



Coping of siblings of children with developmental disabilities in the Bedouin community

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ABSTRACT

This is the first study that examines the coping of siblings of children with developmental disabilities in comparison with siblings of children without disabilities in the Bedouin community in Israel. For this purpose, the study examines the components of self-esteem, stress, and growth. Data were collected from 200 adolescents. The findings of this study show that siblings to children with developmental disabilities have a similar degree of self-esteem to those siblings to children without disabilities, whereas siblings to children with developmental disabilities have higher levels of stress perception and growth compared to siblings of children without developmental disabilities. In addition, a negative correlation was found between perception of stress and growth and a positive correlation between self-esteem and growth.

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1. Introduction

1.1. Children with disabilities in the Bedouin community

This research examines the coping of siblings of children with developmental disabilities in a previously unexamined population: the Bedouin community in Israel.

Bedouin Arab is a generic name for all the nomadic tribes in the Middle East and North Africa. The Bedouin Arabs, though Muslims, are distinct from other Arab populations in the world because they inhabit deserts (Manor-Binyamini, 2010). Bedouin Arab populations reside in Egypt, Israel, Jordan, Saudi Arabia, Syria, Lebanon, and other countries (Peters, 2009).

In Israel, the Bedouin community is an ethnic, religious, national, and geographic minority, and as such it constitutes a particularly interesting case for research. According to estimates, more than 100,000 Bedouin children under 18 years of age live in the Negev, half of them are residents of unrecognized villages, known as “the Pzora” (Israeli Knesset Center for Research and Study, 2006). The proportion of children with disabilities, such as autism, mental retardation, and genetic syndromes, is relatively high in the Bedouin population, compared to other groups (Manor-Binyamini, 2010). It is estimated that there are between 6000 and 8000 children with disabilities in the Bedouin community in the Negev (The Statistical Annual of the Negev Bedouin, 2004). According to the Ministry of Education, 1273 of these children study in the education system. Note, however, that these data are not unambiguous or indisputable and do not provide a complete picture of this

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population, since the data in question do not include information regarding the residents of the unrecognized villages (Israeli Knesset Center for Research and Study, 2006, p. 3).

The relatively high rate of children with disabilities in this community may be explained by several possible factors, including: births at an older age, high incidence of brain damage at birth, primarily due to a premature birth, hereditary diseases that cause physical and mental disabilities, congenital deformities of the skeletal and nervous systems, as well as a tradition of marriage between cousins to ensure the continuance of economic and blood relations (Abudabbeh, 1996; Dagirmanjian, 1996; Israeli Knesset Center for Research and Study, 2006). This tradition of consanguineous marriage accounts for the high number of children born with disabilities in the Middle East in general (Peters, 2009) and among the Bedouin population in particular (Carel, Krispin, & Jaber, 1999; Raz, Atar, Rodnay, Shoham-Vardi, & Carmi, 2003). In addition, the data of the Ministry of Health point to a high rate of infant mortality and infant hospitalization in the Bedouin sector. This is caused by inappropriate health and safety conditions in the unrecognized Bedouin villages. In addition to a lack of precise information concerning the number of children with disabilities, this population has several characteristics that directly affect the quality of life of children with disabilities; the following are the main ones (Manor-Binyamini, 2007).

The socio-economic condition of many Bedouin families: the Bedouin communities are characterized by a below average family income, high rates of unemployment, and low commercial and industrial activity (Litvak, 2002, p. 2). Lacking sources of income and due to economic hardship, many families, usually large families, exist on child benefits and in case of a child with a disability, also on disabilities benefits. Under these conditions, the existential needs of the family take precedence over the particular needs of the child.

Another characteristic is the problem of accessibility, which exists mainly among the residents of unrecognized villages: due to a severe shortage of available public transportation, the high price of bussing and limited mobility, some of the children with disorders do not receive the treatments they require.

Another characteristic is the harsh environmental conditions in which the families of children with disabilities live: the living conditions in the Pzora, which include shacks and tents and no electricity or running water, increase the hardships that the children with disabilities must face and make it very hard and challenging to use accessories and technologies that provide quality of living such as, for example, wheel chairs, walkers, computers, and other accessories. A final characteristic is the lack of treatment resources, which is partially addressed by the welfare services offered to this population (Israeli Knesset Center for Research and Study, 2006, p. 11).

Considering the unique background of the Bedouin community, it is interesting, then, to examine how the siblings of children with developmental disabilities cope with their unique position.

1.2. Siblings to children with developmental disabilities

The majority of people grow up with brothers and sisters (Cicirelli, 1996). The relationships among siblings are one of the most important, dynamic, influential, and long-lasting of all human relationships. Sibling relationships are so consequential, as some of the earliest lessons that children learn are acquired through sibling relationships, which involve also the employment of important capacities like negotiation, co-operation, and competition (Dodd, 2004).

The interactions between siblings may have far-reaching implications on their development: emotional, cognitive (Dunn, Slomkowski, Beardsall, & Rende, 1994), social and professional (Jenkins-Tucker, Barber, & Eccles, 1997). Sibling relationships may differ, however, when one child in the family has a disability that affects his sibling's well-being, coping, and adaptation (Mandleco, Olsen, Dyches, & Marshall, 2003). Given the importance of experiences with sibling, it is essential that we increase our understanding of the impact on children of possible disabilities within this subsystem (Ross & Cuskelly, 2006, p. 77). Studies that have examined the effect of the child with disabilities upon his siblings have shown inconsistent results, when some researchers have reported detrimental outcomes (see Fisman et al., 1996; Hastings, 2003). Researchers have reported that siblings to children with developmental disabilities are at high risk of developing behavioral problems, adaptation difficulties, anger, and aggressive behavior (Fisman, Wolf, Ellison & Freeman, 2000; Hastings, 2003; Ross & Cuskelly, 2006). Others have found clinical levels of depression in adolescent siblings of children with disabilities (Gold, 1993; Smalley, McCracken, & Tanguay, 1995) as well as dominant feelings of sadness, worry, and emotional distress (Hollidge, 2001).

On the other hand, findings from other studies has suggested that brothers and sisters of siblings with disabilities have often been found to be well-adjusted and relatively matured and able to show a responsible attitude beyond their chronological age (Dale, 1996; Seligman & Darling, 1989). There is evidence that they can accrue positive benefits from these relationships, such as augmented levels of empathy and kindness towards others, warmth, compassion, increased tolerance for "the other", and an advanced tendency for happiness (Damiani, 1999; Mandleco, Olsen, Dyches, & Marshall, 2011; Williams, 1997).

The inconsistent findings of the research and the almost exclusive focus on negative outcomes in the stress process emphasize the importance of a further study of this subject. To that end this study will examine three components: stress, self-esteem, and growth.

The first component that affects the coping of siblings, which was examined in this study, was stress. As Pilowsky, Yirmiya, Doppelt, Gross-Tsur, and Shalev (2004) emphasize, it is impossible to overlook the pressure under which siblings to children with developmental disabilities are placed. In contrast, other researchers differentiate between types of disabilities. For instance, researchers report a high level of stress among siblings of crippled children (Breslau, Weitzman, & Messenger, 1982) and children with mental retardation (Bageholm & Gillberg, 1991; Gath, 1974). Other researchers differentiate between sources of stress among siblings of children with developmental disabilities: between a stress that is related to

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