

Research Related to Parents and Autism

Data bases searched were: PsycINFO, PsycEXTRA, PsycARTICLES, ERIC, CINAHL Plus with Full Text, Pre-CINAHL, and MEDLINE. The search terms were: parents, autism, and children. There were 138 articles published in 2007. The abstracts of 32 were reviewed. The following reviews/studies might be of interest to the members of the Virginia's Communities of Practice in Autism. Please note that the abstracts below were written by the authors of each article and taken directly from the database.

Systematic Reviews:

Diggle, T., McConachie, H.R., & Randle, V.R.L. (2007). Parent-mediated early intervention for young children with autism spectrum disorder. Cochrane Database of Systematic Reviews (COCHRANE DATABASE SYST REV), (3).

Background: Recent estimates concerning the prevalence of autistic spectrum disorder are much higher than those reported 30 years ago, with at least 1 in 400 children affected. This group of children and families have important service needs. The involvement of parents in implementing intervention strategies designed to help their autistic children has long been accepted as helpful. The potential benefits are increased skills and reduced stress for parents as well as children.

Objectives: The objective of this review was to determine the extent to which parent-mediated early intervention has been shown to be effective in the treatment of children aged 1 year to 6 years 11 months with autistic spectrum disorder. In particular, it aimed to assess the effectiveness of such interventions in terms of the benefits for both children and their parents.

Search strategy: A range of psychological, educational and biomedical databases were searched. Bibliographies and reference lists of key articles were searched, field experts were contacted and key journals were hand searched.

Selection criteria: Only randomised or quasi-randomised studies were included. Study interventions had a significant focus on parent-implemented early intervention, compared to a group of children who received no treatment, a waiting list group or a different form of intervention. There was at least one objective, child related outcome measure.

Data collection and analysis: Appraisal of the methodological quality of included studies was carried out independently by two reviewers. Differences between the included studies in terms of the type of intervention, the comparison groups used and the outcome measures were too great to allow for direct comparison.

Main results: The results of this review are based on data from two studies. Two significant results were found to favour parent training in one study: child language and maternal knowledge of autism. In the other, intensive intervention (involving parents, but primarily delivered by professionals) was associated with better child outcomes on direct measurement than were found for parent-mediated early intervention, but no differences were found in relation to measures of parent and teacher perceptions of skills and behaviours.

Authors' conclusions: This review has little to offer in the way of implications for practice: there were only two studies, the numbers of participants included were small, and the two studies could not be compared directly to one another. In terms of research, randomised controlled trials involving large samples need to be carried out, involving both short and long-term outcome information and full economic evaluations. Research in this area is hampered by barriers to randomisation, such as availability of equivalent services.

McConachie, H., & Diggle, T. (2007). Parent implemented early intervention for young children with autism spectrum disorder: a systematic review. *Journal of Evaluation in Clinical Practice*, 13(1), 120-129.

Background: Recent estimates concerning the prevalence of autism spectrum disorder (ASD) suggest that at least one in 200 children is affected. This group of children and families have important service needs. The involvement of parents in implementing intervention strategies designed to help their autistic children has long been accepted as helpful. The potential benefits are increased skills and reduced stress for parents as well as children. Methods: This research review focused on interventions for children aged 1-6 years, and was carried out using systematic methodology: a comprehensive search of psychological, educational and biomedical databases, as well as bibliographies and reference lists of key articles, contact with experts in the field, and hand search of key journals. Only studies which involved a concurrent element of control were included. Results: The review found very few studies that had adequate research design from which to draw conclusions about the effectiveness of parent-implemented early intervention. Both randomized and controlled studies tended to suggest that parent training leads to improved child communicative behaviour, increased maternal knowledge of autism, enhanced maternal communication style and parent child interaction, and reduced maternal depression. Conclusion: It seems that parent training can successfully contribute to intervention for young children with ASD. However, the review highlights the need for improved research in this area.

Individual Studies on Resiliency, Coping, Stress, Support:

Silverman, C., & Brosco, J.P., (2007). Understanding autism: Parents and pediatricians in historical perspective. *Archives Of Pediatrics & Adolescent Medicine*, 161 (4), 392-398.

Both primary care providers and subspecialists in pediatrics encounter families who are actively involved in the diagnosis and treatment of their children. Parents of children with an autism spectrum disorder in particular are often aware of scientific issues, and their expertise and desire for a medical cure for autism sometimes put them at odds with the medical team. We investigated the role of parents and advocates in autism research and treatment over the last 50 years. Our review of scientific publications and archival sources documents how parents and advocacy groups have done the following: (1) organized research funding; (2) constructed clinical research networks; (3) suggested new avenues

for research; (4) popularized empirically based therapies; and (5) anticipated paradigmatic shifts in the understanding of autism. We believe that this historical account will help pediatricians and researchers recognize that families can contribute to expert understanding of complex medical conditions such as autism and that the existence of partnerships with families of children with autism is a critical component of future research and treatment programs.

Bayay, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research*, 51(9), 702-714.

Family resilience is a growing field of inquiry, investigating factors that contribute to a family's becoming stronger in spite of dealing with adversity. Despite the growing interest in studying family resilience, the topic has not been explored in families with children who have disabilities. This report, a part of a larger study--using both quantitative and qualitative methodologies--is an examination of factors of family resilience in the families of children with autism. Evidence of family resilience such as family connectedness and closeness, positive meaning-making of the disability, and spiritual and personal growth were identified and examined in this part of the study. The study uses a survey methodology, analysing responses to several rating scales and written responses to three open-ended questions. Survey respondents consisted of 175 parents and other primary caregivers of a child with autism--ages between 2 and 18 years. Results: Results suggest identification of specific resilience processes, such as: making positive meaning of disability, mobilization of resources, and becoming united and closer as a family; finding greater appreciation of life in general, and other people in specific; and gaining spiritual strength. Conclusions: This study presents evidence that a considerable number of families of children with autism display factors of resilience -- reporting having become stronger as a result of disability in the family.

Bishop, S.L., Richler, J., Cain, A.C., & Lord, C. (2007). Predictors of perceived negative impact in mothers of children with autism spectrum disorder. *American Journal Of Mental Retardation*, 112 (6), 450-461.

Mothers of 110 children with autism spectrum disorders (ASD) were interviewed with the Child and Adolescent Impact Assessment when their children were approximately 9 years old. Regression analyses revealed that African American mothers reported lower levels of perceived negative impact of having a child with ASD than did Caucasian mothers. Higher repetitive behavior scores on the Autism Diagnostic Interview-Revised, lower adaptive behavior scores on the Vineland Adaptive Behavior Scales, and less perceived social support were also significant predictors of higher perceived negative impact. Identifying predictors of perceived negative impact is an important first step in designing interventions to support families and target parents who may be at risk for experiencing higher levels of stress.

Twoy, R., Connolly, P.M., & Novak, J.M., (2007). Coping strategies used by parents of children with autism. *Journal of the American Academy of Nurse Practitioners*, 19(5), 251-260.

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 6 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.

Plant, K. M., & Sanders, M. R. (2007). Predictors of care-giver stress in families of preschool-aged children with developmental disabilities. *Journal of Intellectual Disability Research*, 51(2), 109-124.

Background: This study examined the predictors, mediators and moderators of parent stress in families of preschool-aged children with developmental disability. Method: One hundred and five mothers of preschool-aged children with developmental disability completed assessment measures addressing the key variables. Results: Analyses demonstrated that the difficulty parents experienced in completing specific care-giving tasks, behaviour problems during these care-giving tasks, and level of child disability, respectively, were significant predictors of level of parent stress. In addition, parents' cognitive appraisal of care-giving responsibilities had a mediating effect on the relationship between the child's level of disability and parent stress. Mothers' level of social support had a moderating effect on the relationship between key independent variables and level of parent stress. Conclusions: Difficulty of care-giving tasks, difficult child behaviour during care-giving tasks, and level of child disability are the primary factors which contribute to parent stress. Implications of these findings for future research and clinical practice are outlined.

van IJzendoorn, M.H., Rutgers, A.H., Bakermans-Kranenburg, M.J., van Daalen, E., Dietz, C., Buitelaar, J.K., et al. (2007). Parental sensitivity and attachment in children with autism spectrum disorder: Comparison with children with mental retardation, with language delays, and with typical development. *Child Development*, 78(2), 597-608.

This study on sensitivity and attachment included 55 toddlers and their parents. Samples included children with autism spectrum disorder (ASD), mental retardation, language delay, and typical development. Children were diagnosed at 4 years of age. Two years before diagnosis, attachment was assessed with the Strange Situation procedure, and parental sensitivity and child involvement during free play were assessed with the Emotional Availability Scale. Parents of children with ASD were equally sensitive as parents of children without ASD, but their children showed more attachment disorganization and less child involvement. More sensitive parents had more secure children, but only in the group without ASD. Less severe autistic symptoms in the social domain predicted more attachment security. Autism challenges the validity of attachment theory.

Mandell, D.S., & Salzer, M.S. (2007). Who joins support groups among parents of children with autism? *Autism*, 11(2), 111-122.

This study identified factors associated with support group participation among families of children with autism. A survey was administered to 1005 caregivers of children with autism in Pennsylvania. Two-thirds of respondents (66.4%) had ever participated in an autism-specific support group. In adjusted analyses, demographic characteristics, including age and sex of the child, ethnicity and parental education and income, were associated with support group participation. Parents of children with self-injurious behavior, sleep problems or severe language deficits were more likely to belong, as were parents whose diagnosing clinician referred them to a support group. The results of this study suggest the

importance of clinician referrals to groups, and the need to make groups available to under-served populations.

Hillman, J. (2007). Grandparents of children with autism: A review with recommendations for education, practice, and policy. *Educational Gerontology*, 33(6), 513-527.

One in 166 grandparents will become grandparent to a child with autism. A review of empirical studies suggests that these grandparents experience significant role confusion. They provide the autistic child's parents--who are more likely to be depressed, single, or divorced--with both burden (e.g., conflict regarding behavioral symptoms) and emotional and instrumental support (e.g., childcare; financial assistance; advocacy). Unique stressors of autism upon families include social isolation and financial burden. Custodial grandparents face additional stressors. Opportunities for education, practice, and policy that are designed to help grandparents redefine their role, share in the diagnosis and treatment of autism, and obtain social support are advanced.

Individual Studies on Intervention, Treatment, Training:

Goin-Kochel, R.P., Myers, B., & Mackintosh, V.H. (2007). Parental reports on the use of treatments and therapies for children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 1(3), 195-209.

Parents of children with autism spectrum disorders (ASD; N = 479) reported via web-based survey what pharmacological (drug), diet, and behavioral/educational/alternative therapies they had tried and were using now in the treatment of their children with ASD. Depending on type of ASD, children had tried, on average, between seven and nine therapies and were now using between four and six. Children with Asperger's syndrome had tried significantly more drug treatments than had those with autism or PDD-NOS, while those in these latter two groups had tried more behavioral/educational/alternative therapies. Adolescents had a higher prevalence of drug-treatment use compared with those in middle childhood, who, in turn, had a higher frequency of use relative to those in early childhood. For most behavioral/educational/alternative treatments, more children in early and middle childhood had tried them compared with adolescents. Likewise, children in both early and middle childhood were currently using a higher number of behavioral/educational/alternative treatments than were those in the adolescent group. Findings are discussed relative to both the extant literature on treatment use among ASD families and how parents choose among the plethora of available therapies.

Rocha, M. L., Schreibman, L., & Stahmer, A. C., (2007). Effectiveness of training parents to teach joint attention in children with autism. *Journal of Early Intervention*, 29(2), 154 - 172.

Young children with autism have deficits in initiating and responding to joint attention bids. This study was designed to examine a parent-implemented intervention targeting joint attention responding in children with autism. Parents were trained to increase their joint attention bids using behavior analytic techniques to facilitate appropriate responding. Parents effectively employed joint attention intervention techniques. As parent joint attention bids increased, children's responses increased. Children's joint attention initiations also increased, even though they were not direct targets of intervention. Findings suggest that parent behaviors during and after intervention impact generalization and maintenance of behavior changes. Implications for practice and future investigations are discussed.

Solomon, R., Necheles, J., Ferch, C., & Bruckman, D. (2007). Pilot study of a parent training program for young children with autism: The PLAY Project Home Consultation program. *Autism, 11*(3), 205-224.

The PLAY Project Home Consultation (PPHC) program trains parents of children with autistic spectrum disorders using the DIR/Floortime model of Stanley Greenspan MD. Sixty-eight children completed the 8-12 month program. Parents were encouraged to deliver 15 hours per week of 1:1 interaction. Pre/post ratings of videotapes by blind raters using the Functional Emotional Assessment Scale (FEAS) showed significant increases in child subscale scores. Translated clinically, 45.5 percent of children made good to very good functional developmental progress. There were no significant differences between parents in the FEAS subscale scores at either pre-or post-intervention and all parents scored at levels suggesting they would be effective in working with their children. Overall satisfaction with PPHC was 90 percent. Average cost of intervention was \$2500/year. Despite important limitations, this pilot study of The PLAY Project Home Consulting model suggests that the model has potential to be a cost-effective intervention for young children with autism.

Gillett, J. N., & LeBlanc, L.A. (2007). Parent-implemented natural language paradigm to increase language and play in children with autism. *Research in Autism Spectrum Disorders, 1*(3), 247-255.

Three parents of children with autism were taught to implement the Natural Language Paradigm (NLP). Data were collected on parent implementation, multiple measures of child language, and play. The parents were able to learn to implement the NLP procedures quickly and accurately with beneficial results for their children. Increases in the overall rate of vocalizations were observed for all three children with a shift from imitative language at the beginning of intervention to spontaneous language at the end of intervention. Clear improvements in play were observed for two of three children while ceiling effects were observed for a third child who already played effectively. In response to a social validity questionnaire, parents indicated that they found the study useful and

the NLP procedures simple to implement and that that they would continue to use NLP at home following the conclusion of the study.

Ingersoll, B., & Gergans, S. (2007). The effect of a parent-implemented imitation intervention on spontaneous imitation skills in young children with autism. *Research in Developmental Disabilities, 28*(2),163-175.

Children with autism exhibit significant deficits in their ability to spontaneously imitate the play actions and descriptive gestures of others. Reciprocal imitation training (RIT) is a naturalistic imitation intervention designed to teach spontaneous imitation skills during play. This study assessed the effectiveness of parent-implemented RIT using a multiple-baseline design across three young children with autism and their mothers. After an initial baseline, mothers were taught to implement RIT techniques with their child twice a week for 10 weeks in a clinic setting. Two mothers were taught to use RIT to teach object imitation. The third mother was taught to use RIT to target both object and gesture imitation in a multiple-baseline design across behaviors. Generalization was assessed in the families' homes at the end of treatment and a 1-month follow-up. Parents learned to use the intervention strategies and their children exhibited increases in spontaneous imitation. These findings replicate the results from previous studies, indicating that RIT is effective for teaching imitation skills to young children with autism in a naturalistic setting and extend the findings to parents.

Crockett, J.L., Fleming, R.K.,& Stevens, J.S., (2007). Parent training: Acquisition and generalization of discrete trials teaching skills with parents of children with autism. *Research in Developmental Disabilities, 28*(1), 23-36.

This study examined the effects of an intensive parent training program on the acquisition and generalization of discrete trial teaching (DTT) procedures with two parents of children with autism. Over the course of the program, parents applied the DTT procedures to teach four different functional skills to their children, which allowed for an assessment of "free" and programmed generalization across stimulus exemplars. Parent training was conducted by the first author utilizing instructions, demonstrations, role-play, and practice with feedback. Parents' use of DTT skills and children's correct and incorrect responding were measured. A within-subject multiple-baseline across stimulus exemplars (functional skills taught) design was employed both to demonstrate control of the training program over parents' correct use of DTT, and to allow a preliminary investigation of the generalized effects of training to multiple stimulus exemplars. Results demonstrate initial control of the training program over parent responding, and the extent to which each parent extended her use of DTT procedures across untrained and topographically different child skills. The potential for designing more generalizable and thus more cost-effective parent training programs is discussed.

Plant, K. M., & Sanders, M.R. (2007). Reducing problem behavior during care-giving in families of preschool-aged children with developmental disabilities. *Research in Developmental Disabilities*, 28(4), 362-385.

This study evaluated two variants of a behavioral parent training program known as Stepping Stones Triple P (SSTP) using 74 preschool-aged children with developmental disabilities. Families were randomly allocated to an enhanced parent training intervention that combined parenting skills and care-giving coping skills (SSTP-E), standard parent training intervention alone (SSTP-S) or waitlist control (WL) condition. At post-intervention, both programs were associated with lower levels of observed negative child behavior, reductions in the number of care-giving settings where children displayed problem behavior, and improved parental competence and satisfaction in the parenting role as compared with the waitlist condition. Gains attained at post-intervention were maintained at 1-year follow-up. Both interventions produced significant reductions in child problem behavior, with 67% of children in the SSTP-E and 77% of children in the SSTPS showing clinically reliable change from pre-intervention to follow-up. Parents reported a high level of satisfaction with both interventions.

Watson, L.R., Baranek, G.T., Crais, E.R., Reznick, J. Dykstra, J., & Perryman, T. (2007). The First Year Inventory: Retrospective parent responses to a questionnaire designed to identify one-year-olds at risk for autism. *Journal of Autism and Developmental Disorders*, 37(1), 49-61.

The First Year Inventory (FYI) is a parent questionnaire designed to assess behaviors in 12-month-olds that suggest risk for an eventual diagnosis of autism. We examined the construct validity of the FYI by comparing retrospective responses of parents of preschool children with autism spectrum disorders (ASD; n = 38), other developmental disabilities (DD; n = 15), and typical development (TD; n = 40). Children with ASD were rated at significantly higher risk on the FYI than children with DD or TD. The DD group was at intermediate risk, also significantly higher than the TD group. These retrospective data strengthen the validity of the FYI and have implications for refining the FYI to improve its utility for prospective screening of 12-month-olds.