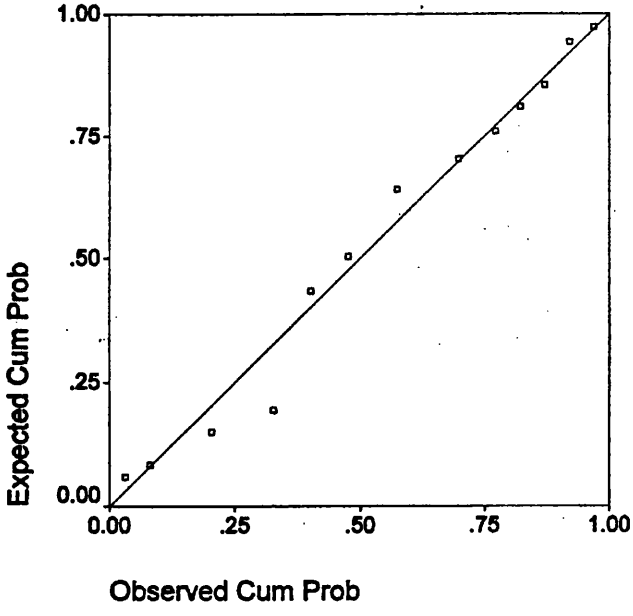


Table 1.3.2-8 : Normal P-P Plot of Daily Hassle Intensity : Normal Group (N=20)

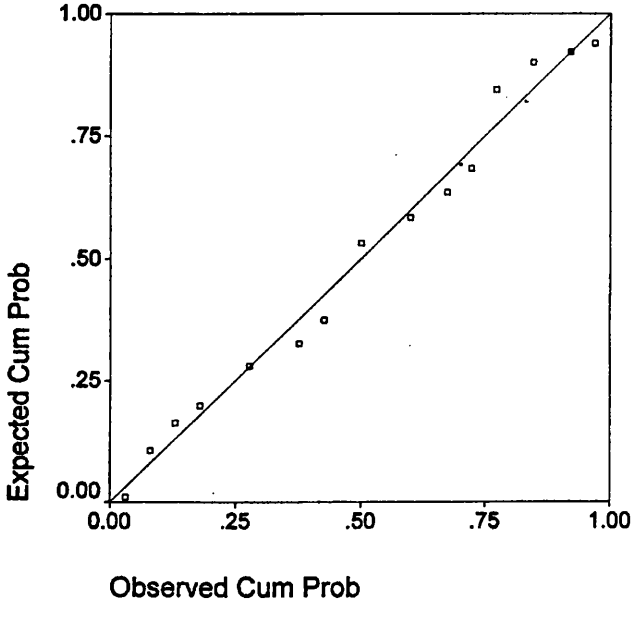


Table 1.3.2-9 : Normal P-P Plot of SES : Normal Group (N=20)

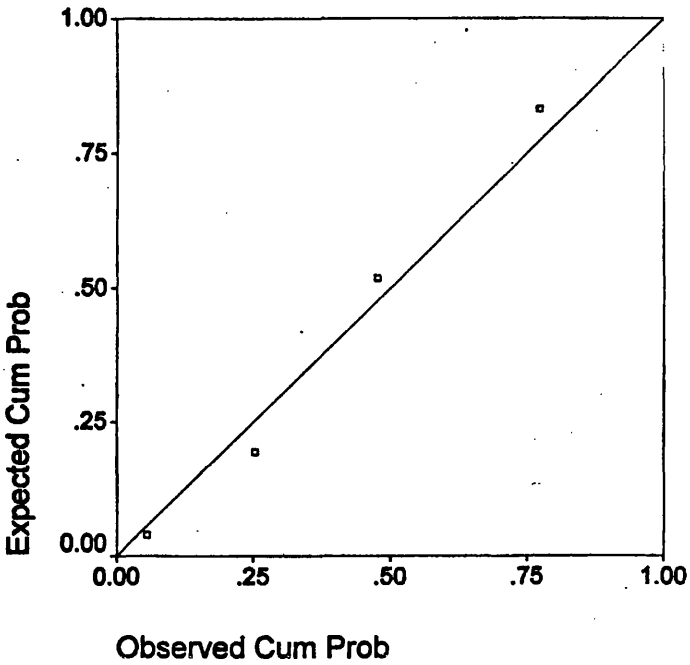


Table 1.3.2-10 : Normal P-P Plot of SPS : Normal Group (N=20)

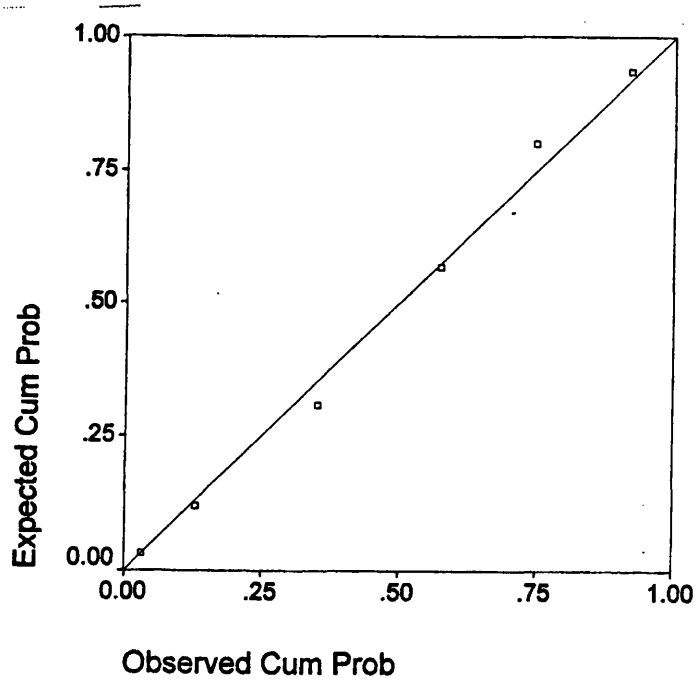


Table 1.3.2-11 : Normal P-P Plot of Parenting Stress : Downs Syndrome Group (N=20)

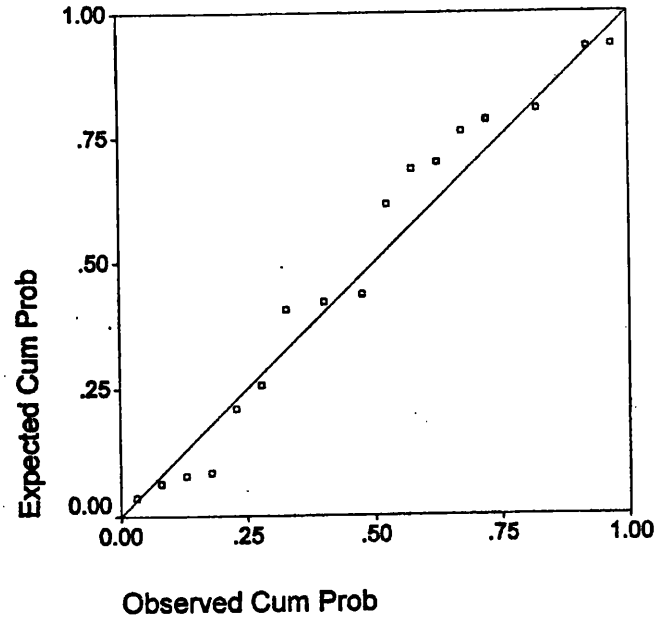


Table 1.3.2-12 : Normal P-P Plot of Daily Hassle Frequency : Downs Syndrome Group (N=20)

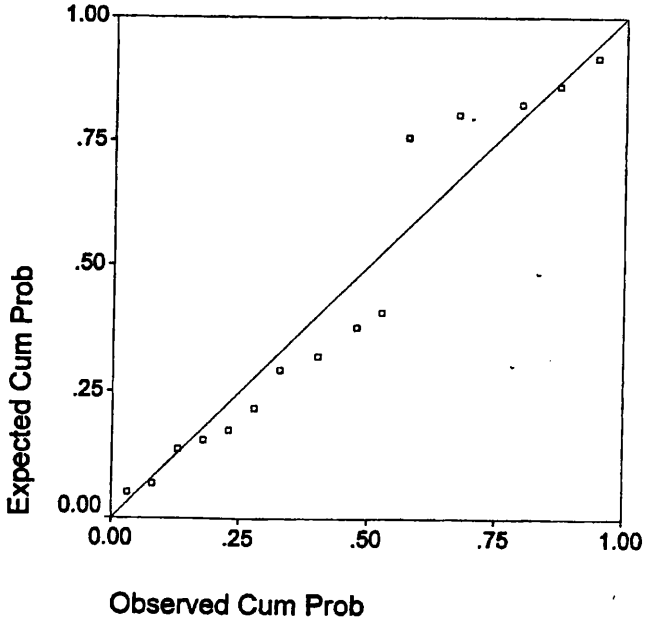


Table 1.3.2-13 : Normal P-P Plot of Daily Hassle Intensity : Downs Syndrome Group (N=20)

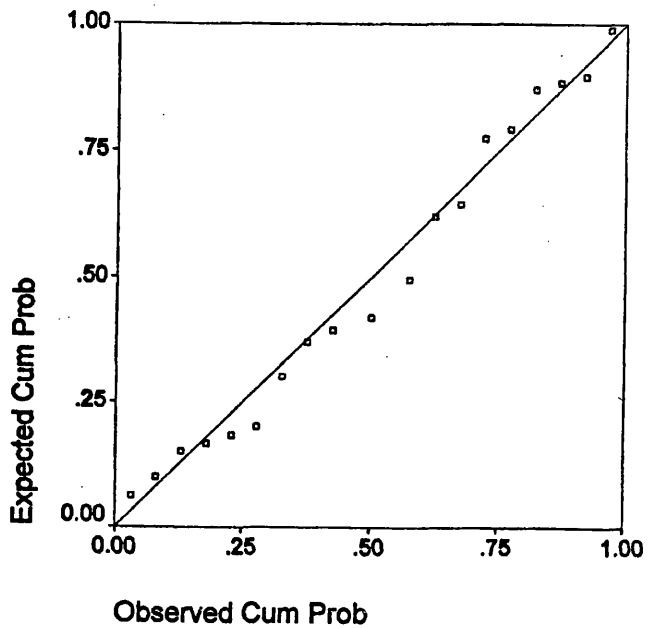


Table 1.3.2-14 : Normal P-P Plot of SES : Downs Syndrome Group (N=20)

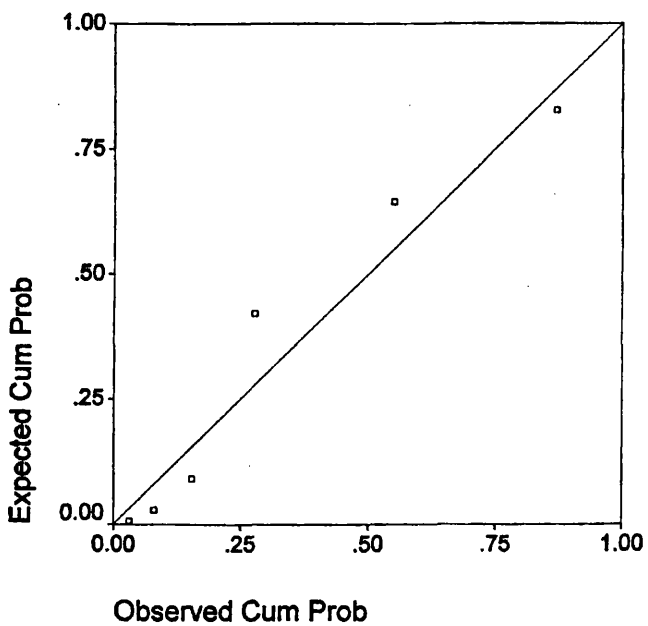


Table 1.3.2-15 : Normal P-P Plot of SPS : Downs Syndrome Group (N=20)

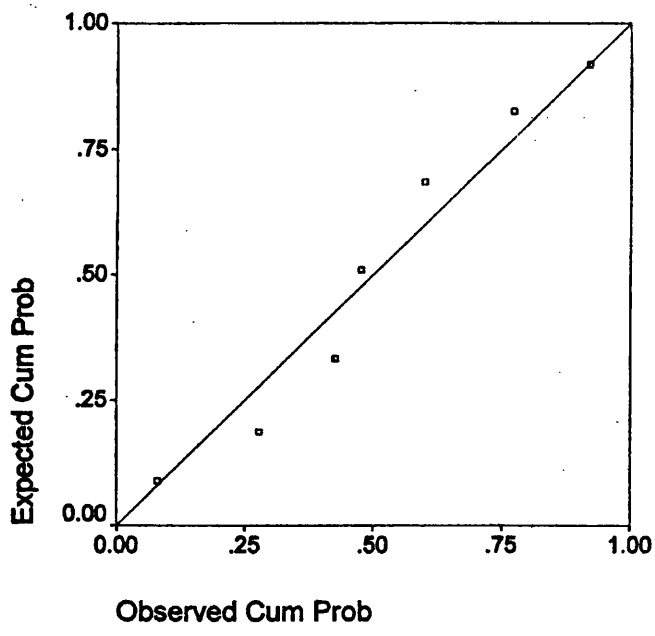


Table 1.3.2-16 : Normal P-P Plot of Parenting Stress : Autistic Group (N=20)

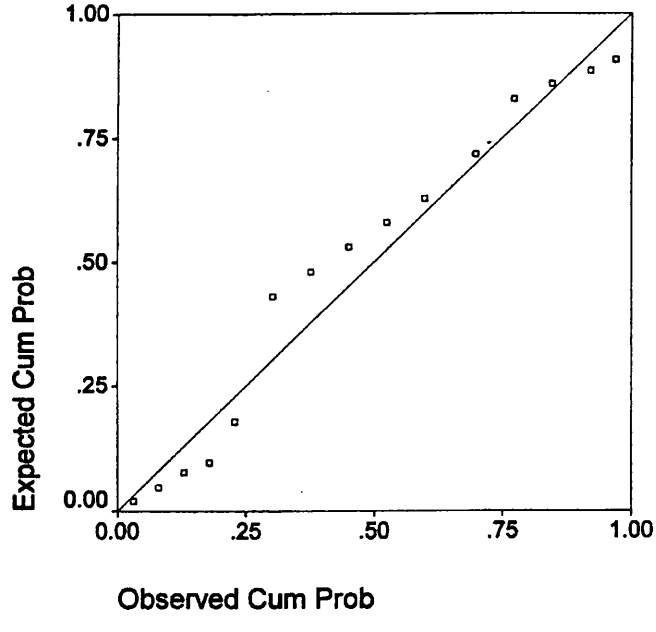


Table 1.3.2-17 : Normal P-P Plot of Daily Hassle Frequency : Autistic Group (N=20)

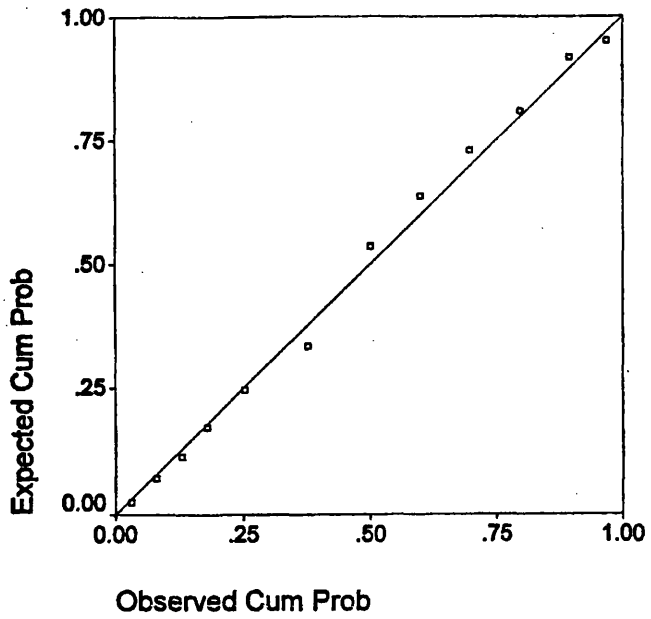


Table 1.3.2-18 : Normal P-P Plot of Daily Hassle Intensity : Autistic Group (N=20)

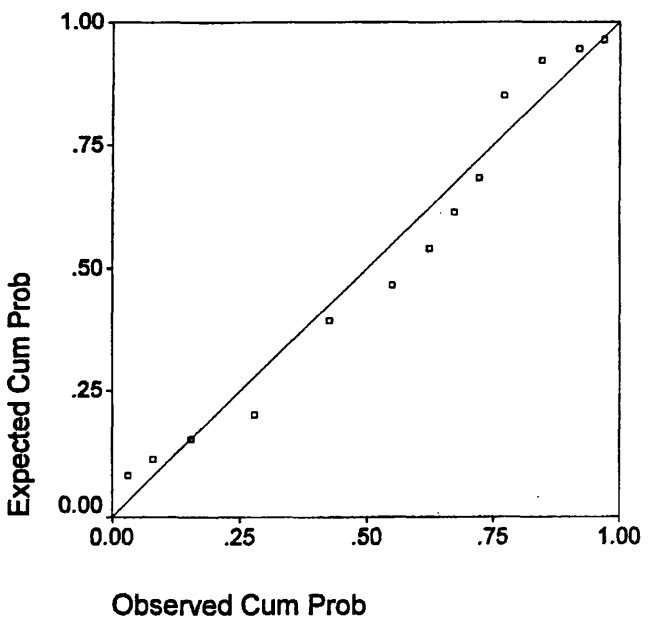


Table 1.3.2-19 : Normal P-P Plot of SES : Autistic Group (N=20)

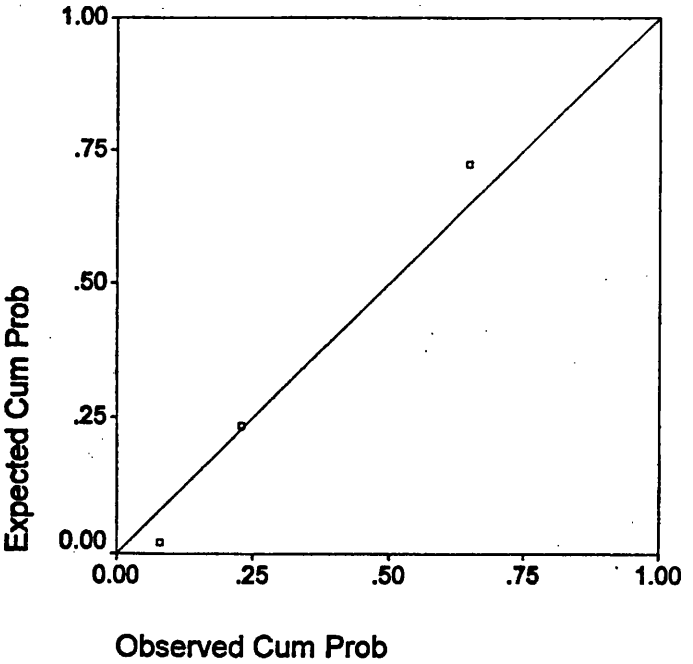
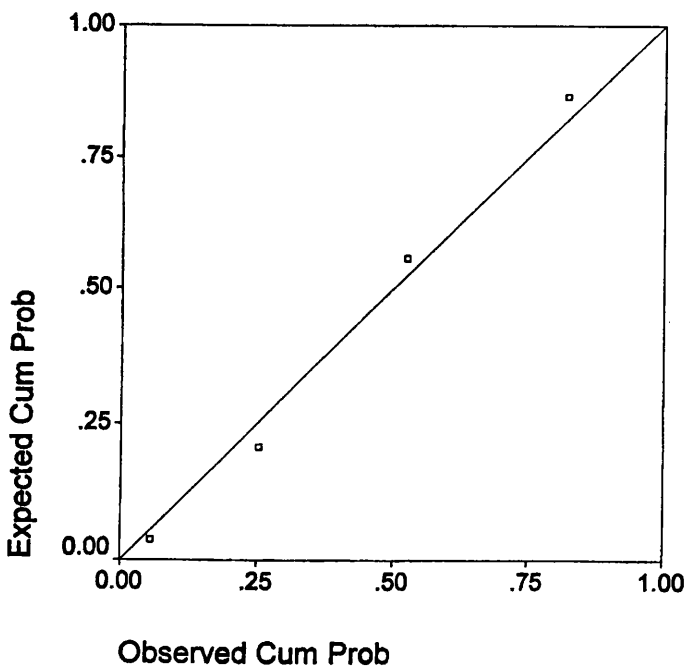


Table 1.3.2-20 : Normal P-P Plot of SPS : Autistic Group (N=20)



Appendix 1.3.3

Statistics : Tables and Graphs

Histograms

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University of Glasgow
Gartnavel Royal Hospital

Histograms

Table 1.3.3-1 : Parenting Stress Index (N=60)

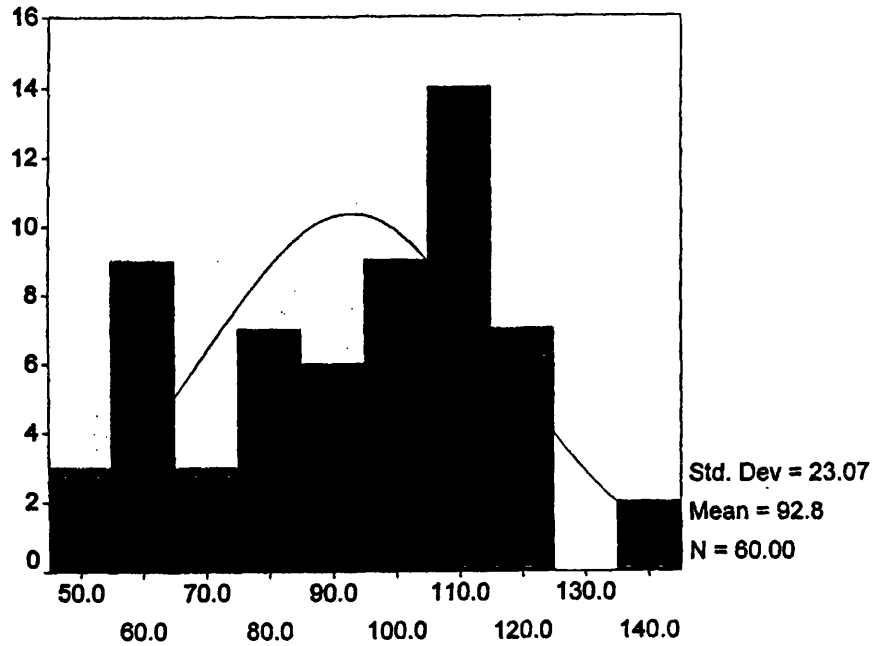


Table 1.3.3-2 : Parenting Stress Index : Normal Group (N=20)

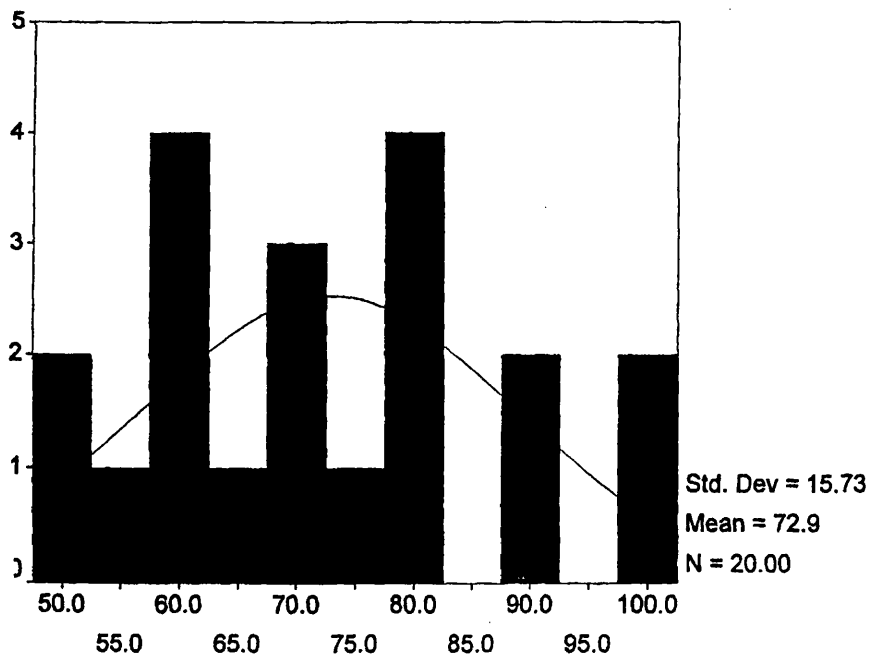


Table 1.3.3-3 : Parenting Stress Index : Downs Syndrome Group (N=20)

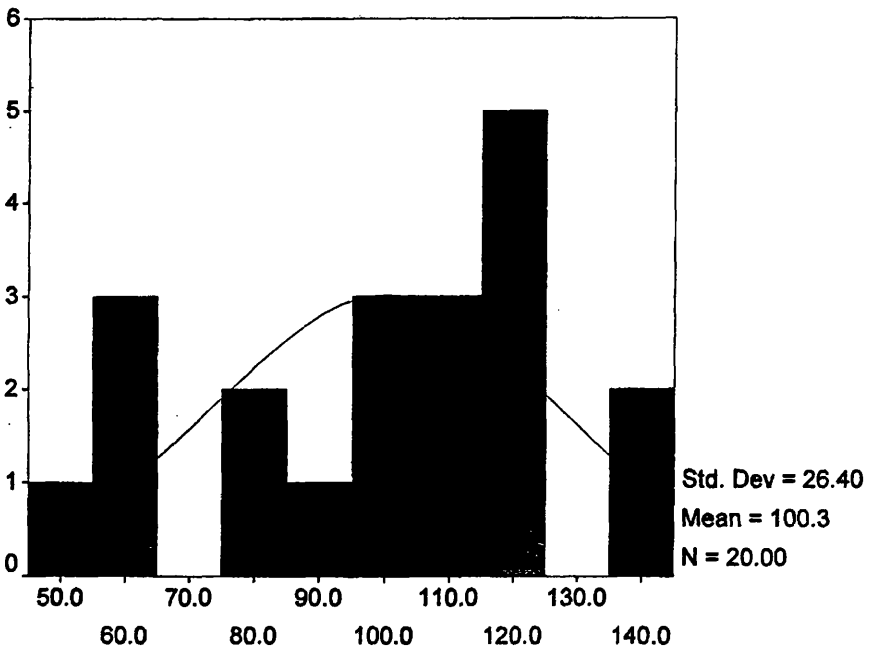


Table 1.3.3-4 : Parenting Stress Index : Autistic Group (N=20)

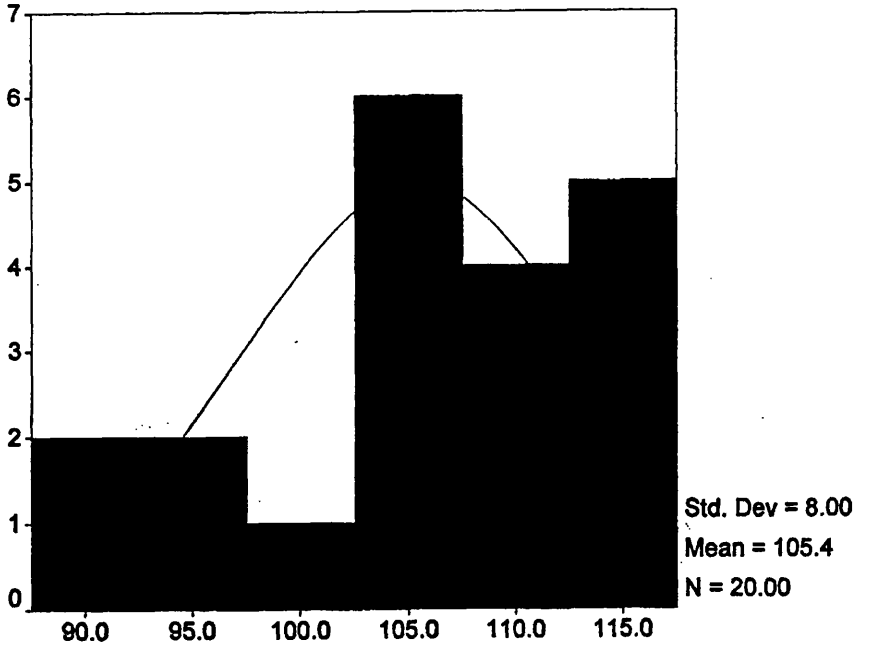


Table 1.3.3-5 : Daily Hassle Intensity (N=60)

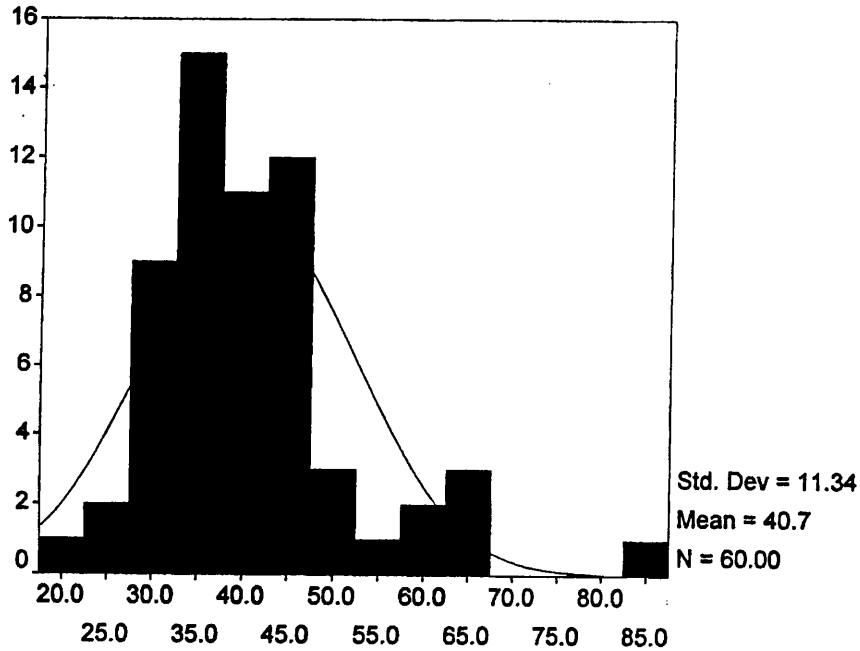


Table 1.3.3-6 : Daily Hassle Intensity : Normal Group (N=20)

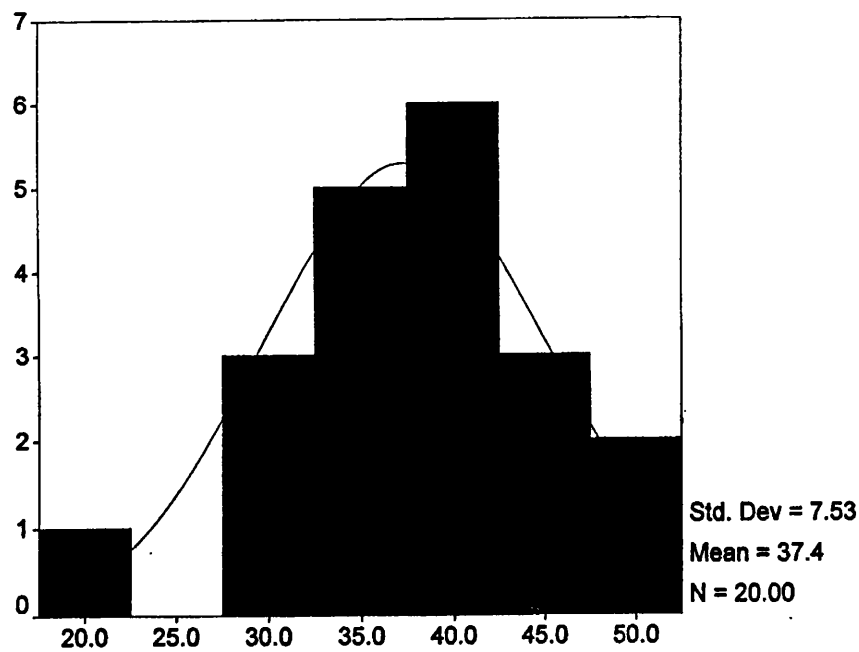


Table 1.3.3-7 : Daily Hassle Intensity : Downs Syndrome Group (N=20)

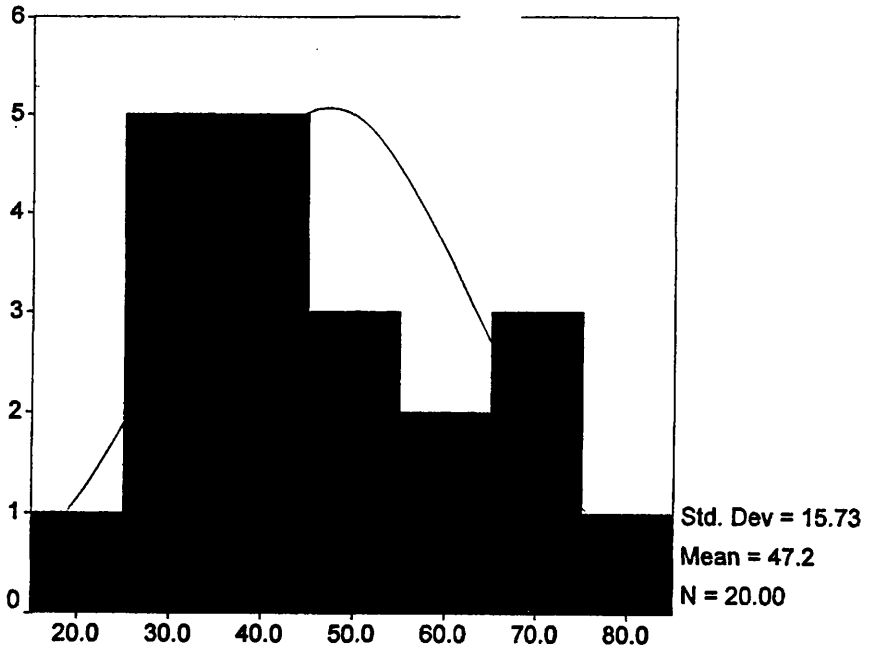
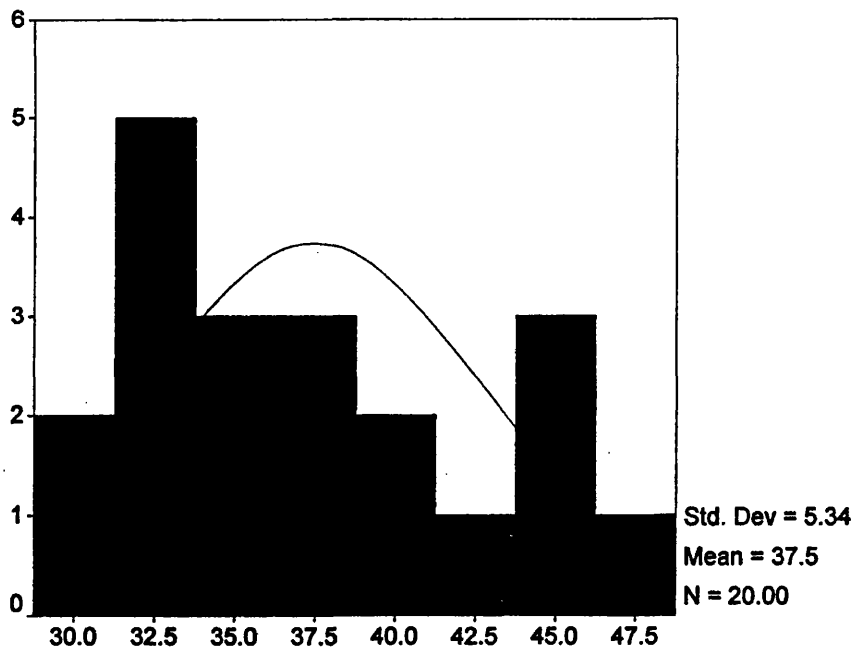


Table 1.3.3-7 : Daily Hassle Intensity : Autistic Group (N=20)



Appendix 2 :
Small Scale Evaluation Project

Evaluating a Clinical Child Psychological Service : Parent Satisfaction and Expectations

Appendix 2.1

Notes for Contributors :

Clinical Psychology Forum

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CLINICAL PSYCHOLOGY FORUM

Clinical Psychology Forum is produced by the Division of Clinical Psychology of The British Psychological Society. It is edited by Steve Baldwin, Lorraine Bell, Jonathan Calder, Lesley Cohen, Simon Gelsthorpe, Laura Golding, Craig Newnes, Mark Rapley and Arlene Vetere, and circulated to all members of the Division monthly. It is designed to serve as a discussion forum for any issues of relevance to clinical psychologists. The editorial collective welcomes brief articles, reports of events, correspondence, book reviews and announcements.

Notes for contributors

Articles of 1000-2000 words are welcomed. Shorter articles can be published sooner. Please check any references. Send two copies of your contribution, typed and double spaced. Contributors are asked to keep tables to a minimum; use text where possible.

News of Branches and Special Groups is especially welcome.

Language: contributors are asked to use language which is psychologically descriptive rather than medical and to avoid using devaluing terminology; i.e. avoid clustering terminology like "the elderly" or medical jargon like "schizophrenic".

Articles submitted to **Forum** will be sent to members of the Editorial Collective for refereeing. They will then communicate directly with authors.

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Appendix 2.2

Parent Satisfaction and Expectation Questionnaire (PSEQ)

Dr E.R. Haldane

Dept. of Psychological Medicine
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Parent Satisfaction and Expectation Questionnaire (PSEQ)

Please take the time to complete this questionnaire honestly as it will help us to improve our service. There is no need to write your name as all questionnaires are completely anonymous. Put the questionnaire into the envelope provided once you have completed it and seal the envelope. This will ensure the psychologist you have seen today will not see your answers.

Please tick the appropriate box.

		no not at all	no not very much	not sure	yes a little	yes a lot
Satisfaction						
1)	Was the psychologist pleasant?	☐	☐	☐	☐	☐
2)	Do you feel the psychologist listened to the problems?	☐	☐	☐	☐	☐
3)	Do you feel the problems were understood?	☐	☐	☐	☐	☐
4)	Were you given an explanation of the problems?	☐	☐	☐	☐	☐
5)	Did you find the visit helpful?	☐	☐	☐	☐	☐
Expectations and Aspirations						
6)	Was the psychologist what you expected?	☐	☐	☐	☐	☐
	If not, how was he/she different?					
	.....					
	.....					
7)	Did the session achieve what you hoped it would?	☐	☐	☐	☐	☐
	If not, how was it different?					
	.....					
	.....					
8)	Did the psychologist go about the job the way you expected?	☐	☐	☐	☐	☐
	If not, how was it different?					
	.....					
	.....					