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reSearch

A collection of research reviews on rehabilitation topics from NARIC and other information resources.

Coping Strategies for Parents of Children with Developmental and Intellectual Disabilities

The National Rehabilitation Information Center serves thousands of patrons each year. Our patrons include people with disabilities, advocates, rehabilitation professionals, educators, and researchers. Requests are answered by phone, mail, email, and AskMe, a chat-based reference service. While reviewing our website statistics we came upon a search string “need of coping strategies of parents of intellectually disabled children.” In this edition of *reSearch*, we explore the topic of coping strategies for parents of children with developmental and intellectual disabilities; specifically, children with autism, autism spectrum disorder (ASD), Asperger’s syndrome, and other developmental disabilities such as Down syndrome.

Being a parent can be both rewarding and challenging, even for parents of children without disabilities. Households today often have two income earners (i.e., both parents work outside of the home). In some cases, parents are co-parenting in a split household (i.e., divorce, single parenting, step-families) adding another dimension of stress and time in caring for children. The expense and time it takes to raise a child is compounded when a child has a disability. Children with developmental and/or intellectual disabilities may require additional time and expense to provide independent living and rehabilitative services (i.e., cognitive behavior therapy). The stress of having a child with a developmental and/or intellectual disability can take a toll on parents and cause relationship stress. A review of online resources and the research literature offers some “words of wisdom” (<http://www.womenshealth.gov/illnesses-disabilities/parenting/parenting-child-with-disability.html>):

- Become an expert on your child’s disability
- Locate resources and/or programs to assist your child
- Communicate with family and/or your co-parent about how you are feeling
- Communicate/reach out to other parents of children with similar disabilities (i.e., social support)

- Consider joining a support group (on- or offline)
- Try to stick with a daily routine and take one moment at a time
- Take care of yourself

This edition of *reSearch* provides a “snapshot” of research on coping strategies for parents of children and youth with developmental and intellectual disabilities. The combined search terms for this edition of *reSearch* included: parenting, children, coping, strategies, developmental disabilities, and intellectual disabilities. A listing of over 100 additional descriptor terms between the NARIC, ERIC, Cochrane, and PubMed databases can be found at the end of this document.

A search of the REHABDATA database resulted in 34 documents published between 1990 and 2013. A search of ERIC and Cochrane databases resulted in 40 documents between 1998 and 2001; and one document from 2013, respectively. Finally, a search of the PubMed database resulted in 28 documents between 1991 and 2013.

References

Office on Women’s Health, U.S. Department of Health and Human Services. (2009). *Parenting a child with a disability*. Retrieved from <http://www.womenshealth.gov/illnesses-disabilities/parenting/parenting-child-with-disability.html>.

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NIDRR Funded Projects Related to Parenting Children with Developmental and Intellectual Disabilities

In addition to document searches, we searched our NIDRR Program Database to locate grantees/projects related to parenting children with developmental and intellectual disabilities. The search resulted in seven currently funded NIDRR and six projects that are no longer active. Project information and their publications are offered as additional resources for our patrons.

Examination of the Use of a Spanish Version of the Online and Applied System for Intervention Skills (OASIS) Training Program with Parents of Children with an Autism Spectrum Disorder

Project Number: H133G110131

Phone: 913/588-5588

Email: lhpowell@ku.edu

www2.ku.edu/~lsi/research/projects/Buzhardt_J/examination_spanish_oasis.shtml

Experimental Evaluation of the Online and Applied System for Intervention Skills (OASIS) Training Program Using Video-Conferencing for Parents of Children with an Autism Spectrum Disorder

Project Number: H133G090136

Phone: 913/588-5588

Email: lhpowell@ku.edu

[www.lsi.ku.edu/research/projects/Heitzman-Powell L/autism children technologies.shtml](http://www.lsi.ku.edu/research/projects/Heitzman-Powell_L/autism_children_technologies.shtml)

Journal Writing Intervention in Alleviating Psychological Distress of Korean Mothers of Children with Developmental Disabilities

Project Number: H133F030018

Phone: 718/646-8255

Email: scho@fordham.edu

Rehabilitation Research and Training Center on Aging with Developmental Disabilities: Lifespan Health and Function

Project Number: H133B080009

Phone: 800/996-8845 (V), 312/413-1520 (V), 312/413-0453 (TTY)

Email: rrtcadd@uic.edu

www.rrtcadd.org

Research and Training Center on Community Living for People with Intellectual Disabilities

Project Number: H133B130006

Phone: 612/624-6024

Email: weste050@umn.edu

rtc.umn.edu

Rehabilitation Research and Training Center on Policies Affecting Families of Children with Disabilities

Project Number: H133B031133

Phone: 785/864-7600

Email: turnbull@ku.edu

www.beachcenter.org

Sustainable Implementation of Family-Centered Transition Planning for Young Adults with Autism Spectrum Disorders

Project Number: H133G110158

Phone: 603/228-2084

Email: david.hagner@unh.edu

www.unh.edu

These projects have completed their research activities...

Cross-Sector Patterns of Treatment for Children with Autism

Project Number: H133F120019

Phone: 815/753-2436

Email: lbilaver@niu.edu

Developing and Evaluating Family Networks: Positive Behavioral Support

Project Number: H133G60119

Phone: 813/974-6104

Email: vaughn@fmhi.usf.edu

Improving Parent Involvement Associated with School to Work Transition for Youth with Disabilities

Project Number: H133F990052

Phone: 614/799-8417

Email: fish.1@osu.edu

Interactive CD-ROM Technology for Home-Based Autism Intervention

Project Number: H133S040124

Phone: 970/495-0532
 Email: jcjjones@aol.com;
mjohnson@lamar.colostate.edu

Rehabilitation Research and Training Center on Policies Affecting Families of Children with Disabilities

Project Number: H133B031133
 Phone: 785/864-7600
 Email: turnbull@ku.edu
www.beachcenter.org

A Social Networking System for Parents and Professionals Working with Children with Autism Spectrum Disorders

Project Number: H133S080021
 Phone: 800/704-7815
 Email: amy.maguire@sandbox-learning.com



Documents from NARIC's REHABDATA search listed are listed below:

2013

McGrail, J.P., & Rieger, A. (2013). **Coping humor and family functioning in parents of children with disabilities.** *Rehabilitation Psychology*, 58(1), 89-97.

NARIC Accession Number: J65606

ABSTRACT: Study investigated whether coping humor predicted certain measures of family functioning in parents of children with disabilities. Seventy-two parents of children diagnosed primarily with autism spectrum disorders and multiple disabilities completed the Coping Humor Scale (CHS) and Family Adaptability and Cohesion Evaluation Scales (FACES IV). The FACES IV measures two major dimensions of family functioning: cohesion and flexibility. The CHS measures the degree to which participants use humor to cope with stressful experiences in their lives. Optimal functioning of the family is theorized to be based on a balanced level

of both cohesion and flexibility. In the present study, coping humor was hypothesized to predict balanced cohesion as well as balanced flexibility. The data were analyzed using single and hierarchical linear regression. The results indicated that coping humor significantly, albeit somewhat weakly, predicted cohesion and flexibility. However, the effects of education level and the number of children in the family also had a significant predictive effect on cohesion and flexibility. Contributions of the study, limitations, and implications for future research and clinical practice are discussed.

2012

Ahmedani, B.K., & Hock, R. (2012). **Parent perceptions of autism severity: Exploring the social ecological context.** *Disability and Health Journal*, 5(4), 298-304.

NARIC Accession Number: J64575

ABSTRACT: Study compared the social ecological contexts of parents of children with an autism spectrum disorder (ASD) and parents of non-autistic children. Social ecological factors of interest included variables depicting family physical environment, family social environment, and individual parent characteristics. Results indicate that parents of children with ASD had increased odds of reporting poor neighborhood social capital, greater aggravation, more difficulty coping, and lower levels of relationship satisfaction and mental health. Parents' perceptions of their child's ASD severity were associated with several factors of their social ecological context. More severe parent-reported ASD was associated with aspects of the physical environment (rundown housing and garbage on the street), the social environment (parent relationship satisfaction) and individual parent characteristics (parent aggravation and mental health). Results suggest ways that professionals can contextualize parent reports to aid in the diagnosis and treatment of children with ASD. Findings also highlight a need for longitudinal research using well-characterized measures to determine the nature and direction of relationships between contextual factors and parents' perceptions.

Serrata, C.A. (2012). **Psychosocial aspects of parenting a child with autism.** *Journal of Applied Rehabilitation Counseling (JARC)*, 43(4), 29-35.

NARIC Accession Number: J65360

ABSTRACT: This literature review examines the psychosocial aspects involved in parenting a child with autism. Parenting a child with autism not only has an impact upon the parents' psychological well-being, but the family and marriage systems as well. Research suggests that depression and stress levels are significantly higher in parents of children with autism than in parents of typically developing children. The literature available also shows that there is a negative correlation between stress and marriage quality for parents of children with autism. Financial stress is also common as treatments for autism are typically expensive. These findings suggest the importance of rehabilitation counselors in assessing the social networks and social supports of parents of children with autism, as well as providing them with professional and educational support.

2011

Hale, N. (2011). **Down syndrome parenting 101: Must-have advice for making your life easier.**

NARIC Accession Number: R09173

ABSTRACT: This book is an inspirational guide for parents, grandparents, and anyone who shares life with a person with Down syndrome. It's full of uplifting advice and best practices gleaned from the author's personal and professional experiences raising a son, now an adult, and 20 years spent tutoring children, teens, and adults with Down syndrome. She offers realistic wisdom and support concerning a host of important issues that parents may confront during their child's lifespan. She discusses everything from recognizing and celebrating your child's personality and gifts, finding a great teachers and therapists, and interacting with medical professionals, to learning how to encourage discipline and independence, dealing with school issues, and acknowledging your child as an adult. Chapters are purposely short so busy parents can read them individually or sequentially. And, an added bonus is the foreword by Martha Beck, parent of a child with Down syndrome and author of the New York Times bestseller, *Expecting Adam*.

2010

Anderson, K., & Forman, V. (Eds.). (2010). **Gravity pulls you in: Perspectives on parenting children on the autism spectrum.**

NARIC Accession Number: R09029

ABSTRACT: Book offers many different perspectives on what it's like being a parent of a child with autism. In 33 essays and poems, mothers and fathers raising children on the autism spectrum explore their lives in the context of autism's gravity, discovering what's important and what they find centering.

Greeff, A.P., & van der Walt, K.J. (2010). **Resilience in families with an autistic child.** *Education and Training in Autism and Developmental Disabilities*, 45(3), 347-355.

NARIC Accession Number: J59248

ABSTRACT: Study identified the characteristics and resources that families possess that enable them to adapt successfully, and be resilient despite the presence of an autistic child in the family. Self-report questionnaires were completed by the parents of 34 families whose children attended a special school for autistic learners. In addition, families were required to complete a biographical questionnaire and an open-ended question relating to their experience of factors relating to adaptation. The results highlight the importance of resilience factors in adaptation. The most significant resilience factors identified include: higher socioeconomic status, social support, open and predictable patterns of communication, supportive family environment, including commitment and flexibility, family hardiness, internal and external coping strategies, a positive outlook, and family belief systems.

2009

Skallerup, S.J. (Comp.). (2009). **Bebes con sindrome de Down: Nueva guía para padres, tercera edición.**

NARIC Accession Number: R09001 – Also available in English as R08947

ABSTRACT: Based on the revised English language edition published in 2008, this Spanish version provides comprehensive information concerning the best practices for raising and caring for children with Down syndrome from birth to age five. The book

incorporates the latest scientific, medical, educational research, and practical information available, as well as parents' advice and support. Topics include: causes, characteristics, and diagnosis of Down syndrome; coping with emotions and informing family and friends; medical concerns and treatments; daily care; family life; development and learning; early intervention; legal rights; and financial issues.

2008

Poston, D., Summers, J.A., Turnbull, A.P., & Turnbull, H.R. (2008). **Partnering with families of children with developmental disabilities to enhance family quality of life.** In H. P. Parette and G. Peterson-Karlan (eds.), *Research-based practices in developmental disabilities*. Austin, TX: Pro-Ed, 481-499.

NARIC Accession Number: J54458

Project Number: H133B031133

ABSTRACT: Chapter advises educators on how to enhance the quality of life (QOL) of families who have children and youth with developmental disabilities. Family QOL consists of: (1) disability-related support, (2) physical/material well-being, (3) parenting, (4) emotional well-being, and (5) family interaction. Teachers can address family QOL outcomes by providing supports, resources, and encouragement related to these five domains.

Skallerup, S.J. (Ed.). (2008). **Babies with Down syndrome: A new parents' guide, third edition.**

NARIC Accession Number: R08947 – Also available in Spanish as R09001

ABSTRACT: Book is designed to be a resource for parents of babies and young children with Down syndrome (DS). Chapters provide information covering what DS is, adjusting to a baby with DS, medical care, daily care, family life, development, early intervention, learning, legal rights, and more. The book includes glossary, reading list, and a resource guide.

2007

Baker, B. L., & Blacher, J. (2007). **Positive impact of intellectual disability on families.** *American Journal on Mental Retardation*, 112(5), 330-348.

NARIC Accession Number: J53974

ABSTRACT: Article discussed 2 studies that examined parents' perceived positive impact of a child with mental retardation. Study 1 involved the mothers of 282 young adults with moderate to profound mental retardation; study 2 involved the parents of 214 young children with or without intellectual disabilities. In both studies, positive impact was inversely related to behavior problems. Furthermore, positive impact moderated the relationship between behavior problems and parenting stress. Also, main and moderating effects of positive impact differed by parent ethnicity. The findings are discussed in the context of cultural beliefs.

Lin, LY., Orsmond, G.I., & Seltzer, M.M. (2007). **Mothers of adolescents and adults with autism: Parenting multiple children with disabilities.** *Intellectual and Developmental Disabilities (formerly Mental Retardation)*, 45(4), 257-270.

NARIC Accession Number: J53370

ABSTRACT: Study investigated the frequency and types of disabilities reported in siblings of adolescents or adults with autism spectrum disorders (ASD) and the impact that having multiple children with disabilities has on the mother's well-being and family functioning. Preliminary analyses indicated that 73 of the 325 families studied included more than one child with a disability. Subsequent analyses focused on 59 families that included only one other child with a disability in addition to the child with ASD. The most frequent disabilities in siblings were attention-deficit and hyperactivity disorders, (4.6 percent), ASD (2.4 percent), psychiatric disabilities (2.1 percent), and learning disabilities (2 percent). Mothers parenting another child with a disability in addition to the one with ASD had higher levels of depressive symptoms and anxiety and lower family adaptability and cohesion compared with mothers whose only child with a disability had ASD.

Marshak, L.E., & Prezant, F.P. (2007). **Married with special-needs children: A couples' guide to keeping connected.**

NARIC Accession Number: R08792

ABSTRACT: This book examines the stress that is often placed on a marriage when a couple has a child with a disability. The authors examine many of the

underlying stresses and concerns and present a wide range of strategies for handling or preventing common problems such as communication breakdowns, lack of romance and sexual intimacy, conflict over parenting styles and roles, intolerance of different coping and problem-solving strategies, differing expectations of a child, and issues arising in second marriages and blended families. For parents looking for ways to strengthen their marriage, prevent future strife, or resolve or move on from significant relationship difficulties, this guide offers guidance and expertise for taking the next step.

2006

Gavidia-Payne, S., & Stoneman, Z. (2006). **Marital adjustment in families of young children with disabilities: Associations with daily hassles and problem-focused coping.** *American Journal on Mental Retardation, 111*(1), 1-14.

NARIC Accession Number: J50521

ABSTRACT: Study examined the impact of stressors and daily hassles and the use of problem-focused coping strategies on marital adjustment (satisfaction) among mother and fathers of children with disabilities. Results showed that when daily stressors/hassles were higher, husbands and wives viewed their marriages more negatively. Mothers reported significantly more daily hassles than did fathers. Problem-focused coping did not differ by parent gender. Fathers who reported a greater number of daily hassles were less likely to use problem-focused strategies. Both mothers' and fathers' reports of marital adjustment were more positive when fathers reported fewer hassles and greater use of problem-focused coping.

2004

Abbeduto, L., Krauss, M.W., Murphy, M.M., Orsmond, G., Seltzer, M.M., & Shattuck, P. (2004). **Psychological well-being and coping in mothers of youths with autism, Down syndrome, or fragile X syndrome.** *American Journal on Mental Retardation, 109*(3), 237-254.

NARIC Accession Number: J48030

ABSTRACT: Study examined differences in the psychological well-being and coping of mothers of adolescents or young adults with autism, Down

syndrome, or fragile X syndrome. The dimensions of psychological well-being evaluated included the mother's feelings of pessimism about their child's future, perceptions of the quality of the mother-child relationship, and self-reported level of depressive symptoms. Researchers also examined the effects of coping strategies and the behavioral symptoms of the adolescent child or young adult on maternal psychological well-being. Results indicated that mothers of children with fragile X syndrome displayed lower levels of well-being than those of children with Down syndrome, but higher levels than mothers of children with autism, although group differences were found across the different dimensions of well-being. The strongest and most consistent predictor of maternal outcomes was the adolescent's or young adult's behavioral symptoms.

Blumberg, E.R., Horner, R.H., Irvin, L.K., Laverty, R., Lucyshyn, J.M., & Sprague, J.R. (2004). **Validating the construct of coercion in family routines: Expanding the unit of analysis in behavioral assessment with families of children with developmental disabilities.** *Research and Practice for Persons with Severe Disabilities (formerly Journal of the Association for Persons with Severe Handicaps JASH), 29*(2), 104-121.

NARIC Accession Number: J48356

ABSTRACT: Study investigated the construct validity of coercion in the daily routines of families raising young children with developmental disabilities and problem behavior. Coercive family process (coercion) refers to the interactions in which the parent and child reciprocally reinforce child problem behavior and ineffective parenting practices. Parent-child interaction in routines were observed, videotaped, coded, and analyzed. Following observation, the parents were interviewed about the social validity of the construct. They responded to a series of questions about family perspectives on the accuracy, acceptability, and potential usefulness of coercion in family routines. Results confirmed the presence of stable, attention-driven coercive processes in routines in which parents were occupied with non-child-centered tasks. Results partially confirmed the presence of escape-driven coercive processes in routines in which parent demands are common. An alternative pattern of parent-child interaction proved

to be more prevalent in escape-driven routines. Family perspectives suggested the social validity of the construct. Implications for behavioral assessment and intervention design are discussed.

Turnbull, A.P. (2004). **President's address 2004: "Wearing two hats": Morphed perspectives on family quality of life.** *Mental Retardation*, 42(5), 383-399.

NARIC Accession Number: J48196

Project Number: H133B980050

ABSTRACT: Current president of the American Association on Mental Retardation presents her own professional and family perspectives on ways to enhance family quality of life for families of children with developmental disabilities. The author provides an overview of the 5 domains of family quality of life: disability-related support, physical/material well-being, emotional well-being, parenting, and family interaction. She illustrates each domain with examples from her own family experiences and shares insights and next steps that families and professionals can take for addressing priority issues.

2003

Brown, C., Goodman, S., Kupper, L., & Smith, P.M. (2003). **Parenting a child with special needs.** *NICHCY News Digest, ND20, 3rd edition*, 1-16.

NARIC Accession Number: O14444

ABSTRACT: Issue discusses problems facing parents of a child with a disability and offers suggestions for potential resources and advice for living and coping with the impact of disability on the family.

Levy, J.M. (2003). **Promoting family health and resilience.** *Exceptional Parent*, 33(2), 54-57.

NARIC Accession Number: J45091

ABSTRACT: Article presents guidelines for reducing stress and promoting family wellness for parents who have a child with a disability. Strategies discussed include (1) parents considering their own needs first; (2) taking time for rest, relaxation, and recuperation; (3) practicing resilient behaviors; (4) dealing with guilt and anger; (5) developing coping strategies; (6) involving siblings; and (7) taking an inventory of stress triggers.

2002

Crowe, T.K., Cunningham-Sabo, L.D., Helitzer, D.L., & VanLeit, B. (2002). **Perceived changes in self-image and coping strategies of mothers of children with disabilities.** *Occupational Therapy Journal of Research*, 22(1), 25-33.

NARIC Accession Number: J43791

ABSTRACT: Mothers of children with disabilities participated in a short-term occupational therapy program. Focus groups were conducted to determine whether the women's coping strategies and views of themselves had changed as a result of the intervention. Results showed that participation in the program enabled the mothers to share their perceptions of their self-image such as feeling overwhelmed with their daily routine, being socially isolated, losing their identity, and expecting less from their careers. The program helped them feel strong, attractive, resilient, respected, and accepted. They expressed gaining coping skills such as increased ability to advocate for themselves and their child, relaxed expectations about their responsibilities, and increased self-care practices.

Lustig, D.C. (2002). **Family coping in families with a child with a disability.** *Education and Training in Mental Retardation and Developmental Disabilities*, 37(1), 14-22.

NARIC Accession Number: J44590

ABSTRACT: Study identifies the problem solving and coping strategies that affect family adjustment in families with a child with a disability. The Family Assessment Device-General Functioning scale measured family adjustment and the Family Crisis Oriented Personal Evaluation Scales (F-COPES) measured the family's problem solving and coping skills. Results indicated that greater use of reframing family problems and less frequent use of family passivity were associated with higher levels of family adjustment.

2001

Floyd, F.J., Greenberg, J.S., Hong, J., Pettee, Y., & Seltzer, M.M. (2001). **Life course impacts of parenting a child with a disability.** *American Journal on Mental Retardation*, 106(3), 265-286.

NARIC Accession Number: J42170

ABSTRACT: Study comparing midlife attainment and well-being for 165 parents of children with a developmental disabilities, 53 parents of children with a serious mental health problem, and 218 parents in a normative control group. Data are from the Wisconsin Longitudinal Study, collected when respondents were 18, 36, and 53 or 54. Results show that measures of attainment and well-being were similar for the three groups at age 18 but diverged thereafter. Parents of children with developmental disabilities had lower rates of employment, larger families, and lower rates of social participation than parents without children with disabilities, but were similar in education, marital status, physical health, and psychological well-being. Parents of children with serious mental health problems had normative patterns of educational and occupational attainment and marriage, but had higher levels of physical symptoms, depression, and alcohol symptoms at mid-life.

Symon, J.B. (2001). **Parent education for autism: Issues in providing services at a distance.** *Journal of Positive Behavior Interventions*, 3(3), 160-174.

NARIC Accession Number: J42378

ABSTRACT: Article reviewing research related to providing support services for families of children with autism, with particular attention to parent education regarding positive behavioral supports. The article highlights the need for additional resources and service delivery to remote rural locations. Other topics include barriers faced by families in obtaining services, family stress and family coping strategies, the role of parents as educators and the importance of teaching parents procedures for working with their children, pivotal response training, parent-professional collaboration, and the ecocultural framework for viewing the individual child within the context of the child's family and culture.

1999

Hughes, R.S. (1999). **An investigation of coping skills of parents of children with disabilities: Implications for service providers.** *Education and Training in Mental Retardation and Developmental Disabilities*, 34(3), 271-280.

NARIC Accession Number: J37357

ABSTRACT: Study using ethnographic methods to evaluate the coping mechanisms of parents of children

with disabilities. Thirty-four parents participated in the study. Results indicated that families who were active in church received ministry from the church, which enabled them to cope with stress and have a positive outlook for their child. The authors conclude that service providers who use family-centered planning can utilize and encourage the religious practices of the family as a resource.

1998

Ainge, D., Baker, S., & Colvin, G. (1998). **Analysis of perceptions of parents who have children with intellectual disabilities: Implications for service providers.** *Education and Training in Mental Retardation and Developmental Disabilities*, 33(4), 331-341.

NARIC Accession Number: J36004

ABSTRACT: Study comparing mothers' and fathers' views and attitudes on parenting a child with an intellectual disability. Fathers were found to be less well-represented by overall mean scores than mothers, and there were also differences between subgroups of mothers. Implications for service providers are discussed.

1997

Kasari, C., & Sigman, M. (1997). **Linking parental perceptions to interactions in young children with autism.** *Journal of Autism and Developmental Disorders*, 27(1), 39-57.

NARIC Accession Number: J33124

ABSTRACT: Examines the relation of parental perceptions and observed parent-child interactive behaviors. Examines parental perceptions of children's temperament and parental feelings of parenting stress observed with: normally developing children, children with autism, and children with mental retardation. Discusses observations.

Patterson, J.M. (1997). **Promoting resilience in families.**

NARIC Accession Number: O12649

Project Number: H133B40019

ABSTRACT: Paper about the concept of family resilience, and about ways service providers and policy makers can promote resilience in families. Discusses ways families become resilient, family

resources, family coping mechanisms, family identity, family adaptation, and the relationship between family functioning and individual development. Concludes with a list of strategies for promoting resilience in families.

1995

(1995). *Autism: Basic information, 3rd Edition*. NARIC Accession Number: R06913

ABSTRACT: Booklet designed to provide basic information about autism. The booklet is organized into the following sections: (1) autism fact sheet; (2) diagnosing autism and other pervasive developmental disorders, prognosis, and intervention; (3) the clinical and laboratory tests that should be performed, possible causes of autism, and genetic factors; and, (4) rights to early intervention and special education services, finding an appropriate school, and the parent's role in finding an appropriate placement. Information about DSM-IV diagnostic criteria, a summary of programmatic requirements, and a suggested reading list are included in appendices.

1993

Krauss, M.W. (1993). **Child-related and parenting stress: Similarities and differences between mothers and fathers of children with disabilities.** *American Journal on Mental Retardation*, 97(4), 393- 404.

NARIC Accession Number: J23993

ABSTRACT: Describes a study examining the extent of differences between mothers and fathers in the amount of stress and type of stress from parenting and care-giving of a disabled child. Data was obtained from the Early Intervention Collaborative Study which monitored developmental changes during the preschool years of 190 children and their families. Results of the study showed that fathers experienced more stress linked to their child's temperament and their relationship. Mothers' stress was associated with personal repercussions of general parenting. Family environmental effects were felt more by fathers while personal support networks were more helpful to mothers. Because the data from this study was obtained from parents at the onset of early intervention services, their feelings and opinions provide invaluable information concerning

their needs as they begin to care and cope with their disabled child, and for the service provider in designing an early intervention program for both the child and their family.

Smith, R. (editor). (1993). *Children with mental retardation: A parents' guide*.

NARIC Accession Number: R06462

ABSTRACT: Information guide for parents of children with mental retardation. Topics are presented by experts working in the various disciplines of assistance to families and children with varied degrees of mental retardation. Topics covered included the evaluation process, challenges presented to families and their daily life, strategies for coping with specific problems, education, and medical, legal, and advocacy issues. A glossary and reading list provides further resources for information.

1992

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

NARIC Accession Number: J22582

ABSTRACT: Study comparing the psychosocial adaptation of fathers of children with autism, Down syndrome, and normal development. Three groups of 20 fathers were matched on the child's adaptive behavior age equivalent, gender, birth order, family size, and socioeconomic status. The groups were compared on measures of perceived parenting competence and satisfaction, coping styles, marital adjustment, family cohesion and adaptability, impact on family, and social support. Fathers of the developmentally disabled children reported more disruption in family planning and increased financial burden because of their child, but their levels of perceived parenting competence, marital satisfaction, and social support were similar to those reported by fathers of normally developing children. The hypothesis that fathers of children with autism would report more adjustment problems than fathers of children with Down syndrome was not supported. However, fathers of sons with developmental disabilities were more satisfied with their parenting role than were fathers of daughters with disabilities.

1991

Cameron, S.J., Day, D.M., & Orr, R.R. (1991). **Coping with stress in families with children who have mental retardation: An evaluation of the double ABCX Model.** *American Journal on Mental Retardation*, 95(4), 444-450.

NARIC Accession Number: J19012

ABSTRACT: Study using path analysis techniques to examine the relations among the variables in the Double ABCX model of family stress and coping. Subjects were 86 families of children with mental retardation. The families' use of resources (B) and perception of the stressor event (C) were examined to determine their relation to the stressor (A) and the stress experiences (X). The causal ordering of the model suggested an ACBX path rather than an ABCX path. The findings are discussed in terms of their consistency with models of clinical intervention.

Geffken, G.R., Morgan, S.B., & Rodrigue, J.R. (1991). **A comparative evaluation of adaptive behavior in children and adolescents with autism, Down syndrome, and normal development.** *Journal of Autism and Developmental Disorders*, 21(2), 187-196.

NARIC Accession Number: J20350

ABSTRACT: Study using the Vineland Adaptive Behavior Scale to compare the adaptive behaviors of 20 children with autism, 20 with Down syndrome, and 20 with normal development. The subjects were matched on adaptive behavior age equivalent, gender, race, birth order, family size, and socioeconomic status. There were three main findings: (1) the socialization skills of children with autism were significantly deficient relative to those of children with Down syndrome or normal development; (2) the children with autism had deficits in all three socialization subdomains (interpersonal relationships, use of play and leisure time, and coping skills); and (3) the children with autism exhibited considerable variability in adaptive behavior compared with children with Down syndrome and those with normal development.

Singer, G., & Todis, B. (1991). **Stress and stress management in families with adopted children who have severe disabilities.** *Journal of the Association for Persons with Severe Handicaps*, 16(1), 3-13.

NARIC Accession Number: J19974

ABSTRACT: Qualitative study examined stress and coping in six families which adopted two or more children with developmental disabilities. Using in-depth, semistructured interviews, researchers collected data over a 5-month period. General topics included sources of family stress, stress management strategies, experiences with schools, medical community, and public agencies, decision to adopt one or more children with disabilities, parent's plans for future, positive aspects of parenting child with disabilities, and sources of instrumental and social support. Researchers also attended adoptive support group meeting to compare views of parents having one child without disabilities with those having adopted more than one with disabilities. According to results, management of daily household tasks and child care routines were not stressful, but interactions with school and medical personnel and other professionals were extremely stressful. Time-limited stressful situations included medical crises and crises due to adolescent behavior problems. Some of their effective stress management techniques were household organizational systems and keeping contact with other families in the same situation. Families who had a positive appraisal of life circumstances more successfully adjusted to potentially stressful situations.

1990

Winston, P.J. (1990). **Promoting a normalizing approach to families: Integrating theory with practice.** *Topics In Early Childhood Special Education*, 10(2).

NARIC Accession Number: J17096

ABSTRACT: Describes how ABCX Model of Family Adaptation can be used as framework for identifying family strengths and linking that information to outcomes and implementation plans in ways reflective of normalization principle. Also looks at how to apply ABCX model as structure for collecting data with family around one individualized family service plan (IFSP) related topic. Focuses on how to promote normalizing approach to intervention with families. Examines ABCX model of family functioning in terms of defining family strengths (external resources, internal coping strategies, passive appraisal, and reframing). Discusses application of ABCX model

to parental selection of preschool program (potential family resources; potential family perceptions; and interaction of resources and perception).

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Documents from the Education Resource Information Center (ERIC) search at www.eric.ed.gov are listed below:

2013

Bradshaw, C.P., Stuart, E.A., & Zablotsky, B. (2013). **The association between mental health, stress, and coping supports in mothers of children with autism spectrum disorders.** *Journal of Autism and Developmental Disorders*, 43(6), 1380-1393.

ERIC Number: EJ1004130

ABSTRACT: Raising a child with an autism spectrum disorder (ASD) can be a stressful experience for parents. When left unmanaged, high stress levels can lead to the development of depressive symptomatology, highlighting the importance of coping supports. The current paper examined the stress level and psychological wellbeing of mothers with a child with ASD in a national survey. After adjusting for child, mother and family level characteristics, it was determined that mothers of children with ASDs were at greater risk for poor mental health and high stress levels compared to mothers of children without

ASDs. The presence of maternal coping strategies, in the form of emotional and neighborhood social supports, as well as strong coping skills, reduced these risks between models.

Clifford, T., & Minnes, P. (2013). **Who participates in support groups for parents of children with autism spectrum disorders? The role of beliefs and coping style.** *Journal of Autism and Developmental Disorders*, 43(1), 179-187.

ERIC Number: EJ998734

ABSTRACT: One hundred forty-nine parents of children with autism spectrum disorders (ASD) completed online questionnaires measuring their beliefs about support groups and ASD, coping style, social support, mood, and use of support groups. Those currently using parent support groups (PSGs) reported using more adaptive coping strategies than both parents who had never used PSGs and parents who had used PSGs in the past. Past PSG users reported that they did not find the groups as beneficial as current users, and parents who had never participated in PSGs reported difficulties with the accessibility of PSGs. Based on the current results, interventions for parents of children with ASD that are focused on meeting the needs identified by participating parents may be most effective.

Kelly, G., McConkey, R., & Samadi, S.A. (2013). **Enhancing parental well-being and coping through a family-centered short course for Iranian parents of children with an autism spectrum disorder.** *Autism: The International Journal of Research and Practice*, 17(1), 27-43.

Full-text is available at <http://aut.sagepub.com/content/16/1/5.full.pdf+html>

ERIC Number: EJ1008837

Parents of children with Autism Spectrum Disorders (ASD) generally experience high levels of stress and report poorer emotional well-being and family functioning compared to parents of children with other disabilities. They also tend to rely on emotional rather than problem-focused coping strategies. Seven group-based sessions were offered to two groups of parents of children with ASD in Iran (37 in all). In addition to providing information about ASD emphasis was placed on families sharing their experiences and learning from one another. A pre-

post, cross-over design was used to evaluate the specific impact of the course. The changes found among the parents in the first group were replicated with the second group. Moreover the changes were sustained up to 15 weeks after the course ended. Although there were variations across the parents, in general they reported feeling less stress, had better emotional well-being and family functioning and made more use of problem-focused coping strategies. The changes were attributed mainly to an increase in the informal supports among the parents and their feelings of empowerment. A resource pack has been developed to enable the group sessions to be easily repeated and for facilitators to be trained in its use.

Mulder, E., Tudor, M.E., & Walsh, C.E. (2013). **Predictors of parent stress in a sample of children with ASD: Pain, problem behavior, and parental coping.** *Research in Autism Spectrum Disorders*, 7(2), 256-264.

ERIC Number: EJ1006373

ABSTRACT: Studies have shown that children with ASD have increased severity and incidence of pain symptoms compared to typically developing children and children with other disorders. Pain has also been shown to act as a setting event for problem behavior. Further, problem behavior is one of the biggest impediments to quality of life for families and highly relates to parent stress. This study examined pain and problem behavior as predictors of parent stress and also examined how parenting style interacted with pain and problem behavior to influence parent stress. Results showed that problem behavior was a moderating factor between pain and parent stress and there was a significant interaction between pain and problem behavior predicting stress. An overprotective parenting style also moderated the relationship between pain and parent stress and there was an interaction between the two factors predicting stress. Implications are discussed in terms of treatments that focus on children's behavior and parenting behavior in order to improve quality of life in families of children with ASD.

2012

Balandin, S., Hines, M., & Togher, L. (2012). **Buried by autism: Older parents' perceptions of autism.** *Autism: The International Journal of Research and*

Practice, 16(1), 15-26.

Full-text is available at <http://aut.sagepub.com/content/16/1/15.full.pdf+html>

ERIC Number: EJ956809

ABSTRACT: In this study, we explored older parents' perceptions of their adult sons and daughters with autism in order to gain insights into how parents' beliefs about autism may influence their coping. Narrative analysis of in-depth interviews held with 16 parents aged 60 years and older of adults with autism revealed that these parents perceived that their son's or daughter's intelligence, sense of humor and social personality are blocked by autism. Adherence to these beliefs appeared to comprise important coping strategies that supported these parents in their caregiving roles by assisting them to maintain positive perceptions of their son or daughter with autism. Yet such beliefs also held costs for the parents, including reinforcing the belief that they need to regulate their own behavior in order to realize the true son or daughter buried by autism.

Cappadocia, M.C., Lunsy, Y., MacMullin, J.A., Viecili, M., & Weiss, J.A. (2012). **The impact of child problem behaviors of children with ASD on parent mental health: The mediating role of acceptance and empowerment.** *Autism: The International Journal of Research and Practice*, 16(3), 261-274.

ERIC Number: EJ967971

ABSTRACT: Raising a child with an autism spectrum disorder (ASD) has often been associated with higher levels of parenting stress and psychological distress, and a number of studies have examined the role of psychological processes as mediators of the impact of child problem behavior on parent mental health. The current study examined the relations among child problem behavior, parent mental health, psychological acceptance, and parent empowerment. Participants included 228 parents of children diagnosed with ASD, 6-21 years of age. As expected, psychological acceptance and empowerment were negatively related to the severity of parent mental health problems. When acceptance and empowerment were compared with each other through a test of multiple mediation, only psychological acceptance emerged as a significant partial mediator of the path between child problem behavior and parent mental health problems. As child problem behavior increased,

parent psychological acceptance decreased, resulting in an increase in parent mental health problems. These findings suggest that for problems that are chronic and difficult to address, psychological acceptance may be an important factor in coping for parents of young people with ASD, in line with the growing literature on positive coping as compared with problem-focused coping.

Glazzard, J., & Overall, K. (2012). **Living with autistic spectrum disorder: Parental experiences of raising a child with autistic spectrum disorder (ASD).** *Support for Learning*, 27(1), 37-45.

ERIC Number: EJ955676

ABSTRACT: The focus of the study was to explore parental experiences of raising a child with autistic spectrum disorder (ASD). A mixed-method approach consisting of questionnaires and semi-structured interviews was used in order to elicit parental perspectives of raising a child with ASD. Two semi-structured interviews were conducted with parents of children with ASD. Questionnaires were sent to parents of children with ASD in two special schools. The findings indicate that although each of the parents had a child with ASD, their experiences were all different. Many interesting accounts were documented and a wealth of information regarding the characteristic traits that children with ASD portray was recorded. The findings suggested that the majority of the parents experienced a low level of support from agencies and professionals. The general verdict was that of poor communication and a lack of understanding of parents' needs following formal diagnosis. Finally, a series of coping strategies were discovered ranging from family support to paid help.

Manor-Binyamini, I. (2012). **Parental coping with developmental disorders in adolescents within the ultraorthodox Jewish community in Israel.** *Journal of Autism and Developmental Disorders*, 42(5), 815-826.

ERIC Number: EJ962761

ABSTRACT: This preliminary study compares the coping strategies used by 100 ultraorthodox Jewish parents and 100 secular Jewish parents for dealing with adolescent children with developmental disorders. The parents completed two questionnaires on the sense of stress-related personal growth and

the sense of coherence. The ultraorthodox parents reported a higher sense of growth and a higher sense of coherence than the secular parents. In addition, there were associations found between demographic characteristics. Gender differences between mothers and fathers in the sense of growth and community differences between ultraorthodox fathers and secular fathers in the sense of coherence are discussed. The study highlights the uniqueness of the religious point of view in dealing with adolescent children with developmental disorders.

2011

Crais, E.R., & Flippin, M. (2011). **The need for more effective father involvement in early autism intervention: A systematic review and recommendations.** *Journal of Early Intervention*, 33(1), 24-50.

ERIC Number: EJ920652

ABSTRACTS: Fathers of children with autism spectrum disorders (ASD) are underrepresented in both early intervention and research. However, fathers have unique interaction styles that make important contributions to the language and symbolic play development of typically developing children. Fathers may make similar contributions to the development of their children with ASD, who struggle with social-communicative deficits, particularly in the areas of language and symbolic play. This article provides a theoretical rationale for enhancing father-child involvement in early autism intervention that may lead to improved outcomes in child communication and symbolic play and have cascading benefits for families in reducing stress and enhancing coping mechanisms. To support this rationale, systematic reviews of the literature were conducted to (a) identify the extent of father involvement in parent training programs for children with autism, (b) identify the contributions of parents to the symbolic play outcomes of their children with ASD and other disabilities, and (c) examine differences in stress and coping experienced by mothers and fathers of children with ASD. Finally, possible barriers to father participation in early autism intervention are discussed and recommendations are offered for making parent-implemented early intervention for children with ASD more amenable to fathers.

Day, M.S., Michaels, C.A., & Wang, P. (2011). **Stresses and coping strategies of Chinese families with children with Autism and other developmental disabilities.** *Journal of Autism and Developmental Disorders*, 41(6), 783-795.

ERIC Number: EJ925314

ABSTRACT: Data from 368 families of children with autism and other developmental disabilities in the People's Republic of China were gathered to understand the stresses that families experience and the coping strategies they employ. Chinese families of children with developmental disabilities perceived high levels of stress related to pessimism, child characteristics, and parent and family problems. Regarding coping strategies, acceptance, active coping, positive reinterpretation and growth, suppression of competing activities, and planning were the most frequently employed coping strategies. Parents of children with autism experienced more stress and used planning as a coping strategy to a greater degree than parents of children with other developmental disabilities. The implications and limitations of these findings are discussed.

Kaniel, S., Siman-Tov, A. (2011). **Stress and personal resource as predictors of the adjustment of parents to autistic children: A multivariate model.** *Journal of Autism and Developmental Disorders*, 41(7), 879-890.

ERIC Number: EJ928801

ABSTRACT: The research validates a multivariate model that predicts parental adjustment to coping successfully with an autistic child. The model comprises four elements: parental stress, parental resources, parental adjustment and the child's autism symptoms. 176 parents of children aged between 6 to 16 diagnosed with pervasive developmental disorders (PDD) answered several questionnaires measuring parental stress, personal resources (sense of coherence, locus of control, social support) adjustment (mental health and marriage quality) and the child's autism symptoms. Path analysis showed that sense of coherence, internal locus of control, social support and quality of marriage increase the ability to cope with the stress of parenting an autistic child. Directions for further research are suggested.

Manor-Binyamini, I. (2011). **Mothers of children with developmental disorders in the Bedouin community in Israel: Family functioning, caregiver burden, and coping abilities.** *Journal of Autism and Developmental Disorders*, 41(5), 610-617.

ERIC Number: EJ921938

ABSTRACT: This preliminary study compares the family functioning, caregiver burden, and coping abilities between mothers of 300 children with developmental disorders and mothers of 100 children with no such disorders in the Bedouin community in Israel. The mothers completed the McMaster Family Assessment Device Scale, the Caregiver Burden Index, and the Sense of Coherence Scale. Mothers of children with developmental disorders reported lower family functioning, a higher caregiver burden, and a lower sense of coherence and thus lower coping abilities than mothers of children with no disorders. The study highlights the need to provide professional support for mothers of children with developmental disorders and to develop awareness and culturally appropriate intervention programs to enhance these mothers' coping abilities.

2010

Benson, P.R. (2010). **Coping, distress, and well-being in mothers of children with autism.**

Research in Autism Spectrum Disorders, 4(2), 217-228.

ERIC Number: EJ869977

ABSTRACT: As is the case in stress research generally, studies examining the relationship between coping and mental health outcomes in parents of children with autism frequently classify parental coping methods as being either problem- or emotion-focused. We argue that this dichotomization of coping strategies oversimplifies the way parents respond to their child's autism. In the present study, the coping methods employed by 113 mothers of children with autism were investigated using the Brief COPE (Carver et al., 1989). Exploratory factor analysis of Brief COPE subscales identified four reliable coping dimensions: engagement coping, distraction coping, disengagement coping, and cognitive reframing coping. In addition, using multiple regression, we examined the relationship of

coping strategies to negative and positive maternal outcomes (depression, anger, and well-being). In general, maternal use of avoidant coping (distraction and disengagement) was found to be associated with increased levels of maternal depression and anger, while use of cognitive reframing was associated with higher levels of maternal well-being. In several instances, child characteristics, particularly severity of child maladaptive behavior, moderated the effect of coping on maternal outcomes. Study findings are discussed in light of previous research in the area; in addition, study limitations and clinical implications are highlighted.

Burroughs, T., Darragh, A.R., Kuhaneck, H.M., Lemaczyk, T., & Wright, J. (2010). **A qualitative study of coping in mothers of children with an autism spectrum disorder.** *Physical & Occupational Therapy in Pediatrics, 30*(4), 340-350.

ERIC Number: EJ961923

ABSTRACT: A significant body of research exists that explores the stressors of raising a child with an autism spectrum disorder (ASD). There are fewer studies, however, that examine specific effective coping strategies of mothers of children with an ASD. This qualitative study explored mothers' perceptions of effective coping strategies for their parenting stressors. In-depth interviews were conducted with 11 mothers to inquire about their personal coping methods. Interviews were coded and emergent themes identified that included coping strategies such as "me time," planning, knowledge is power, sharing the load, lifting the restraints of labels, and recognizing the joys. The information from this study may benefit mothers of children with ASD and inform pediatric therapists providing services to children with ASD and their families.

Cant, R., Gething, L., Kendig, H., Llewellyn, G., & McConnell, D. (2010). **Health status and coping strategies among older parent-carers of adults with intellectual disabilities in an Australian sample.** *Research in Developmental Disabilities: A Multidisciplinary Journal, 31*(6), 1176-1186.

ERIC Number: EJ900320

ABSTRACT: Background: Older parent-carers in Australia are the subject of increasing policy and practice attention due to concerns about their ongoing

ability to care in the light of their own ageing and the ageing of their adult son or daughter. This paper examines health status and the coping strategies of a group of older Australian parents caring for an adult son or daughter with intellectual disabilities. Method: Health status using the SF-12 (Ware, Snow, Kosinski, & Gandek, 1993), caring stress using the CADI (Nolan, Grant, & Keady, 1998), and coping strategies using the CAMI (Nolan et al., 1998) were assessed in 64 older parent-carers of adults with intellectual disabilities. Results: The self-reported health status of this sample of older parent-carers did not differ significantly from Australian population norms, with one exception. That is, the younger parent-carers in the sample (55-64 years) reported significantly poorer mental health. Better health was associated with having a partner, a larger and close support network of family, friends and neighbors, and a lower care-load. Overall, the study participants identified both satisfaction as well as stress associated with caring, a finding that runs counter to the common perception that being a carer is overwhelmingly burdensome. Common sources of stress were feeling helpless or not in control, and poor professional support. Analysis of older parent-carers coping strategies suggests that self-reliance, whether by choice or necessity, was the norm. Conclusions: The health status of older parent-carers may present less cause for concern than anecdotal reports suggest. That said, the strong self-reliance particularly of the older carers presents a challenge to service providers seeking to engage those whose situation appears to warrant support from the service system.

Dabrowska, A., & Pisula, E. (2010). **Parenting stress and coping styles in mothers and fathers of pre-school children with autism and Down syndrome.** *Journal of Intellectual Disability Research, 54*(3), 266-280.

ERIC Number: EJ872989

ABSTRACT: Background: The study examined the profile of stress in mothers and fathers of preschool children with autism, Down syndrome and typically developing children. A further aim was to assess the association between parenting stress and coping style. Methods: A total of 162 parents were examined using Holroyd's 66-item short form of Questionnaire of Resources and Stress for Families with Chronically Ill

or Handicapped Members and the Coping Inventory for Stressful Situations by Endler and Parker. Results and Conclusions: The results indicated a higher level of stress in parents of children with autism. Additionally, an interaction effect was revealed between child diagnostic group and parent's gender for two scales of parenting stress: dependency and management and limits of family opportunities. Mothers of children with autism scored higher than fathers in parental stress; no such differences were found in the group of parents of children with Down syndrome and typically developing children. It was also found that parents of children with autism differed from parents of typically developing children in social diversion coping. Emotion-oriented coping was the predictor for parental stress in the samples of parents of children with autism and Down syndrome, and task-oriented coping was the predictor of parental stress in the sample of parents of typically developing children. The results strongly supported earlier findings on parenting stress in parents of children with autism. They also shed interesting light on the relationship between coping styles and parental stress.

Dunleavy, A.M., Leon, S.C., Lyons, A.M., & Roecker Phelps, C.E. (2010). **The impact of child symptom severity on stress among parents of children with ASD: The moderating role of coping styles.** *Journal of Child and Family Studies*, 19(4), 516-524.

ERIC Number: EJ891099

ABSTRACT: We examined the impact of autism severity and parental coping strategies on stress in parents of children with ASD. Children's autism symptoms and parental coping strategies (task-oriented, emotion-oriented, social diversion, and distraction) were evaluated as predictors of four types of parental stress (parent and family problems, pessimism, child characteristics, and physical incapacity). In order to examine potential buffering effects of coping strategies on stress associated with the child's symptom severity, the interactive effects of autism symptoms with coping strategies were also examined. Participants included 77 primary caregivers of a child with ASD. Using multiple regression analyses, emotion-oriented coping scores were associated with more parent and family problems, and task-oriented coping was associated with lower physical incapacity scores. The child's

autism severity was the strongest and most consistent predictor of stress. Further, emotion-oriented coping moderated the relationship between pessimism stress and autism symptomatology, and distraction coping was a moderator between parent and family stress and autism symptoms. Results indicate that increasing our knowledge of the coping strategies that are more or less effective and under what conditions some coping strategies may be either beneficial or harmful for this population of parents has direct implications for treatment and parent education efforts.

Ebata, A.T., Halle, J.W., & Meadan, H. (2010). **Families with children who have autism spectrum disorders: Stress and support.** *Exceptional Children*, 77(1), 7-36.

ERIC Number: EJ898538

ABSTRACT: Many individuals with autism spectrum disorders (ASD) have behavior repertoires that might be expected to have an impact on members of both the immediate and extended family. This article examines this impact, reviewing relevant literature related to stressors and supports for families of individuals with ASD. The focus of the article highlights research on stressors and supports in the following areas (a) stress in the marital subsystem, (b) stress in the parental subsystem, (c) stress in the sibling subsystem, (d) coping strategies used by families, and (e) informal and formal sources of support used by families. Implications and recommendations for future research and practice are discussed.

Kossakowska, Z., & Pisula, E. (2010). **Sense of coherence and coping with stress among mothers and fathers of children with autism.** *Journal of Autism and Developmental Disorders*, 40(12), 1485-1494.

ERIC Number: EJ905279

ABSTRACT: The purpose of the study was to compare the level of sense of coherence (SOC) in parents of children with autism and in parents of typically developing children, and to examine the association between SOC level and coping strategies. Two questionnaires were used: Sense of Coherence Scale (SOC-29) and Ways of Coping Questionnaire. Parents of children with autism had a lower level of the total SOC, meaningfulness, and manageability compared with controls, and used

escape-avoidance coping more often. No differences in SOC level were found between mothers and fathers. In parents of children with autism the SOC level was positively associated with seeking social support and self-controlling, and negatively with accepting responsibility and positive reappraisal.

2009

Altieri, M.J., & von Kluge, S. (2009). **Family functioning and coping behaviors in parents of children with autism.** *Journal of Child and Family Studies*, 18(1), 83-92.

ERIC Number: EJ851257

ABSTRACT: We analyzed family dynamics and coping behaviors of parents with a child with an autistic spectrum disorder. Previous research suggests that moderate levels of cohesion and adaptability are associated with higher levels of positive coping, and that the more coping strategies a family implements, the greater their satisfaction with family functioning. Using a family systems approach, the relationships among the familial variables of cohesion, adaptability, and social support were evaluated for their contributions to coping in the family unit. We also compared the responses of mothers and fathers. Surprisingly, for these parents of children with autism, those who rated their family as enmeshed implemented more positive coping strategies than did those from other cohesion styles. This finding suggests that the enmeshed style may be more adaptive for a family that encounters extreme challenges. Notably, mothers and fathers agreed on all variables except for perception of social support from family and friends. Mothers perceived more social support from family and friends. The results lead to several interesting suggestions for future research.

Bedesem, P., Boyd, B.A., & Mancil, G.R. (2009). **Parental stress and autism: Are there useful coping strategies?** *Education and Training in Developmental Disabilities*, 44(4), 523-537.

ERIC Number: EJ883887

Full-text is available at <http://tinyurl.com/pejgtjq>

ABSTRACT: According to previous researchers, parents of children diagnosed with Autism Spectrum Disorders (ASD) consistently report more stress than parents of typically developing children or children with other developmental disorders (e.g., Down

syndrome). This has peaked interest in the field in a related area, that being, identifying the coping strategies parents use to deal with the stressors of rearing a child on the autism spectrum. The available literature on coping strategies primarily has focused on interviewing parents to find out what strategies they currently use and if these are effective, which has resulted in mixed findings. A selected synthesis of the stress literature pertaining to coping strategies is provided to highlight the high levels of reported stress already experienced by families of children with ASD and what strategies the parents report aid them in coping with the stress. This literature review is presented for two purposes: (a) highlight relevant findings and methodological issues with current research, and (b) discuss implications for researchers and practitioners working with children with ASD and their families who exhibit increased levels of stress.

Canham, D., Luong, J., Yoder, M.K. (2009). **Southeast Asian parents raising a child with autism: A qualitative investigation of coping styles.** *Journal of School Nursing*, 25(3), 222-229.

ERIC Number: EJ877329

ABSTRACT: Autism is a developmental disability increasing in incidence over the past decade. Parents of children with autism experience prolonged levels of stress and isolation. Using qualitative research design, nine parents of children with autism participated in this study that focused on the effect of autism on the family, coping styles, and support systems. The target population was first-generation Southeast Asian American parents. Results revealed nine coping style patterns: (a) denial/passive coping, (b) empowerment, (c) redirecting energy, (d) shifting of focus, (e) rearranging life and relationships, (f) changed expectations, (g) social withdrawal, (h) spiritual coping, and (i) acceptance. The school was considered the primary supportive entity. Although findings may not be unique to the Southeast Asian group, the research provides an in-depth perspective on their lived experience, their struggles, and strengths. Insight gained from this investigation can help school nurses better understand the effect of autism on families, identify specific needs, and address these needs by advocating for appropriate supportive programs.

Garnefski, N., Kraaij, V., & van der Veek, S.M.C. (2009). **Cognitive coping strategies and stress in parents of children with Down syndrome: A prospective study.** *Intellectual and Developmental Disabilities, 47*(4), 295-306.

Full text is available at <http://www.aiddjournals.org/doi/pdf/10.1352/1934-9556-47.4.295>

ERIC Number: EJ851889

ABSTRACT: The purpose of this study was to explore the cross-sectional and prospective relationships between cognitive coping strategies and parental stress in parents of children with Down syndrome. A total of 621 participants filled out questionnaires, including the Cognitive Emotion Regulation Questionnaire to measure cognitive coping and the Nijmeegse Ouderlijke Stress Index-Korte Versie (A. J. L. L. De Brock, A. A. Vermulst, J. R. M. Gerris, & R. R. Abidin, 1992) to measure parental stress. After 8 months, stress was measured again. Cross-sectionally, using acceptance, rumination, positive refocusing, refocusing on planning, and catastrophizing to a greater extent was related to more stress, whereas using positive reappraisal more often was related to less stress. Prospectively, acceptance and catastrophizing were related to more stress, whereas positive reappraisal was related to less stress. Implications for future research and prevention and intervention activities are discussed.

Glidden, L.M., Natcher, A.L. (2009). **Coping strategy use, personality, and adjustment of parents rearing children with developmental disabilities.** *Journal of Intellectual Disability Research, 53*(12), 998-1013.

ERIC Number: EJ864404

ABSTRACT: Background: Parents rearing children with developmental disabilities encounter stressors that require coping and adaptation. In Glidden et al. 2006, the use of problem-focused coping strategies was more often associated with positive adjustment outcomes than was the use of emotion-focused coping strategies, and parental personality was shown to influence outcomes, with Neuroticism, in particular, associated with lower well-being. Method: In the current study we aimed to replicate these results for adjustment outcomes measured six years later. Sixty-eight married couples parenting at least one child with developmental disabilities completed

measures of depression and subjective well-being, and the Transition Daily Rewards and Worries Questionnaire, an inventory that assesses parental reaction to children transitioning into adulthood. Results: For both mothers and fathers, combinations of personality factors and coping strategies were able to significantly predict outcome variables measured six years later. Personality, however, was a better predictor for mothers, whereas coping strategies predicted more variance for fathers. Distancing, especially, demonstrated mother-father differences. Conclusions: For the most part, the current results demonstrated that the relations among personality, coping and parental outcomes were consistent and stable over the 6-year interval. In addition, although we found some differences between mothers and fathers, there were also many similarities in the frequency of use of different coping strategies, and in the direction of influence of personality and coping strategy on outcome variables.

Kishore, M.T., & Verma, R.K. (2009). **Needs of Indian parents having children with intellectual disability.** *International Journal of Rehabilitation Research, 32*(1), 71-76.

ERIC Number: EJ885843

ABSTRACT: Disability in children gives rise to various needs in parents, which may vary according to the nature of disability and parental characteristics. Cross-cultural findings will help in understanding the process of meeting those needs, which ultimately help in designing appropriate interventions. The main objectives of the study were to compare the perceived needs of fathers and mothers having a child with intellectual disability, and to understand their cumulative needs with reference to the age, sex, and severity of functional disability of the child. Thirty couples, each having a child with intellectual disability, were assessed with the National Institute of Mental Health (NIMH) Family Needs Schedule. The needs expressed by fathers and mothers differed significantly. Needs of the parents varied according to the age and sex of the child. Severity of intellectual disability had less impact on the nature of parental needs. The needs of mothers and fathers can be different. Some needs of the parents may subside as their intellectually disabled child grows, but they are duly replaced by others. Needs of the parents

grossly vary according to the sex but not the severity of intellectual disability of the child. Wherever applicable, family intervention should focus on the needs of the mothers and fathers separately with due consideration to the sex and age of the child.

2008

Carter, A.S., Greenberg, J.S., Seltzer, M.M., Smith, L.E., & Tager-Flusberg, H. (2008). **A comparative analysis of well-being and coping among mothers of toddlers and mothers of adolescents with ASD.** *Journal of Autism and Developmental Disorders*, 38(5), 876-889.

ERIC Number: EJ792457

ABSTRACT: The present study examined the impact of autism symptoms and coping strategies on the well-being of mothers of children with autism spectrum disorder (ASD). The sample consisted of 153 mothers of toddlers and 201 mothers of adolescents drawn from two ongoing, longitudinal studies of families of individuals with ASD. For mothers of toddlers, lower levels of emotion-focused coping and higher levels of problem-focused coping were generally associated with better maternal well-being, regardless of the level of child symptomatology. For mothers of adolescents, coping often acted as a buffer when autism symptoms were high. Although there was evidence of maternal distress in both groups, the presence of significant buffering effects reflects adaptation in the face of stress, particularly for mothers of adolescents.

Chang, M-Y., McConkey, R. (2008). **The perceptions and experiences of Taiwanese parents who have children with an intellectual disability.** *International Journal of Disability, Development and Education*, 55(1), 27-41.

Full text is available at <http://www.tandfonline.com/doi/pdf/10.1080/10349120701827961>

ERIC Number: EJ786264

ABSTRACT: Most research into family care-giving has been undertaken in western, English-speaking societies with little cognizance taken of possible differences across cultures. Home-based interviews were conducted with 117 mothers and fathers in Taipei City, Taiwan and five main themes were identified using content analysis. Three themes expressed the impact of the child on family functioning, parental health, and levels of stress and two themes described

parents' coping strategies and sources of support. Although these themes broadly replicate findings from other cultures, certain features of Taiwanese-Chinese society appear to accentuate the impact on mothers especially of having a child with an intellectual disability. The implications for the provision of family-centered services are discussed, especially in helping parents to recognize their strengths and coping capabilities, and to promote their influence in changing cultural attitudes.

Hastings, R.P., Huws, J.C., Reilly, D.E., & Vaughan, F.L. (2008). **"When your child dies you don't belong in that world any more." Experiences of mothers whose child with an intellectual disability has died.** *Journal of Applied Research in Intellectual Disabilities*, 21(6), 546-560.

ERIC Number: EJ835138

ABSTRACT: Background: Individuals with intellectual disability are at higher risk of premature death compared with individuals without intellectual disability, and therefore parents of people with intellectual disability are more likely to outlive their children. However, there has been relatively little research investigating the bereavement experiences of parents of deceased children with intellectual disability. Method: Semi-structured interviews were used to explore the experiences of nine mothers whose child with intellectual disability had died. The transcripts were analyzed qualitatively using Interpretative Phenomenological Analysis. Results: Five themes emerged from the analysis: loss, benefit finding, coping, sources of support and medical relationships. An analysis of the accounts indicated similarities and differences between the experiences of the mothers. In particular, continuing in their caring role by working within the world of intellectual disability following the death of their child was important to all of the mothers. Support from similarly bereaved parents was the most useful source of support, although it was not always readily accessible. Conclusions: Implications for theory and practice are described including suggestions that service providers should aim to maintain links with families after the death of their child, a parent-to-parent program that enables parents to contact others in a similar situation might be beneficial and further research into the functions of coping strategies and supports in loss would be worthwhile.

Howe, N., & Orfus, M. (2008). **Stress appraisal and coping in siblings of children with special needs.** *Exceptionality Education International*, 18(3), 166-181.

Full-text is available at <http://spectrum.library.concordia.ca/8618/1/MR16243.pdf>

ERIC Number: EJ869873

ABSTRACT: Self-reports from siblings of children with special needs regarding their appraisal of family stress and coping are important additions to the disability literature. Twelve school-age siblings of children with special needs were interviewed about their daily hassles, uplifts, and coping strategies related to living in a family with a child with a disability. Parents also reported on family coping strategies. Children reported that the most frequent daily hassle was when their sibling with special needs cried, screamed, or yelled when he/she did not want to do something. The most frequent daily uplift was when their sibling gave hugs or kisses. Children reported feeling most stressed when embarrassed by their sibling with special needs in front of friends and happiest when playing with their sibling. Wishful thinking was a common child coping strategy during stressful times. Implications for working with families with special needs are discussed.

2007

Ho, G.S.M., & Mak, W.W.S. (2007). **Caregiving perceptions of Chinese mothers of children with intellectual disability in Hong Kong.** *Journal of Applied Research in Intellectual Disabilities*, 20(2), 145-156.

ERIC Number: EJ835575

ABSTRACT: Background: In this study, we tested the effects of three different coping strategies (i.e. problem-focused, emotion-focused and relationship-focused coping) on both positive and negative caregiving perceptions. Materials and Methods: Two hundred and twelve Chinese mothers of children with intellectual disability from a major non-governmental organization were recruited across various districts in Hong Kong. Chinese versions of the Daily Caregiving Stress Scale, Modified Family Support Scale, COPE Inventory, Relationship-Focused Coping Scale, Caregiver Burden Inventory, and subscales of the Kansas Inventory of Parental Perceptions were completed. Results: Findings of

the hierarchical regression analyses indicated that whereas problem-focused and emotion-focused coping was differentially related to positive and negative perceptions, respectively, relationship-focused coping was significantly related to both types of perceptions. Results of the relationship between positive and negative perceptions showed preliminary support for their orthogonality. Conclusions: Relationship-focused coping was found to be more suitable for understanding caregiver perceptions within collectivistic cultures. Implications for professional services were discussed.

Todd, S. (2007). **Silenced grief: Living with the death of a child with intellectual disabilities.** *Journal of Intellectual Disability Research*, 51(8), 637-648.

ERIC Number: EJ767805

ABSTRACT: Background: This paper examines the bereavement experiences of parents of people with intellectual disabilities (IDs). It is based upon an understanding that there exists little research-based understanding of those experiences or of the support needs of parents after the death of their child. Methods: In-depth interviews were held with 13 parents on the deaths of their children with IDs. Results: The data highlighted the deep sense of loss that these parents experience after the death of their child. The loss was intensely felt. They also show that their loss was a form of compounded loss. To begin with the scale and depth of loss is misrecognized. They also lose contact with a world that they had previously been heavily involved in. There was a sense that ID services and professionals withdrew from the family with too much haste. The data reveal that there exists no adequate supportive emotional community for these parents to express their grief. Conclusions: It is argued that the experiences of these parents have much in common with understandings of disenfranchised grief. The implications of these findings for research and practice are briefly discussed.

2006

Billings, F.J., Glidden, L.M., & Jobe, B.M. (2006). **Personality, coping style and well-being of parents rearing children with developmental disabilities.** *Journal of Intellectual Disability Research*, 50(12), 949-962.

ERIC Number: EJ746129

ABSTRACT: Background: Parents with children with developmental disabilities (DD) encounter a variety of stressors associated with rearing their children and must develop effective coping mechanisms in order to adapt successfully to these challenges. Previous research has failed to establish the role of parental individual differences in the reported use of different coping strategies. The current study explores parental personality and whether children with DD were adopted or born into the families and their influence on the coping strategies used by mothers and fathers. Methods: A total of 97 mother-father dyads rearing at least one child with DD were participants. They narrated stressful situations related to their child and completed the Ways of Coping Questionnaire twice. Data were also collected with regard to personality, depression and subjective well-being (SWB). Results: Both adoptive and birth mothers and fathers used more problem-focused than emotion-focused strategies. Personality factors, Neuroticism especially, were predictive of coping strategy use. Higher levels of Positive Reappraisal were associated with higher levels of SWB, whereas higher levels of Escape-Avoidance were associated with lower levels of SWB, but only for mothers. Results were consistent with a dispositional model of strategy use in that frequency of use was associated with personality characteristics, was consistent over time, and for different children in the same families. Future research should focus on the persistence of the associations between strategy use and well-being and whether they hold true at different stages of the lifespan when coping contexts may change quite dramatically.

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

Full-text is available at <http://storage.cet.ac.il/SharvitNew/Storage/765088/366980.pdf>

ERIC Number: EJ738816

ABSTRACT: Background: Siblings of children with autistic spectrum disorder (ASD) express more problem behaviors and experience more difficulties in their relationships than do children in families where all children are developing typically. We know little

about what contributes to these difficulties. Method: Mothers of a child with ASD completed the "Child Behavior Checklist" (Achenbach, 1991) with respect to a non-disabled sibling. Siblings responded to a questionnaire tapping their knowledge about their brother or sister's disorder. They reported on problems they had experienced with their brother or sister with ASD and on the coping strategies they had used in response to these events. Problems were classified into one of five problem types. Results: Aggressive behavior was the most commonly reported interaction problem and anger was the usual response. Siblings did not generally choose blaming (either self or other) as a coping strategy when facing difficulties with their brother or sister with ASD. Neither coping strategies nor knowledge of ASD were associated with adjustment. Forty percent of non-disabled siblings had scores on the "Child Behavior Checklist" that placed them in the borderline or clinical range. Conclusions: The current study indicated that siblings of children with ASD are at increased risk of developing internalizing behavior problems. The contributing factors to this outcome are unknown at this point. It is important for research to focus on dynamic variables in the search for these contributors, as they are open to change.

Gray, D.E. (2006). **Coping over time: The parents of children with autism.** *Journal of Intellectual Disability Research, 50*(12), 970-976.

ERIC Number: EJ746126

ABSTRACT: Background: Although coping with autism has been examined in a number of papers, virtually no research exists on how families cope over time. This paper reports the results of a longitudinal study of parents coping with autism over a period of approximately a decade. Methods: The research method for the study was based on ethnographic methods that emphasized in-depth interviews and participant observation. The sample for this study consisted of 28 parents (19 mothers and nine fathers) of children with autism. The instrument for the interviews consisted of questions concerning: the child's medical history and referral experience, the child's present symptomatology, the effects of the child's problems on the parent's well-being, the effects of autism on the family's social life, parental coping strategies, illness conceptualization and the

parents' expectations for the future. Results and conclusions: Coping strategies changed from the time of the initial study, as fewer parents coped through reliance on service providers, family support, social withdrawal and individualism and relatively more parents coped through their religious faith and other emotion-focused strategies. The results tentatively support previous research on coping that indicates that aging is linked to the use of more emotion-focused coping strategies.

Kerns, K.A., & Siklos, S. (2006). **Assessing need for social support in parents of children with autism and Down syndrome.** *Journal of Autism and Developmental Disorders*, 36(7), 921-933.

ERIC Number: EJ748111

ABSTRACT: Parents of children with autism frequently turn to the service delivery system to access supports designed to help adapt to the challenges of having a child with a life-long impairment. Although studies have suggested various supports and coping strategies that are effective for adapting, few studies have examined parents' own perceptions of needs, and whether parents felt their needs were being met. In the present study the Family Needs Questionnaire (FNQ; Waaland et al., 1993) was modified to address needs for children with developmental disorders. A sample of fifty-six parents of children with autism and a comparison group of thirty-two parents of children with Down syndrome completed the FNQ. The groups did not differ significantly on the number of important needs reported nor the number of important needs being met. However, the two groups differed in the types of supports they most frequently endorsed as "important" or "unmet."

2005

Bailey, S.R., Higgins, D.J., & Pearce, J.C. (2005). **Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder.** *Autism: The International Journal of Research and Practice*, 9(2), 125-137.

ERIC Number: EJ689764

ABSTRACT: A survey of parents/caregivers of a child with an autism spectrum disorder (ASD) was conducted to examine the relationship between

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

Brown, T., Espinosa, F.D., Hastings, R.P., Kovshoff, H., Remington, B., & Ward, N.J. (2005).

Coping strategies in mothers and fathers of preschool and school-age children with autism.

Autism: The International Journal of Research and Practice, 9(4), 377-391.

ERIC Number: EJ717983

ABSTRACT: Despite the theoretical and demonstrated empirical significance of parental coping strategies for the wellbeing of families of children with disabilities, relatively little research has focused explicitly on coping in mothers and fathers of children with autism. In the present study, 89 parents of preschool children and 46 parents of school-age children completed a measure of the strategies they used to cope with the stresses of raising their child with autism. Factor analysis revealed four reliable coping dimensions: active avoidance coping, problem-focused coping, positive coping, and religious/denial coping. Further data analysis suggested gender differences on the first two of these dimensions but no reliable evidence that parental coping varied with the age of the child with autism. Associations were also found between coping strategies and parental stress and mental health. Practical implications are considered including reducing reliance on avoidance coping and increasing the use of positive coping strategies.

Canham, D.L., Cureton, V.Y., & Luther, E.H. (2005). **Coping and social support for parents of children with autism.** *Journal of School Nursing, 21*(1), 40-47.

ERIC Number: EJ885158

ABSTRACT: Autism in children has increased significantly in the past 15 years. The challenges and stressors associated with providing services and caring for a child with autism affect families, educators, and health professionals. This descriptive study used a survey to collect data on parents' perceptions of coping strategies and social support. Instruments included the Social Support Index and the Family Crisis Oriented Personal Evaluation Scales. One half of the families identified serious stressors in addition to autism. Acquiring social support and reframing were the most frequently used coping strategies. The school nurse is in a position to identify needs and refer families to local support groups and agencies, facilitating social support and development of coping strategies.

2004

Hastings, R.P., & White, N. (2004). **Social and professional support for parents of adolescents with severe intellectual disabilities.** *Journal of Applied Research in Intellectual Disabilities, 17*(3), 181-190.

ERIC Number: EJ836200

ABSTRACT: Background: Previous research has identified various dimensions of social support that are positively associated with parental well-being. However, most research does not include multiple measures of social support and uses heterogeneous samples in terms of child characteristics such as age and severity of intellectual disability. Methods: Thirty-three parents of adolescent children with moderate-profound intellectual disabilities completed measures of parental well-being (stress, anxiety and depression, and caregiving satisfaction), social support (informal and formal sources, and practical and emotional support), and child characteristics (adaptive and problem behaviors). Results: Correlation analyses showed that parental well-being was associated with the child's adaptive and problem behaviors and with the child's autism diagnosis. Parents' ratings of the helpfulness of informal sources of support (spouse,

extended family, friends, etc.) was most reliably associated with parental well-being, and remained so after controlling for child characteristics. Parents' access of service and professional support was not associated with parental well-being, but there was some evidence that it was related to their child's needs. Conclusions: The research emphasizes the significance of including multiple measures of social support in research with families of children with an intellectual disability. Furthermore, the possibility that parents, during their child's adolescence, may be especially vulnerable to the disruption of their informal support networks is an important practical consideration.

1998

Judge, S.L. (1998). **Parental coping strategies and strengths in families of young children with disabilities.** *Family Relations, 47*(3), 263-68.

ERIC Number: EJ583375

This study investigates the relationship between parental perceptions of coping strategies and family strengths in families of young children with disabilities (N=69). Use of social supports was highly associated with family strengths; in contrast, wishful thinking, self-blame, distancing, and self-control were negatively related to family strengths.



Document from the Cochrane Database of Systematic Reviews search at www.thecochranelibrary.org are listed below:

Honey, E.J., McConachie, H., & Oono, I.P. (2013). **Parent-mediated early intervention for young children with autism spectrum disorders (ASD).** *Cochrane Database of Systematic Reviews*, Issue 4. Art. No.: CD009774. DOI: 10.1002/14651858.CD009774.pub2.

Full text is available at <http://onlinelibrary.wiley.com/doi/10.1002/ebch.1952/pdf>

ABSTRACT: Young children with autism spectrum disorders (ASD) have impairments in the areas of communication and social interaction and often display repetitive or non-compliant behavior. This early pattern of difficulties is a challenge for parents. Therefore, approaches that help parents develop strategies for interaction and management of behavior are an obvious route for early intervention in ASD. This review updates a Cochrane review first published in 2002 but is based on a new protocol.

Plain Language Summary:

Autism spectrum disorders (ASD) affect more than 1% of children and is usually evident in behaviour before the age of three years. A child with ASD lacks understanding of how to interact with another person, may not have developed language or understand other people's communication, and may insist on routines and repetitive behaviours. This early pattern of difficulties is a challenge for parents. Therefore, helping parents to develop strategies for interaction and management of behaviour is an obvious route for early intervention. The present review brings up to date one published in 2003, which found only two well-designed studies. This review, based on a new protocol, includes 17 randomised controlled trials, most published since 2010, in which interventions delivered by parents were compared with no treatment or local services, or alternative child-centred intervention such as nursery attendance, or another parent-delivered intervention that differed in some way from the main condition. We were able to combine outcome information and so increase confidence in the results. All the studies were rated on the quality of their evidence, which was then taken into account

in judging how firmly conclusions could be drawn.

The studies varied in the content of what parents were trained to do, and over what length of time parents had contact with professionals. Parents received training either individually with their child or in groups with other parents. In the majority of the studies, the interventions aimed to help parents be more observant and responsive during interactions with their child in order to help their child develop communication skills.

In summary, the review finds sufficient evidence that the ways in which parents interacted with their children did change as intended. The review also suggests improvement in child outcomes such as understanding of language and severity of autism characteristics as a result of interventions delivered by parents. However, important outcomes such as other aspects of children's language, children's adaptive skills and parent stress did not show change. The evidence is not yet strong for any outcome and would benefit from researchers measuring effects in the same ways.



Documents from the National Library of Medicine PubMed search at www.pubmed.com are listed below:

2013

Ahmad, M.M., & Dardas, L.A. (2013). **Coping strategies as mediators and moderators between stress and quality of life among parents of children with autistic disorder.** *Stress and Health: Journal of the International Society for the Investigation of Stress*, doi: 10.1002/smi.2513. [Epub ahead of print] PMID: 23868562

ABSTRACT: The purpose of this cross-sectional study was to examine coping strategies as mediators and moderators between stress and quality of life (QoL) among parents of children with autistic disorder. The convenience sample of the study consisted of 184 parents of children with autistic disorder. Advanced statistical methods for analyses of mediator and moderator effects of coping strategies were used. The results revealed that 'accepting responsibility' was the only mediator strategy in the relationship between stress and QoL. The results also revealed that only 'seeking social support' and 'escape avoidance' were moderator strategies in the relationship between stress and QoL. This study is perhaps the first to investigate the mediating and moderating effects of coping on QoL of parents of children with autistic disorder. Recommendations for practice and future research are presented.

Ahmad, M.M., & Dardas, L.A. (2013). **Quality of life among parents of children with autistic disorder: A sample from the Arab world.** *Research in Developmental Disabilities*, 35(2), 278-287. PMID: 24316492

ABSTRACT: BACKGROUND: A growing body of research has sought to examine issues associated with the Quality of Life (QoL) of parents of children with Autistic Disorder. However, no studies have examined the QoL of Arab parents whose parenting experience is expected to be substantially different from that of their western counterparts. Therefore, the purposes of this study were: (1) to examine differences in the QoL between fathers and mothers of children with Autistic Disorder in a sample from

an Arab country, and (2) to examine the psychosocial correlates of the QoL of Arab parents of children with Autistic Disorder. **METHODS:** Self-administered questionnaires on parents' QoL, stress, coping strategies, and demographic characteristics were completed by 184 parents of children with Autistic Disorder. The participants were recruited using the convenience sampling design. **RESULTS:** Fathers and mothers of children with Autistic Disorder showed no significant differences in their physical, psychological, social, and environmental health. Further, both parents showed almost similar bivariate correlations between the reported QoL levels and their parenting stress, coping strategies, and demographic characteristics. **CONCLUSION:** This is the first study to examine the QoL of parents of children with Autistic Disorder in the Arab world and, in doing so, it highlighted the distinct lack of research in this area. The QoL of Arab parents of children with Autistic Disorder crosses lines with their stress levels, coping strategies, demographic characteristics, and to some extent their cultural context.

Brioso, A., Pozo, P., & Sarriá, E. (2013). **Family quality of life and psychological well-being in parents of children with autism spectrum disorders: A double ABCX model.** *Journal of Intellectual Disability Research (JIDR)*, doi: 10.1111/jir.12042. [Epub ahead of print]. PMID: 23600450

ABSTRACT: BACKGROUND: This study examined family quality of life (FQOL) and psychological well-being from a multidimensional perspective. The proposed model was based on the double ABCX model, with severity of the disorder, behavior problems, social support, sense of coherence (SOC) and coping strategies as components. **METHOD:** One hundred and eighteen parents (59 mothers and 59 fathers) with a child diagnosed with autism spectrum disorders (ASD) participated in the study. Separate path analyses were performed to evaluate models of FQOL and psychological well-being for mothers and fathers. **RESULTS:** In all models, behavior problems had a negative indirect effect on adaptation (FQOL and psychological well-being) through SOC. For both mothers and fathers, the severity of the disorder and social support played significant roles in FQOL models. Coping strategies

were related with adaptation, active avoidance coping with FQOL for fathers and positive and problem-focused coping with psychological well-being for mothers. **CONCLUSIONS:** The results of this study highlight the value of the multidimensional approach. The specific patterns of results for mothers and fathers contribute to comprehension of the psychological adaptation of parents. Findings could be taken into account in interventions with families.

Giallo, R., Jellett, R., Seymour, M., & Wood, C. (2013). **Fatigue, stress and coping in mothers of children with an autism spectrum disorder.** *Journal of Autism and Developmental Disorders*, 43(7), 1547-54.

PMID: 23124359

ABSTRACT: Raising a child with an autism spectrum disorder (ASD) can be exhausting, which has the potential to impact on parental health and wellbeing. The current study investigated the influence of maternal fatigue and coping on the relationship between children's problematic behaviors and maternal stress for 65 mothers of young children (aged 2-5 years) with ASDs. Results showed that maternal fatigue but not maladaptive coping mediated the relationship between problematic child behaviors and maternal stress. These findings suggest child behavior difficulties may contribute to parental fatigue, which in turn may influence use of ineffective coping strategies and increased stress. The significance of fatigue on maternal wellbeing was highlighted as an important area for consideration in families of children with an ASD.

Hauser-Cram, P., & Woodman, A.C. (2013). **The role of coping strategies in predicting change in parenting efficacy and depressive symptoms among mothers of adolescents with developmental disabilities.** *Journal of Intellectual Disability Research (JIDR)*, 57(6), 513-30.

PMID: 22563652

ABSTRACT: BACKGROUND: Parents of children with developmental disabilities (DD) face greater caregiving demands than parents of children without DD. There is considerable variability in parents' adjustment to raising a child with DD, however. In line with a strengths-based approach, this study explores coping strategies as potential mechanisms of resilience among mothers of adolescents with DD.

This study examines the frequency with which mothers use various coping strategies and the extent to which those strategies moderate the relationship between adolescent behavior problems and aspects of maternal well-being. Both positive and negative dimensions of well-being are explored, with maternal depressive symptoms and perceived parenting efficacy examined as outcomes cross-sectionally and longitudinally. **METHODS:** The present study focuses on 92 mothers and their adolescents with DD. The adolescents had a wide range of diagnoses, all with continuing special needs. Data were collected from mothers through interviews and self-administered questionnaires when their adolescents were aged 15 and aged 18. A structured assessment of the adolescent was completed during home visits at age 15. **RESULTS:** Mothers reported frequently using strategies of denial and planning but rarely using strategies of mental and behavioral disengagement to cope with recent stressful situations. Adolescent behavior problems were found to contribute to greater symptoms of depression and lower feelings of parenting efficacy as well as increases in depressive symptoms over time. Mothers of sons, but not daughters, reported increases in parenting efficacy across their child's adolescent period. Above and beyond adolescent factors, several coping strategies emerged as significant predictors of mothers' symptoms of depression and perceived parenting efficacy. Moreover, use of Active Coping/Planning, Positive Reinterpretation/Growth, and Behavioral/Mental Disengagement as coping strategies moderated the impact of adolescent behavior problems on maternal depressive symptoms. **CONCLUSIONS:** This study extends previous findings by focusing on both positive and negative dimensions of parent well-being during their child's adolescent period. Adolescence can be a stressful time for parents, with typical developmental tasks entailing additional strains for parents of adolescents with DD. The present findings point to several coping strategies that may reduce the impact of challenging behaviors during this period on mothers' symptoms of depression and feelings of parenting efficacy. Certain coping strategies were found to exert a greater impact on maternal well-being for parents of adolescents with higher levels of behaviour problems, suggesting that interventions may benefit from an increased focus on this group of mothers with heightened caregiving demands.

Magiati, I., Ooh, J., & Xue, J. (2013). **Family functioning in Asian families raising children with autism spectrum disorders: The role of capabilities and positive meanings.** *Journal of Intellectual Disability Research (JIDR)*, doi: 10.1111/jir.12034. [Epub ahead of print].

PMID: 23510076

ABSTRACT: **BACKGROUND:** There has been increasing interest in exploring the factors contributing to successful adaptation and family functioning in ethnically and culturally diverse families who raise children with autism spectrum disorders (ASD), in order to inform more appropriate strength-based family support services. This pilot study used the Family Adjustment and Adaptation Response (FAAR) model as a theoretical framework to investigate the role of families' capabilities (coping strategies and resources of support) and positive meanings in raising a child with ASD in family functioning in an Asian context. **METHODS:** Sixty-five Singaporean parents of 3- to 11-year-old children with ASD completed a series of questionnaires on demands, coping strategies, social support, positive meanings and family functioning. **RESULTS:** Families reported a number of helpful coping strategies. Coping through family integration/optimism was most helpful, followed by understanding the condition and by developing esteem and psychological stability. Reported capabilities, but not positive meanings, mediated the relationship between demands and family functioning. **CONCLUSION:** The findings are discussed in relation to existing literature, possible specific cultural issues, and the strengths and limitations of the study. Implications for supporting families of children with ASD in different social and cultural contexts are also discussed.

2012

Desai, M.U., Divan, G., Patel, V., Strik-Lievers, L., & Vajaratkar, V. (2012). **Challenges, coping strategies, and unmet needs of families with a child with autism spectrum disorder in Goa, India.** *Autism Research: Official Journal of the International Society for Autism Research*, 5(3), 190-200.

Full text is available at <http://onlinelibrary.wiley.com/doi/10.1002/aur.1225/pdf>

PMID: 22473816

ABSTRACT: Autism Spectrum Disorders (ASD) are increasingly recognized in developing countries like India. However, little is known about the experiences of parents raising a child with ASD. This study aimed to describe the experiences of families in Goa, India with a view to understanding the unmet needs of families raising a child with ASD. Twenty in-depth interviews and nine focus group discussions were carried out with families of children with ASD and key community stakeholders such as special educators, teachers, and parents of typically developing children. This qualitative data was triangulated to explore the experiences, life impact, and unmet needs of raising a child with ASD. Key findings suggest that raising a child with ASD puts a tremendous strain on families due to competing commitments, often leading to initial social withdrawal with later reintegration into social networks. Second, the impact is multidimensional, involving the personal sphere but also extending into the wider community with negative experiences of discrimination. Third, parents actively respond to these challenges through a range of approaches with help from existing and new social support networks and health care providers. Fourth, professionals from the health, education, and religious sectors have a low awareness of the unique needs of families living with ASD which leads to a considerable economic and emotional burden on families. Finally, as a consequence of these experiences, several unmet needs can be identified, notably for supporting increasingly isolated families and the limited access to multidisciplinary evidence-based services for ASD.

Hall, H.R. (2012). **Families of children with autism: Behaviors of children, community support, and coping.** *Issues in Comprehensive Pediatric Nursing*, 35(2), 111-32.

PMID: 22545692

ABSTRACT: **BACKGROUND:** The diagnosis of autism for children (from birth to age 21) continues to increase, with the current rate being 1 in 110 children in the US. Besides financial strain, families often experience reduced quality of life due to disruptive behaviors related to autism. Research indicates that social support for families of children with autism improves family coping and adaptation. **METHOD:**

A descriptive, correlational, cross-sectional study was conducted with 38 parents of children with autism. Using the McCubbin and Patterson (1983) model of family behavior, associations among behaviors of children with autism, community support for family, and family coping were analyzed. **RESULTS:** Findings of this study indicate an association between increased community supports and increased family coping strategies ($r=.451$; $p=.005$). Results also suggest the levels of disruptive behaviors associated with autism vary, community support can be but is not always helpful, and that the family's ability to cope with the challenges of autism is important to the family.

Joosten, A., Molineux, M., & Safe, A. (2012). **The experiences of mothers of children with autism: Managing multiple roles.** *Journal of Intellectual & Developmental Disability, 37*(4), 294-302.

PMID: 23171310

ABSTRACT: BACKGROUND: Mothers of children with autism experience poorer health and well-being compared to mothers of children with other disabilities or typically-developing children. This qualitative phenomenological study aimed to explore the daily life experiences of mothers of children with autism, and the strategies they use to manage their roles, their emotions, and their child's behaviors. **METHOD:** In-depth interviews were conducted with seven mothers and the data were analyzed using interpretative phenomenological analysis. **RESULTS:** Findings revealed that the mothers were challenged by the demands of their multiple roles while dealing with the paradox of accepting their child for who they were, and at the same time also desiring their typical growth and development. However, the mothers reported various strategies they used to manage their roles, their emotions, and their child's behaviors. **CONCLUSIONS:** The findings indicate that health professionals working with these families must support mothers in managing various aspects of their lives, including those not directly related to their child with autism.

Ludlow, A., Rohleder, P., & Skelly, C. (2012). **Challenges faced by parents of children diagnosed with autism spectrum disorder.** *Journal of Health Psychology, 17*(5):702-11.

PMID: 22021276

ABSTRACT: Few studies address the daily challenges faced by parents of children diagnosed with autism spectrum disorder. This article reports on a qualitative interview study with 20 parents exploring their experiences, challenges faced, and what has helped them to cope. A thematic analysis of the data identified five core categories: Dealing with challenging behavior; dealing with judgments from others; lack of support; impact upon the family; coping and the importance of appropriate support. The findings emphasize where the parents themselves believe they still require additional support. It raises key strategies and resources that parents have found helpful.

Taylor, J.L., Vehorn, A.C., Warren, Z.E., & Weitlauf, A.S. (2012). **Relationship satisfaction, parenting stress, and depression in mothers of children with autism.** *Autism: The International Journal of Research and Practice, doi: 10.1177/1362361312458039.* [Epub ahead of print].

PMID: 22987895

ABSTRACT: Mothers of children with autism report higher levels of depression than mothers of children with other developmental disabilities. We explored the relations between child characteristics of diagnostic severity and problem behaviors, parenting stress, relationship quality, and depressive symptoms in 70 mothers of young children with autism. We hypothesized that relationship quality and parenting stress would relate to maternal depression beyond contributions of child characteristics. Multiple regression analysis revealed a main effect of parenting stress above and beyond child problem behaviors and autism severity. A significant interaction emerged, with relationship quality buffering the effect of parenting stress on depression. Results suggest that the relation between child problem behaviors and maternal depression should be considered in conjunction with other measures of marriage and family stress. Relationship quality and parenting stress may also represent important factors to be explicitly considered within intervention paradigms for young children with autism spectrum disorders.

2011

Chen, H.J., Huang, Y.P., St. John, W., & Tsai, S.W. (2011). **Taiwanese fathers' experiences of having their child diagnosed with a developmental disability.** *The Journal of Nursing Research (JNR)*, 19(4), 239-49.

PMID: 22089649

ABSTRACT: BACKGROUND: Receiving a diagnosis of a developmental disability in a child can be a crisis event for parents. Gender differences in parental roles are worth considering when exploring the impact of having a child with a disability. However, most studies on this topic have focused on the mother's experience, and little is known about what the father goes through as the parent of a child diagnosed with a disability. Even less is known regarding this experience in the context of the Chinese culture. **PURPOSE:** The goal of this study was to explore fathers' experiences of having a child diagnosed with a developmental disability in a Chinese cultural context. **METHODS:** This study used a hermeneutic phenomenological approach informed by the philosophical world views of Heidegger. The 16 fathers who participated in the study were purposively sampled from a teaching hospital in central Taiwan. Data were collected using in-depth and semi-structured interviews and were analyzed using hermeneutic analysis. **RESULTS:** Data analysis revealed four shared meanings: losing hope, feelings of failure, being frustrated with family conflicts, and searching for positive coping strategies. **CONCLUSIONS/IMPLICATIONS FOR PRACTICE:** Fathers feel shock and despair as well as personally devalued when learning that their child has been diagnosed with a developmental disability. Chinese cultural beliefs and values can elicit different experiences for fathers while helping them make sense of their experiences and accept their child in meaningful ways. Nurses can actively engage fathers as well as mothers to understand their feelings and thoughts about their child's disability to provide appropriate emotional and informational support. Providing support or referral is necessary particularly when fathers encounter issues with the child's grandparents. Nurses can assist fathers to find a way to make sense of having a child with a disability within their cultural frame of reference by adapting cultural beliefs and values to their situation and to make meaning of their child's life.

Graff, J.C., & Hall, H.R. (2011). **The relationships among adaptive behaviors of children with autism, family support, parenting stress, and coping.** *Issues in Comprehensive Pediatric Nursing*, 34(1), 4-25.

PMID: 21341964

ABSTRACT: BACKGROUND: As the number of children diagnosed with autism continues to rise, resources must be available to support parents of children with autism and their families. Parents need help as they assess their unique situations, reach out for help in their communities, and work to decrease their stress levels by using appropriate coping strategies that will benefit their entire family. **METHODS:** A descriptive, correlational, cross-sectional study was conducted with 75 parents/primary caregivers of children with autism. Using the McCubbin and Patterson model of family behavior, adaptive behaviors of children with autism, family support networks, parenting stress, and parent coping were measured. **FINDINGS AND CONCLUSIONS:** An association between low adaptive functioning in children with autism and increased parenting stress creates a need for additional family support as parents search for different coping strategies to assist the family with ongoing and new challenges. Professionals should have up-to-date knowledge of the supports available to families and refer families to appropriate resources to avoid overwhelming them with unnecessary and inappropriate referrals.

Kishore, M.T. (2011). **Disability impact and coping in mothers of children with intellectual disabilities and multiple disabilities.** *Journal of Intellectual Disabilities (JOID)*, 15(4), 241-51.

PMID: 22158461

ABSTRACT: Understanding the disability impact on parenting and caregiving is important for intervention. The present study was designed to understand the differences in perceived disability impact and related coping in mothers having children with intellectual disabilities alone compared to those having children with intellectual disabilities and additional disabilities. Accordingly, 30 mothers of children with intellectual disabilities and 30 mothers of children with intellectual and additional disabilities were assessed for disability impact and coping. Group differences for disability impact were present in

specific domains but not overall. Despite variations in coping pattern, both positive and negative coping strategies were observed in both groups. The results may imply that the impact of intellectual disability is so pervasive that except in certain domains mothers may not perceive the further impact of additional disabilities. Positive coping does not rule out negative coping strategies. These findings have specific relevance to service delivery in a cultural context.

2010

Graff, J.C., & Hall, H.R. (2010). **Parenting challenges in families of children with autism: A pilot study.** *Issues in Comprehensive Pediatric Nursing*, 33(4), 187-204.

PMID: 21047211

ABSTRACT: A pilot study was conducted using a focus group interview with parents of children with autism to provide parents with the opportunity to express their concerns related to parenting a child with autism and to discuss strategies parents can use to manage these challenges. Parents' desire and need for information related to autism is evident. Parents' identified supports and resources in need of expansion and development to assist with their child's needs. These findings support previous research with families communicating a need for partnership with healthcare providers. Nurses are often the first contact with children with autism and their families; they can support the partnership between parents and healthcare professionals. Using the Double ABCX Model of family behavior as the conceptual framework, a study investigating the findings of this pilot study has been completed.

Long, B.C., & Marshall, V. (2010). **Coping processes as revealed in the stories of mothers of children with autism.** *Qualitative Health Research*, 20(1), 105-16.

PMID: 20019351

ABSTRACT: Copious research evidence identifies the many stressors faced by mothers of children with autism. The aim of this study was to examine the ways in which coping is revealed in the content and structure of stories told by five mothers of children with autism. Narrative data were analyzed using both holistic-form and categorical-content

approaches. Manifestations of coping were revealed in the macrostructures of stories. Cognitive coping strategies were particularly apparent in the life stories, which tended to focus on the emotional and cognitive journeys of the storytellers. Stories of discrete coping episodes added information about behavioral coping strategies employed in specific situations. Analysis of form, particularly of the structure of the life stories, yielded strategies the mothers employed to make meaning of autism in their lives.

Zmijewska, A. (2010). **[Asperger's syndrome in family context--review of studies].** *Psychiatria Polska*, 44(5), 713-22. [Article in Polish]
PMID: 21452506

ABSTRACT: In recent years in the face of still growing number of diagnosis of pervasive developmental disorders there has been an increase in number of research in the functioning of family of children with autism or Asperger's Syndrome. Studies concerning families of children with autism have been predominantly occupied with the stress-coping strategies and also with the therapeutic effect of interaction between disabled children and the rest of the family. New studies with families of children with Asperger's Syndrome, apart from the coping styles of parents and the received support, are also examining the properties of the system of these families, like: cohesion, adaptability, organization, control, expressiveness or conflict. Such a perspective enables researchers to describe the circularity of influences in these families, on the other hand, however; some methodological deficiencies of this research, as well as the lack of longitudinal studies prevent researchers from creating a comprehensive picture of functioning of these families.

2008

Chang, H.L., Lin, C.R., & Tsai, Y.F. (2008). **Coping mechanisms of parents of children recently diagnosed with autism in Taiwan: A qualitative study.** *Journal of Clinical Nursing*, 17(20), 2733-40.
PMID: 18808642

ABSTRACT: OBJECTIVE: To understand the coping mechanisms of Taiwanese parents whose children have recently been diagnosed with autism. BACKGROUND: When a child is diagnosed with

autism, the family's life changes. Parents of a child with autism have been shown to cope with problem- or emotion-focused coping strategies. However, it is not known how parents in Taiwan adapt and cope with the stresses of taking care of an autistic child, especially in the early period after learning their child's diagnosis and while waiting for free national day care arrangements at hospital. **DESIGN:** A descriptive qualitative design was used, with in-depth interviews. **METHODS:** Parents of children diagnosed with autism (n = 17) were recruited from a children's psychiatric outpatient clinic at a medical center in northern Taiwan. The parents were still waiting for free national day care arrangements at hospital. Data were collected through individual, tape-recorded interviews and observations, and transcripts were analyzed by content analysis for emerging themes and concepts. **RESULTS:** The study sample of parents of children with autism described nine main coping mechanisms that fell into three core categories: adjusting to self-change, developing treatments for the autistic child and seeking support. **CONCLUSIONS:** The results of this study could be used by clinicians to help parents of autistic children become aware of whether or not they are using healthy coping mechanisms, and to suggest concrete and healthy coping strategies, particularly in the period after the diagnosis is confirmed and they are waiting for free national day care arrangements at hospital. **RELEVANCE TO CLINICAL PRACTICE:** Clinicians in child psychiatry are encouraged to become part of the social support network for parents of autistic children, thus helping them adjust to the long journey of caring for their children.

2007

Connolly, P.M., Novak, J.M., & Tway, R. (2007). **Coping strategies used by parents of children with autism.** *Journal of the American Academy of Nurse Practitioners*, 19(5), 251-60.
PMID: 17489958

ABSTRACT: **PURPOSE:** The purpose of this research was to determine (a) the level of family adaptation, as measured by the Family Crisis Oriented Personal Evaluation Scales (F-COPESs) instrument, among persons with a child diagnosed with autism spectrum disorder (ASD) aged 12 years and under,

(b) if there was a difference in F-COPES scores based on family demographics, and (c) the time lag between parent's suspicion of ASD and the actual professional diagnosis of ASD. **DATA SOURCES:** A descriptive survey was used with a convenience sample derived from ASD treatment agencies and a parental support group in the California Bay Area that supports the children and parents of children with special needs. **CONCLUSIONS:** Overall, the level of adaptation was within the normal limits with coping scores similar to the norm scores of the F-COPES with males scoring slightly higher than females in the coping scale. Subscale scores of the F-COPES indicated that the parents sought encouragement and support from friends, informal support from other families who faced similar problems, and formal support from agencies and programs. Reframing revealed similar results as the norm with less use of spiritual support, and more passive appraisals were noted from the parents of children with ASD. Within internal comparisons, there were no statistical differences among gender and amount of time a member spent in coordination of services. Comparisons in ethnicity for Caucasians and Asian Americans revealed a higher coping score for reframing in Asian Americans and a higher passive appraisal score among Caucasians. Non-English speakers scored higher on spiritual support, while English speakers scored higher in passive appraisals. Because of insufficient statistical power, comparisons in education, income, marital status, and relocation of residence were deferred. The time from parents' suspicions of developmental delays or disability to a professional diagnosis of ASD was at least six months or greater. **IMPLICATIONS FOR PRACTICE:** It is imperative for nurse practitioners (NPs) to provide appropriate professional support and other social support systems to families with children with ASD. Educating parents to sound therapy approaches to provide them with the skills needed to directly address stressful events in order to increase the parent's confidence level as to avoid passive appraisals is also a crucial role of the NP. NPs may want to use the F-COPES as part of the assessment to ascertain the areas of needs of families. This study reveals the resiliency and highly adaptive nature of these parents who are under severe strain and stress of caring for a child with ASD. The effective ways they coped as a family were in the areas of informal and

formal social support networks. Participants also used passive appraisal to cope. The study also supports the need for early recognition and diagnoses of ASD and referral for early intervention for better outcomes for the children and families affected by ASD.

2006

Hauser-Cram, P., Hedvat, T.T., Kersh, J., & Warfield, M.E. (2006). **The contribution of marital quality to the well-being of parents of children with developmental disabilities.** *Journal of Intellectual Disability Research (JIDR)*, 50(Pt 12), 883-93.

PMID: 17100949

ABSTRACT: **BACKGROUND:** This study examines the contribution of the marital relationship to the well-being of both mothers and fathers of children with developmental disabilities. Parent well-being is conceptualized in terms of mental health, parenting stress and parenting efficacy. **METHODS:** These analyses are based on data from 67 families participating in the Early Intervention Collaborative Study, an ongoing longitudinal investigation of the development of children with disabilities and the adaptation of their families. Multidimensional assessment techniques were used to collect data from married mothers and fathers and their child with a disability. Mother and father data were analyzed separately using parallel hierarchical regression models. **RESULTS:** For both mothers and fathers, greater marital quality predicted lower parenting stress and fewer depressive symptoms above and beyond socio-economic status, child characteristics and social support. In relation to parenting efficacy, marital quality added significant unique variance for mothers but not for fathers. For fathers, greater social support predicted increased parenting efficacy. Child behavior was also a powerful predictor of parental well-being for both mothers and fathers. **CONCLUSION:** The findings support the importance of the marital relationship to parental well-being and illustrate the value of including fathers in studies of children with developmental disabilities.

2003

Gray, D.E. (2003). **Gender and coping: The parents of children with high functioning autism.** *Social Science & Medicine*, 56(3), 631-42.

PMID: 12570979

ABSTRACT: Gender is a concept that is frequently discussed in the literature on stress, coping and illness. Research has reported that women are more vulnerable than men to stressful events and use different strategies to cope with them. Furthermore, it is often asserted that these gender-based differences in coping may partially explain the differential impact of stressful events on men and women. Unfortunately, much of this research has equated gender with sex and failed to contextualize the experience of illness and coping. This paper presents a qualitative analysis of the role of gender and coping among parents of children with high functioning autism or Asperger's syndrome in an Australian sample. It attempts to analyze the different meanings of the disability for mothers and fathers and describes the various strategies that parents use to cope with their child's disability.

2002

Hiebert-Murphy, D., & Trute, B. (2002). **Family adjustment to childhood developmental disability: A measure of parent appraisal of family impacts.** *Journal of Pediatric Psychology*, 27(3), 271-80.

Full text is available at <http://jpepsy.oxfordjournals.org/content/27/3/271.full.pdf+html>

PMID: 11909934

ABSTRACT: **OBJECTIVE:** To develop the Family Impact of Childhood Disability Scale (FICD) to assess subjective interpretation or "primary appraisal" of parents regarding the impact of a child with developmental disabilities on the family. **METHOD:** A random sample of 87 families was assessed while children with developmental disabilities were in the preschool years. After 7 years had elapsed, 64 of these families were interviewed again when the children were in the preteen years. A set of standardized self-report measures provided mother and father views of child, parent, and family functioning. **RESULTS:** The FICD demonstrated adequate internal consistency, with some evidence of discriminant and

predictive validity. The FICD total score, based on the discrepancy between positive and negative subscale scores, was found to be a significant predictor of future parenting stress of mothers and of fathers, even when controlling for other important explanatory variables such as marital adjustment and level of disability in a child. **CONCLUSIONS:** The 15-item FICD offers a brief assessment of both positive and negative parent appraisals, with a total discrepancy score that predicts long-term parenting stress.

Järvelin, M.R., Kokkonen, J., Syrjälä, L., & Taanila, A. (2002). **Coping of parents with physically and/or intellectually disabled children.** *Child: Care, Health, and Development*, 28(1), 73-86.
PMID: 11856190

ABSTRACT: **OBJECTIVE:** The aim was to clarify how families with physically and/or intellectually disabled children cope, what kind of coping strategies they use and how the families with good and poor coping capacities differ. **METHODS:** The parents of eight children (aged 8-10 years) with physical and/or intellectual disability were interviewed twice, and the data elicited in these interviews were analyzed qualitatively using the grounded theory method. **RESULTS:** Information and acceptance, good family co-operation and social support were related to the coping strategies most frequently used. Half of the families seemed to have found successful ways of coping, whereas another half had major problems. There were five main domains in which the high- and low-coping families differed most from each other: (1) parents' initial experiences; (2) personal characteristics; (3) effects of the child's disability on family life; (4) acting in everyday life; and (5) social support. **CONCLUSION:** The findings can be utilized in developing supportive activities for families with disabled children. By recognizing the coping strategies used by the family, professionals and service providers can find the right ways to support their adaptation. As the role of physicians, nursing staff and other professionals in this process is very important, more attention should be attached to the collaboration between these groups, to enable them to view the situation from the perspective of the whole family.

Lam, L.W., & Mackenzie, A.E. (2002). **Coping with a child with Down syndrome: The experiences of mothers in Hong Kong.** *Qualitative Health*

Research, 12(2), 223-37.
PMID: 11837372

ABSTRACT: Chinese mothers' experiences of parenting a child with Down syndrome were explored through semi-structured interviews with 18 key informants selected by purposive sampling. Seven major themes were identified: unexpected birth of an abnormal child, acceptance of the child, special needs of the child, worry about the future, knowledge deficit, effect on the marital relationship, and social restrictions. The types of stressors changed over time according to the child's age, and coping strategies varied accordingly. Strategies frequently used were avoidance, self-reliance, and seeking social support. The particular problems faced by mothers of children with Down syndrome in Hong Kong were discussed in view of the sociocultural background of the region and the highly competitive nature of its society.

Sullivan, A. (2002). **Gender differences in coping strategies of parents of children with Down syndrome.** *Down's Syndrome, Research, and Practice: The Journal of the Sarah Duffen Centre/University of Portsmouth*, 8(2), 67-73.

Full text is available at <http://www.down-syndrome.org/reports/132/reports-132.pdf>

PMID: 12407971

ABSTRACT: Little research has been conducted on the reactions of parents, and fathers in particular, following the birth of a child with Down syndrome. Previous studies suggest that gender differences exist in coping strategies and a number of theories have supported this. The current study is informed by Pleck's (1981) Gender Role Strain model which attempts to explain the different socialization processes males encounter which influence their development in our society. Questionnaires from Carver, Scheier and Weintraub's COPE inventory (1989) were given to parents (n = 150) to measure coping strategies and a number of gender differences were found. Females scored significantly higher than males in seeking instrumental and emotional support; in focusing on and venting emotions; and suppression of competing activities. An additional analysis carried out on parents of young children (n = 74) yielded similar results. The overall findings from the study provided mixed implications for Pleck's theory. Gender differences were found but no value can be ascribed to these different coping strategies.

1997

Milo, E.M. (1997). **Maternal responses to the life and death of a child with a developmental disability: A story of hope.** *Death Studies*, 21(5), 443-76.

PMID: 10175163

ABSTRACT: Losing a child is probably the most devastating event that a mother can experience. When a child with a developmental disability dies, this painful loss may follow months or years of exhausting parenting. How do mothers of children with developmental disabilities respond to this dual loss (the loss of their ideal child and then the loss of their actual child)? This project used a semi-structured interview and the Grief Experience Inventory to explore the bereavement experience of eight mothers who have lost such children. It explored variables that are associated with optimal or complicated bereavement. It was found that most of the mothers were very successful in using cognitive coping strategies to find meaning and benefit in the life and death of their children and were able to continue seeing the world as benevolent and purposeful. Exceptional cases are discussed, and implications for helping professionals are offered. The findings of this study fill a significant gap in the theory of parental coping and bereavement.

1994

Rogner, J., & Wessels, E.T. (1994). **[Coping strategies of mothers and fathers with a first- or second-born mentally handicapped child].** *Praxis der Kinderpsychologie und Kinderpsychiatrie*, 43(4), 125-9. [Article in German].

PMID: 8016022

ABSTRACT: In 25 families with two children and one child with mental retardation, differences in coping between mothers and fathers were studied, taking into consideration the ordinal position of the handicapped child. Mothers showed more emotional stress, more self-criticism, searched more for social support and experienced more "up and down" in the process of adaptation. If the first child was handicapped, mothers coped more by "mastery" than mothers of a second born handicapped child and more by "expression" than fathers.

1991

Floyd, F.J., & Zmich, D.E. (1991). **Marriage and the parenting partnership: Perceptions and interactions of parents with mentally retarded and typically developing children.** *Child Development*, 62(6), 1434-48.

PMID: 1786726

ABSTRACT: The quality of the parents' marital bond and their ability to work together in the parenting role were examined for the parents of school-aged children (ages 6-18) with mild and moderate mental retardation (n = 38) and a comparable group of parents of typically developing children (n = 34). Significantly more negative functioning for the parents of mentally retarded children was observed during marital interactions, and parent-child interactions but was not reflected in their self-reports of marriage and parenting, suggesting that expectations about marital and parenting strains may modulate negative sentiments for these parents. Across both groups, marital quality and the parenting partnership, together with child behavior problems, accounted for 23 to 53 percent of the variance in parenting confidence and in aversive parent-child exchanges. Negative marital interaction was a particularly important predictor of aversive parent-child exchanges.



Quick Looks

Online Resources Related to Parenting Children with Developmental and Intellectual Disabilities

The [Parent Advocacy Coalition for Educational Rights \(PACER\)](#) is the leading organization for parents of children with disabilities. PACER was established in 1977 as a way for parents with children with disabilities to educate other parents and improve the lives of children with disabilities in Minnesota. It later evolved into a nationwide organization. Since its inception, PACER has established countless projects and contributed to the disability community by providing technical assistance through the Technical Assistance for Parents Project (TAPP) Regional Office; collaborations with European countries on assistive technology projects; and assisting with writing national legislation for parent training and information center. PACER's first project, "Parents Helping Parents" evolved from five-month pilot project to demonstrate the effectiveness of "parents helping parents" model to become the foundation for the more than [30 programs PACER offers](#) parents, students, professionals, and other parent organizations. The [Parent Training and Information Center](#) (Parents Helping Parents) offers [individual assistance](#), [webinars](#) and [workshops](#), and [publications](#) and [resources for specific disabilities](#). Finally, another PACER Center project, [Alliance: National Parent Technical Assistance Center \(NPTAC\)](#) provides [Parent Centers](#), Parent Training and Information Centers, and Community Parent Resource Centers with innovative technical assistance, up-to-date information, and high quality resources and materials. The major goal of Alliance NPTAC is to build the capacity of Parent Centers to improve results for children with disabilities ages 0-26 in rural, urban and suburban areas, and from underrepresented and underserved populations.

Online Resources

AbilityPath.org

AbilityPath.org is an online hub and special needs community for parents and professionals to learn, connect, and live a more balanced life - through all phases of a child's growth and development. The website combines social networking features with expert content from AbilityPath.org's team of educators, parents, therapists, and medical professionals.

Contact: www.abilitypath.org/about-us/contact-abilitypath.html
www.abilitypath.org

American Association on Intellectual and Developmental Disabilities (AAIDD)

AAIDD promotes progressive policies, sound research, effective practices, and universal human rights for people with intellectual and developmental disabilities.

Contact: aaidd.org/about-aaidd/contact-us#.Um_P7-IphnE
aaidd.org

The Arc of the United States (ARC)

The Arc promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.

Phone: 301/565-3842

Email: info@thearc.org

Find a local chapter: www.thearc.org/find-a-chapter
www.thearc.org

Autism Research Institute (ARI)

ARI is a support network that provides resources on Autism, advocates for the rights of individuals with autism spectrum disorder, and supports autism research.

Toll Free: 866/366-3361

Search results for parenting: www.autism.com/index.php/search/4b880c19f8402c0d40d651cee29b289a/

Search results for coping: <http://www.autism.com/index.php/search/133c4a83d16f70e4bbe89f420a453b52/>

www.autism.com

Autism Speaks

Autism Speaks is an advocacy organization dedicated to global biomedical research into the causes, prevention, treatments, and a possible cure for autism. This organization raises public awareness about autism and its effects on individuals, families, and society.

Toll Free: 888/288-4762

Email: familyservices@autismspeaks.org

Combating Bullying: www.autismspeaks.org/family-services/bullying

www.autismspeaks.org

Autism Society (U.S.)

The Autism Society works to improve the lives of all affected by autism by increasing public awareness about the day-to-day issues faced by people on the spectrum; advocating for appropriate services for individuals across the lifespan; and providing the latest information regarding treatment, education, research and advocacy.

Contact: www.autism-society.org/about-us/contact-us.html

For family members: www.autism-society.org/a-family-member.html

www.autism-society.org

Beach Center on Disability

The Beach Center on Disability is a multidisciplinary research and training center committed to making a significant and sustainable positive difference in the quality of life of individuals and families affected by disability and the professionals who support them.

Phone: 785/864-7600

Email: beachcenter@ku.edu

Families: www.beachcenter.org/families/default.aspx

Parent-to-Parent: www.beachcenter.org/families/parent-to-parent/default.aspx

www.beachcenter.org

The Council for Exceptional Children (CEC)

CEC is the largest international professional organization dedicated to improving educational outcomes for individuals with exceptionalities, students with disabilities, and/or the gifted.

Phone: 703/620-3660 (V), 866/915-5000 (TTY)

www.cec.sped.org

Exceptional Parent (EP) – Eparent.com

EP is an online resource providing information, support, ideas, encouragement and outreach for parents and families of children with disabilities and the professionals that work with them.

Contact: www.eparent.com/contact.php

www.eparent.com

Federation for Children with Special Needs (FCSN)

FCSN provides information, support, and assistance to parents of children with disabilities, their professional partners, and their communities.

Phone: 617/236-7210, 800/331-0688 (in MA)

Email: fcsninfo@fcsn.org

Parenting Training and Information:

fcsn.org/pti/index.php

fcsn.org

Interactive Autism Network

IAN was established in January 2006 at the Kennedy Krieger Institute to facilitate research leading to advancements in understanding and treating autism spectrum disorders.

Contact: www.iancommunity.org/contact

www.iancommunity.org

My Child Without Limits

MyChildWithoutLimits.org is an early intervention resource for families of young children ages 0-5 with developmental delays or disabilities, and professionals looking for a single, trusted, aggregate source of information that relates to their needs and interests.

Contact: www.mychildwithoutlimits.org/resources/contact-us

Autism: www.mychildwithoutlimits.org/understand/autism

Down Syndrome: www.mychildwithoutlimits.org/understand/down-syndrome

www.mychildwithoutlimits.org

National Autism Association (NAA)

NAA is a parent-run, 501(c)(3) nonprofit organization and the leading voice on urgent issues related to severe autism, regressive autism, autism safety, autism abuse, and crisis prevention.

Toll Free: 877/622-2884

Email: naa@nationalautism.org

nationalautismassociation.org

National Autistic Society (NAS U.K.)

NAS is the United Kingdom's leading organization for people affected by autism including Asperger's Syndrome. NAS is dedicated to improving the lives of individuals living with autism, and their friends and family.

Contact: www.autism.org.uk/news-and-events/about-the-nas/contact-us.aspx

Topics "P" for parents: www.autism.org.uk/about-autism/P.aspx

www.autism.org.uk

National Center for Learning Disabilities (NCLD)

NCLD improves the lives of all people with learning difficulties and disabilities by empowering parents, enabling young adults, transforming schools, and creating policy and advocacy impact.

Toll Free: 888/575-7373

Email: nclد@nclد.org

Resources for parents:

www.nclد.org/parents-child-disabilities

www.nclد.org

National Center on Birth Defects and Developmental Disabilities (NCBDDD)

The NCBDDD promotes the health of babies, children, and adults with and without disabilities. The mission of NCBDDD is to identify the causes of birth defects and developmental disabilities; assist children develop and reach their full potential; and promote the health and well-being among people of all ages with disabilities through research, partnerships, and prevention and education programs.

Toll Free: 800/232-4636

Email: cdcinfo@cdc.gov

Autism: www.cdc.gov/ncbddd/autism/index.html

Developmental Disabilities: www.cdc.gov/ncbddd/developmentaldisabilities/index.html

Down Syndrome: www.cdc.gov/ncbddd/birthdefects/downsyndrome.html

Intellectual Disabilities: www.cdc.gov/ncbddd/actearly/pdf/parents_pdfs/IntellectualDisability.pdf
www.cdc.gov/ncbddd

National Dissemination Center for Children with Disabilities (NICHCY)

NICHCY has been the center providing information to the nation on disabilities in children and youth; programs and services for infants, children, and youth with disabilities; and IDEA, the nation's special education law; as well as research-based information on effective practices for children with disabilities. Funding ended September 30, 2013 but the website and all of its free resources will remain available until September 30, 2014. As a result NICHCY is no longer able to take phone or email requests.

Autism Spectrum Disorders:

nichcy.org/disability/specific/autism

Down Syndrome:

nichcy.org/disability/specific/downsyndrome

Intellectual Disabilities:

nichcy.org/disability/specific/intellectual

nichcy.org

National Down Syndrome Congress (NDSC)

NDSC provides information, advocacy, and support concerning all aspects of life for individuals with Down syndrome while working to create a national climate where people with Down syndrome are accepted and embraced with dignity.

Toll Free: 800/232-6372

Email: info@ndscenter.org

New and Expectant Parents:

ndscenter.org/resources/new-and-expectant-parents/

www.ndscenter.org

National Down Syndrome Society (NDSS)

The NDSS is the national advocate for the value, acceptance, and inclusion of people with Down syndrome.

Toll Free: 800/221-4602

Email: info@ndss.org

New and Expectant Parents:

www.ndss.org/Resources/New-Expectant-Parents

www.ndss.org

Parent Technical Assistance Center (PTAC)

The National PTAC provides Parent Centers with innovative technical assistance, up-to-date information, and high quality resources and materials. Find a Center in your State:

www.parentcenternetwork.org/parentcenterlisting.html

www.parentcenternetwork.org

Parents Helping Parents (PHP) - The Family Resource Center in Santa Clara

PHP is a parent-directed, community-based organization developed in response to the need in the community for information, training, and support services for families who have children with special needs and the professionals who serve them.

Toll Free: 855/727-5775 (in-state), 408/727-5775

Email: info@php.com

www.php.com

Support for Families of Children with Disabilities

Support for Families of Children with Disabilities ensures that families of children with any kind of disability or special health care need have the knowledge and support to make informed choices that enhance their children's development and well-being by fostering partnerships among families, professionals, and the community.

Phone: 415/282-7494

Email: info@supportforfamilies.org
















Resources: www.supportforfamilies.org/resources.html

www.supportforfamilies.org

Search Terms for Parenting Children with Developmental and Intellectual Disabilities

- 📖 Access to Health Care
- 📖 Adjustment
- 📖 Adolescents
- 📖 Adoption
- 📖 Aggression
- 📖 Antisocial Behavior
- 📖 Anxiety
- 📖 Asperger Syndrome
- 📖 Attitude/toward Disabilities/Negative/Parental
- 📖 Autism
- 📖 Autism Spectrum Disorder
- 📖 Barriers
- 📖 Behavior/Adaptive/Child/Problems
- 📖 Beliefs
- 📖 Bereavement
- 📖 Caregivers
- 📖 Child Development/Rearing
- 📖 Children with Disabilities
- 📖 Clinical Diagnosis
- 📖 Communication Skills
- 📖 Community Resources
- 📖 Comorbidity
- 📖 Coping
- 📖 Correlation
- 📖 Counseling
- 📖 Cross-Cultural Studies
- 📖 Culture/Cultural Differences/Influences/
Relevance
- 📖 Daily Living
- 📖 Death
- 📖 Depression
- 📖 Developmental Disabilities
- 📖 Down Syndrome
- 📖 Early Diagnosis/Intervention
- 📖 Education/Special
- 📖 Emotions/Emotional Disturbances/Response
- 📖 Empowerment
- 📖 Ethnic Groups
- 📖 Ethnography
- 📖 Evaluation/Methods/Techniques
- 📖 Evidence-Based
- 📖 Family/Environment/Influence/Life/Needs/
Problems/Programs/Relationship/Support
- 📖 Family-Centered Care
- 📖 Father-Child Relationship
- 📖 Fathers
- 📖 Foreign Countries
- 📖 Gender Differences/Identity
- 📖 Grief
- 📖 Health/Promotion/Services
- 📖 Individual Characteristics/Differences
- 📖 Influences
- 📖 Information Resources
- 📖 Intellectual Disability
- 📖 Interpersonal Relations
- 📖 Intervention
- 📖 Labeling (of Persons)
- 📖 Learning
- 📖 Legal Issues
- 📖 Life Satisfaction
- 📖 Longitudinal Studies
- 📖 Marital Satisfaction
- 📖 Marriage
- 📖 Medical Aspects/Treatment
- 📖 Mental Disorders/Health/Retardation/Stress
- 📖 Models
- 📖 Mother-Child Relationship
- 📖 Mothers
- 📖 Needs Assessment
- 📖 Parent-Child Relationship
- 📖 Parent Education/Responsibility/Role/Style
- 📖 Parents
- 📖 Perception
- 📖 Personality Traits
- 📖 Pervasive Developmental Disorders
- 📖 Physical Health/Stress
- 📖 Planning
- 📖 Prejudice
- 📖 Problem Solving
- 📖 Program Effectiveness
- 📖 Psychosocial Factors
- 📖 Qualitative Research
- 📖 Quality of Life
- 📖 Referral and Consultation
- 📖 Rehabilitation
- 📖 Religion/Factors









Search Terms for Parenting Children with Developmental and Intellectual Disabilities continued ...

-  Remote Service Delivery
-  Respite Care
-  Rural Areas/Services
-  Self-Concept/Control/Efficacy/Help
-  Service Delivery
-  Severity (of Disability)
-  Sibling Relationship
-  Social Influences/Isolation/Support
-  Spirituality
-  Stereotyping
-  Stress Management/Variables
-  Treatment
-  Well Being
-  Young Adult
-  Youth

About reSearch:

reSearch is an information product from the National Rehabilitation Information Center (NARIC). Each issue is based on real-world queries received by our information specialists from researchers, educators, and rehabilitation professionals around the world.

We search several sources both in-house and online, to fill these requests including:

-  REHABDATA and the NIDRR Program database
-  Education Resources Information Center
-  National Clearinghouse of Rehabilitation Training Materials
-  Campbell and Cochrane Collaborations
-  PubMed and other National Library of Medicine databases
-  Agency for Health Care Policy and Research databases
-  Center for International Rehabilitation Research Information and Exchange
-  and other reputable, scholarly information resources.

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