

Parental Stress in Families of Children with Disabilities: A Literature Review

Erjona Dervishalaj

Universiteti i Vlores "Ismail Qemali",
Fakulteti i Shkencave Humane, Vlora, Albania.
edailaj123@gmail.com

Doi:10.5901/jesr.2013.v3n7p579

Abstract

A lot has been written about the stressors in the lives of parents of children with disabilities. Several studies indicate that parents of children with disabilities experience higher levels of stress compared to parents of children without disabilities. Studies have focused on understanding the types, causes and the effects of these stresses, discussing further implications for family intervention. Anyway, little research is done in this area in Albania. This paper examines the existing research on stress in families of children with disabilities, highlighting different variables related to stress. Through a literature review and conceptual framework the aim of this article is to help professionals to a better understanding of variables related to stress, and to create some basis and guidelines for further empirical research in Albania. Suggestions for research in the future are discussed.

Keywords: parental stress, children with disabilities, literature review, typically developing children

1. Introduction

Parenting, a wonderful and rewarding experience, is often accompanied by high levels of stress, because of the difficulties, frustrations, and challenges that parents face in everyday life. The coming of a child with developmental disabilities brings unexpected demands and challenges to parents, for which they are often not prepared. Having a child with developmental disabilities brings life changing implications and long-lasting effects in the life of the whole family (Simmerman, 2001; Martin & Colbert, 1997). Many studies conducted on this area show that parents of children with developmental disabilities experience higher levels of stress compared to parents of children with typical development (Sanders & Morgan 1997; Roach et al 1999). The impact that a child with developmental disabilities has on the family is not only linear and it does not lie on only on direction. The impact is multidimensional, reciprocal, it affects the whole family system, it affects the relationships between the family members (Harris 1994; Rodrigue, Gefken & Morgan 1994; Breslau 1982; Breslau & Prabucki 1987). The wellbeing of the siblings of children with developmental disabilities may be compromised due to the stress experienced in the family (Rossiter & Sharpe 2001).

This paper examines the existing research on parental stress in families of children with developmental disabilities (DD), highlighting different variables related to stress. The papers selected for literature review met two criteria: a) the papers were focused on parental stress (or its correlations with other variables) in families of children with developmental disabilities, b) the child's developmental disability was one from the above mentioned; Down syndrome, autism, intellectual disabilities, ADHD.

According to Stein dhe Jessop (1989) the caregivers of children with chronic conditions, experience similar concerns and needs for support. This paper was designed upon the assumption that different diagnosis of developmental disabilities affect families in similar ways. The term Developmental Disabilities (DD) refers to a wide range of disabilities. It would have been unrealistic and out of the researcher's possibilities trying to cover all types of DD on this paper. The before mentioned types of DD were selected by the researcher as many studies were conducted on them and their impact on families.

2. Why is it important to study stress experienced by parents of children with DD?

Research suggest that parents of children with DD not only experience higher levels of stress compared to families of children with typical development, but their mental health in general might be complicated as well. Parents may experience depression, anxiety (Beckman 1991; Dyson 1991; Emerson 2003; Bristol & Schopher 1984; Hoppes &

Hoppes 1990), higher levels of hopelessness, failure, guilt (Jones 1997; Powers 1989; Tommasone & Tommasone 1989), they report less parental skills and less marital satisfaction (Rodrigue et al 1990).

Parents' psychological well-being is considered to be very important. Research stress the importance of intervention programs in parental stress in order to alleviate it (Davis 1985; Schilling & Schinke 1984), because high levels of parental stress may have a negative impact on the functioning of the child with DD. Parents may behave ways that have a negative impact on children (Hastings 2002). Studies suggest that parents who experience higher levels of stress interact differently with their children, compared to parents who experience lower levels of stress, and they respond differently to their child's problematic behavior (Conger et al 1995). According to Floyd & Phillippe (1993) self reported depression from parents was a strong predictor for their efforts to manage actively and successfully their child's problematic behaviors.

The child with developmental disabilities is not the only one who affects his family's life and dynamics. The family also affects positively or negatively the child's development. Research suggests that higher levels of parental stress predict less positive outcomes from the early intervention programs for children with disabilities (Brinker et al, 1994), whereas early interventions for children with disabilities are more successful when family problems, parental stress included, are addressed before the intervention program begins (Rhodes 2003). Thus knowing and dealing with parental stress is important for professionals. At last, not only it seems that parental stress interferes with success of intervention programs for children with DD (Robbin et al 1991; Brinker et al 1994), but parents as well, while experiencing high levels of stress, have less positive outcomes from intervention programs designed to improve parental skills (Rhodes 2003; Baker et al 1991).

Many variables have been related to stress experienced by parents of children with DD. In this paper they are conceptualized in three categories: stress related to child characteristics, parental cognitive appraisals of the situation, and family resources and support.

3. Child related stress- Diagnosis, child characteristics and behavior

According to research parents' psychological well-being is strongly affected by their child's primary diagnosis. Shock, denial, disbelief, grief are parents' common reactions in this case (Martin & Colbert, 1997). A considerable amount of literature show that at first parents deal with their loss of expectancies, with lost possibilities and dreams of their perfect child, and all this process of loss that they go through, results in emotional distress (Martin & Colbert, 1997; McCubbin et al., 1982). Nevertheless, according to Martin & Colbert (1997), some parents report some sense of relief after the diagnosis is set, because it finally puts an end to their doubts, and provides them with answers.

Waisbren (1980) underlined that having a child with DD requires that parents reformulate and readopt new roles and identities as parents of children with DD. This may result in ambivalence or/and anxiety, which does nothing less than increasing stress' levels.

Other studies suggest that maybe it is not just the diagnosis the source of stress experienced by parents, but instead child's characteristics and behaviors related to diagnosis are the source of stress. According to them parental stress may be strongly related to the level of the child's disability (Minnes, 1988), to child's characteristics and his challenging behaviors, and all of them are time consuming for the parents. (Simmernan et al 2001).

Maladaptive behaviors, challenging behaviors and self mutilation of children with DD may be strong source of stress for parents. Children require constant supervision for their own safety, and their siblings' safety as well (Cole 1986).

Many parents relate stress to their children's demands for constant care (Minnes 1988; Beckman-Bell, 1981). Many children who have DD may not be able to take care of themselves, or perform behaviors that are expected from other children of their age and who have a typical development. This means that parents have to commit more to their child and invest more time and energy on him. The possible result is alleviated stress in parents (Martin & Colbert, 1997). Parenting a child with DD does not only affect the intensity of caretaking, but its extension on time as well. The child's autonomy may be delayed or compromised by the disability.

It seems that certain child related characteristics like communication skills or the level of difficulties the child has while performing a behavior, are all strongly correlated to levels of stress experienced by parents (Frey et al 1989, Quine & Pahl 1991). Special health care demands, continuous accompany of the child by parents or constant supervision interfere with parents' everyday activities. Their limited possibilities, because of lack of time, to take a rest, to have fun or to take some time for themselves, results into tiredness, burnout, distress (Martin & Colbert, 1997; Cole, 1986). Children's abruptive behavior is correlated to low levels of self efficacy of parents and to mental health problems

(Herring et al 2006).

Normally, parents' involvement in their children's education process is very important. When it comes to children with special needs, parents need to engage more than they would do with normally developed children (Westling, 1997). Because of new responsibilities for which they are often not prepared, they participate in special trainings and instruction sessions for parents, they need to interact regularly and very often with teachers, etc, and all this means less time for other activities. Parents can easily get discouraged because of their children's failure to meet educational goals. All this adds up to stress (Martin & Colbert, 1997).

4. Parental Cognitions

Parental cognitive appraisals of the child's disability mediate levels of stress experienced by parents. Whether having a child with disabilities leads toward stress or towards positive coping and adaptation this will depend upon the family's perceptions on the child's disability, the explanations made by the family, their understanding of why events occur and what can they do to alleviate stress. Many studies have focused on the role of parental cognitive appraisals on stress. Mash & Johnston (1990) suggest that a combination of child characteristics and parental cognitions may affect levels of parental stress. Others studies suggest that when it comes to cognitions they may be stronger predictors of parental stress than the child's maladaptive behavior (Plant & Sanders, 2007; Hastings & Brown, 2002). Being able to reframe the disability in a positive way and perceiving themselves as competent rather than passive was found helpful to family adjustment in a study conducted by Lustig (2002). Some of the studies on the role of parental cognitions on stress have focused on parental self-esteem (Johnston & Mash, 1989), some on self-efficacy (Hastings & Brown 2002), and others on locus of control (Hagekull *et al.*2001; Hasall *et al.* 2005). It seems that parental cognitions mediate the role of different variables on parental stress. Quine & Pahl (1991) found that cognitive appraisals mediated the child's behavior problems on parental stress. Hastings & Brown (2002) found that self-efficacy mediated the effects of child's maladaptive behavior on anxiety and depression experienced by mothers of children with autism. According to Hasall *et al.* (2005) most of the variance in parenting stress that they measured was explained by parental locus of control, parenting satisfaction and child behavior difficulties. They also found that the strong correlation between family support and parenting stress was mediated by parental locus of control.

5. Family resources and support

When a family member is diagnosed with a chronic disease the whole family functioning may be affected and change as a result (Seligman & Darling, 1997). On the other hand, the way the family functions in respond to the child's disability affects levels of stress experienced by parents (Abeduto, 2004). Some studies suggest that family functioning and couple functioning may be stronger predictors, than just the presence or absence of the disability, to higher levels of stress and depression experienced in family. According to Oliver & Innocenti (2001) family functioning is a stronger predictor of parental stress than the child's poor skills.

Other studies show that raising a child with developmental disabilities can have negative impact on family functioning and on family's relationships with others outside the family (Cole, 1986; Martin & Colbert, 1997).

Family cohesion is another variable related to parental stress. It seems that high levels of family cohesion predict lower levels of parental stress in the families of children with DD. When mothers perceive support from within the family they report lower levels of stress related to child-rearing (Warfield *et al.* 1999). Some studies show that raising a child with a disability may be related to parents' difficulties with maintaining a cohesive relationship (Bristol *et al.*, 1988). Helping parents build and maintain a cohesive relationship while taking care of a child with a disability might help them lower levels of stress. Anyway, some other studies suggest that poor family functioning, while is a risk factor for stress, is not found in families of children with disabilities more often than in other families. According to research many families of children with developmental disabilities function quite well (Lustig, 1997).

There's a considerable amount of research on the role of support in the families of children with DD (Minnes, 1988; Perry 1989; Jones and Passey, 2004; Thompson 2006) . All of them agree that support formal or informal can pile up stress. When parents perceive lack of support while talking to doctors or other professionals, or when they have trouble in dealing with relatives, and this results in lack of support, parents report higher levels of stress (Perry 1989, Thompson 2006). Jones and Passey (2004) found that lack of perceived help from social support was a predictor for levels of stress experienced by parents.

6. Differences between mothers and fathers

Though the child's disability affects the whole family there is considerable evidence that mothers experience greater impact than fathers by their child's disability (Hastings et al., 2005; Oelofsen and Richardson 2006; Gray 2003). For example in a study conducted by Gray (2003) on families of children with autism, he found that mothers and fathers were affected on different ways and levels by their child's condition. Fathers claimed that their child's condition didn't affect them personally as it did with their wives. They also admitted that the way their child's autism affected them was through the stress that their wives experienced. According to Gray different levels of stress experienced by mothers and father may be explained by gender roles connected to work and child rearing. While mothers usually are more involved in child rearing, fathers are more into working harder in order to support their family's financial needs.

There is difference between mothers and fathers in the coping strategies they use. While fathers tend to suppress their feelings, or to avoid them by working until late or staying away from home, mothers tend to vent their feelings. Mothers tend to experience a wider range of feelings (from grief, sadness, anger and crying) and talk more about their emotional distress with others. Mothers are found to be more stigmatized by their child's disorder (Gray, 1993).

There are also differences in mothers' and fathers' perceptions or cognitive appraisals. For example, research suggest that they may perceive family cohesion and adaptability differently. When asked about family cohesion and adaptability mothers reported having a significantly more cohesive and adaptable family as compared to the reports from the fathers (Kraus, 1993).

Yet, findings are contradictory. While many studies describe mothers as suffering from increased symptoms of depression, increased burden of child rearing, and increased stress compared to fathers, some other studies have found little to no differences between mothers and fathers (Dyson, 1991)

This literature review points to different factors related to stress for professionals and researchers to bear in mind while working with families of children with DD. There is a large variation in the experience of caring for a child with a disability. Professionals working with these families need to be aware of the fact that care giving produces both positive and negative experiences. This review of literature points out that healthy family functioning is important for the well being of the family, and that practitioners need to support the needs of the entire family and not just the needs of the child with a disability. Practitioners working with young children can play an important role in helping family members reframe their care giving experience in positive ways and assisting family members in feeling like they have the knowledge, skills, and ability to successfully advocate for what their children need.

There's the need for additional research on the role of these variables on the Albanian context.

References

- Abbeduto, L., Seltzer, M. M., Shattuck, P., Krauss, M. W., Orsmond, G., & Murphy, M. M. (2004). Psychological wellbeing and coping in mothers of youths with autism, Down Syndrome or Fragile X Syndrome. *American Journal on Mental Retardation*, 109, 237-254.
- Baker, B.L., Blacher, J., Crnic, K., & Edelbrock, C. (2002). Behavior problems and parenting stress in families of three-year-old children with and without developmental delays. *American Journal on Mental Retardation*, 107, 433-444.
- Baker, B.L., McIntyre, L.L., Blacher, J., Crnic, K., Edelbrock, C., & Low, C. (2003). Pre-school children with and without developmental delay: Behaviour problems and parenting stress over time. *Journal of Intellectual Disability Research*, 47, 217-230.
- Baxter, C. (1987). Professional services as support: Perceptions of parents. *Australia and New Zealand Journal of Developmental Disabilities*, 13, 243-253
- Baxter, C., Cummins, R.A., & Yiollitis, L. (2000). Parental stress attributed to family members with and without disability: A longitudinal study. *Journal of Intellectual and Developmental Disability*, 25, 105- 118.
- Beckman, P.J. (1991). Comparison of mothers' and fathers' perceptions of the effect of young children with and without disabilities. *American Journal on Mental Retardation*, 95, 585-595
- Beckman-Bell, P. (1981). Child-related stress in families of handicapped children. *Topics in Early Childhood Special Education*, 1, 45-53.
- Blacher, J. (1994). Placement and its consequences for families with children who have mental retardation. In J. Blacher (Ed.), *When there's no place like home: Options for children living apart from their natural families* (pp. 213-244). Baltimore: Paul H. Brookes.
- Blacher, J., Shapiro, J., Lopez, S., Diaz, L., & Fusco, J. (1997). Depression in Latina mothers of children with mental retardation: A neglected concern. *American Journal on Mental Retardation*, 101, 483-496.
- Breslau, N. (1982). Siblings of disabled children: Birth order and age-spacing effects. *Journal of Abnormal Child Psychology*, 10, 85-96.
- Breslau, N., & Prabucki, K. (1987). Siblings of disabled children. *Archives of General Psychiatry*, 44, 1040- 1046.
- Brinker, R. P., Seifer, R., & Smeroff, A. J. (1994). Relations among maternal stress, cognitive development, and early intervention in middle and low SEC infants with developmental disabilities. (I) *American journal on Mental Retardation*, 98, 463-480
- Bristol, M.M. & Schopler, E. (1984) 'A Developmental Perspective on Stress and Coping in Families of Autistic Children', in E. Schopler & G. Mesibov (eds) *Autism in Adolescents and Adults*, pp. 251-78. New York: Plenum

- Cole, D. A. (1986). Out-of-home child placement and family adaptation: A theoretical framework. *American Journal of Mental Deficiency*, 91, 226-236.
- Conger, R., Patterson, G.R., & Ge, X. (1995). It takes two to replicate: A mediational model for the impact of parents' stress on adolescent adjustment. *Child Development*, 66, 80-97.
- Davis, H. (1985). Counselling parents of children who have intellectual disabilities. *Early Child Development and Care*, 22, 19-35.
- Dyson, L.L. (1991). Families of young children with handicaps: Parental stress and family functioning. *American Journal on Mental Retardation*, 95, 623-629.
- Emerson, E. (2003). Mothers of children and adolescents with intellectual disability: Social and economic situation, mental health status, and the self-assessed social and psychological impact of the child's difficulties. *Journal of Intellectual Disability Research*, 47, 385-399
- Floyd, F.J., & Phillippe, K.A. (1993). Parental interactions with children with and without mental retardation: Behavior management, coerciveness, and positive exchange. *American Journal on Mental Retardation*, 97, 673-684.
- Frey K. S., Greenberg M. T. & Fewell R. R. (1989) Stress and coping among parents of handicapped children: a multi-dimensional approach. *American Journal on Mental Retardation* 94, 240-9
- Gray DE. *Gender and coping: The parents of children with high functioning autism*. *Social Science and Medicine* 2003; 56: 631-642.
- Gray DE. *Perceptions of stigma: The parents of autistic children*. *Sociology of Health and Illness* 1993; 15: 102-120.
- Hagekull B., Bohlin G. & Hammarberg A. (2001) The role of parental perceived control in child development: a longitudinal study. *International Journal of Behavioral Development* 25, 429-37
- Harris, S. L., (1994). Siblings of children with autism: a Guide for families, Bethesda, MD: Woodbine House
- Hasall, R. , Rose, J., McDonald, J. (2005). Parenting stress in mothers of children with an intellectual disability: the effects of parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research*, 49, 405-418
- Hastings R. P. & Brown T. (2002) Behavior problems of children with autism, parental self-efficacy, and mental health. *American Journal on Mental Retardation* 107, 222-32
- Hoppes, K. & Harris, S. L. (1990) 'Perceptions of Child Attachment and Maternal Gratification in Mothers of Children with Autism and Down Syndrome', *Journal of Clinical Child Psychology* 19: 365-70.
- Herring, S., Gray, K., Taffe, J., Tonge, B., Sweeney, D., & Einfeld, S. (2006). Behavior and emotional problems in toddlers with pervasive developmental disorders and developmental delay: associations with parental mental health and family functioning. *Journal of Intellectual Disability Research*, 50, 874-882.
- Johnston C. & Mash E. J. (1989) A measure of parenting satisfaction and efficacy. *Journal of Clinical Child Psychology* 16, 167-75
- Jones, G. (1997) 'Disabling Children: Autism, the Effect on Families and Professionals', *Educational and Child Psychology* 14 (3): 71-6.
- Koegel, R. L. , Schreibman, L. , Loos, L. M. , Dirlich-Wilhelm, H. , Dunlap, G. , Robbins, F.R. & Plienis, A. J. (1992) 'Consistent Stress Profiles in Mothers of Children with Autism', *Journal of Autism and Developmental Disorders* 22: 205-16.
- 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, 393-404.
- Lustig, D. C. (1997). Families with an adult with mental retardation: Empirical family typologies. *Rehabilitation Counseling Bulletin*, 41, 138-157.
- Lustig, D. C. (2002). Family coping in families with a child with a disability. *Education and Training in Mental Retardation and Developmental Disabilities*, 37, 14-22.
- Martin, C. A., & Colbert, K. K., (1997). Parenting children with special needs. In *Parenting: A life span perspective* (pp. 257-281). New York: McGraw-Hill.
- Mash E. J. & Johnston C. (1990) Determinants of parenting stress: illustrations from families of hyperactive children and physically abused children. *Journal of Clinical Child Psychology* 19, 313-28
- McCubbin, H. I., Cauble, A. E., & Patterson, J. M. (1982). *Family stress, coping, and social support*. Springfield, IL: Charles C. Thomas.
- Minnes P. M. (1988) Family resources and stress associated with having a mentally retarded child. *American Journal on Mental Retardation* 93, 184- 92.
- Oelofsen, N., & Richardson, P. (2006). Sense of coherence and parenting stress in mothers and fathers of preschool children with developmental disability. *Journal of Intellectual & Developmental Disability*, 31, 1-12.
- Perry, A. (1989). *Families of Developmentally Disabled Children: Theoretical conceptualizations of stress & a proposed new integrative model*. Ph.D Major Area Paper, Yourk University, Toronto, ON.
- Plant, K. M., & Sanders, M. R. (2007). Care-giver stress in families of preschool-aged children with developmental disabilities. *Journal of Intellectual Disability Research*, 51, 109-124.
- Powers, M.D. (1989) 'Children with Autism and Their Families', in M.D. Powers (ed.) *Children with Autism: A Parent's Guide*, pp. 105-39. Bethesda, MD:Woodbine House.
- Quine L. & Pahl J. (1991) Stress and coping in mothers caring for a child with severe learning difficulties: a test of Lazarus' transactional model of coping. *Journal of Community and Applied Social Psychology* 1, 57-70.
- Rhodes, P. (2003). Behavioural and family systems interventions in developmental disability: Towards a contemporary and integrative approach. *Journal of Intellectual and Developmental Disability*, 28, 51-64.
- Roach, M. A., Orsmond G. I. & Barratt M. S. (1999) Mothers and father of children with Down syndrome: parental stress and involvement in childcare. *American Journal on Mental Retardation* 104, 422-36
- Robbins, F.R., Dunlap, G. & Plienis, A. J. (1991) 'Family Characteristics, Family Training and the Progress of Young Children with

- Autism', *Journal of Early Intervention* 15: 173–84.
- Rodrigue, J.R., Morgan, S. B. & Gefken, G. (1990) 'Families of Autistic Children: Psychological Functioning of Mothers', *Journal of Clinical Psychology* 19:371–9.
- Rodrigue, J.R., Geffken, G., & Morgan, S. B. (1994). Perceived competence and behavioral adjustment of siblings of children with autism. *Journal of autism and Developmental Disorders*, 23, 665-674
- Rossiter, L., & Sharpe, D. (2001). The siblings of individuals with mental retardation: A quantitative integration of the literature. *Journal of Child and Family Studies*, 10, 65–84.
- Sanders, J. L., & Morgan, S. B., (1997). Family stress and Adjustment as perceived by parents of children with autism or down syndrome: implications for intervention. *Child & Family Behavior Therapy*, Vol. 19 (4) (pp. 15-32) The Haworth Press, Inc
- Schilling, R.F., & Schinke, S.P. (1984). Personal coping and social support for parents of handicapped children. *Children and Youth Services Review*, 6, 195–206.
- Seligman, M., & Darling, R.B. (1997). *Ordinary families, special children* (2nd ed.). New York: Guilford Press.
- Simmerman, S., Blacher, J., & Baker, B. L. (2001). Fathers' and mothers' perceptions of father involvement in families with young children with a disability. *Journal of Intellectual and Developmental Disability*, 26, 325-338.
- Smith, T.B., Oliver, M. N.I., & Innocenti, M. S. (2001). Parenting stress in families of children with disabilities. *American Journal of Orthopsychiatry*, 71, 257-261.
- Stein, R. E. K., & Jessop, D.J. (1989). What diagnosis does not tell: The case for a noncategorical approach to chronic illness in childhood. *Social Science & Medicine*, 29, 769-778.
- Thompson, R., Flood, M.F. & Goodvin, R. (2006) Social Support and Developmental Psychology. In D. Cicchetti & D. Cohen (Eds), *Developmental Psychopathology: Risk, Disorder and Adaptation* (2nd ed., vol 3) (fq. 1-37). New Jersey: John Wiley & Sons, INC.
- Tommasone, L. & Tommasone, J. (1989) 'Adjusting to Your Child's Diagnosis', in M.D. POWERS (ed.) *Children with Autism: A Parent's Guide*, pp. 31–54. Bethesda, MD: Woodbine House.
- Waisbren, S. E. (1980). Parents' reactions after the birth of a developmentally disabled child. *American Journal of Mental Deficiency*, 84, 345-351.
- Westling, D. L. (1997). What parents of young children with mental disabilities want: The views of one community. *Focus on Autism and Other Developmental Disabilities*, 12(2), 67-78.