



Stigma Experienced by Parents of Children with Special Needs: A Theoretical Review

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Abstract:

Stigma may affect the stigmatized person and those closely associated with that person, such as parents. Parents are often in the role of primary caregivers for Children with Special Needs. Some of the studies have looked at the experiences of stigma in parents of Children with Special Needs. This article attempts to explore the research carried out in the area of Stigma and its consequences among parents of children with Special Needs.

INTRODUCTION:

Families are dynamic functioning units perpetually propelled from situations of stability and balance to those of development and transmute. Individuals and their families evolve within a single system, perpetually striving for balance. The birth of a Special Needs child engenders a rigorous breach of this balance, and the family undergoes an arduous existential experience.

Parents play a most prominent part in the care, improvement, and supervision of children with Special Needs. The parents and families having children with Special Needs face several challenges that interfere with functioning and social life like self-blame, stigma, helplessness, behaviour difficulties, unauthentic prospects, worry about the future, marital predicaments, etc. The children and their families face these challenges, especially mothers, but the stigma is most challenging; it affects a personal, emotional, gregarious, and psychological aspect of life.

Stigma is a social process that negatively labels an individual. This labelling occurs due to an attribute perceived as a mark, such as any disabilities or mental health quandaries which subsequently devalues the individual's identity within their society (Goffman, 1963). Link and Phalen (2001) defined stigma as a process that sanctions not only for labelling but also leads to stereotyping, disunion, status loss, and discrimination within a potency situation. Stigma increases the perceived encumbrance of caregiving tasks in parents (Green, 2003), and parents sometimes incriminate themselves for their child's condition (Mak & Kwok, 2010).

The term 'stigma' is utilized to refer to a mark of social disgrace. Its roots lie in antediluvian Greece, where "stizein" was a physical mark placed on slaves for the public to identify their social standing and position as indicative of their low social value. The earliest definitions of stigma were given by Goffman (1963), who described it as an "attribute that is deeply discrediting" truncating the bearer "from a whole and conventional person to a discounted, tainted one".

Several researchers have further conceptualized the term stigma and its related dimensions. Social psychologists defined stigma as emotional, cognitive, and behavioural aspects kenneled as stereotypes, prejudice, and discrimination. The negative postures and stereotypes about a discredited subgroup lead to bias toward such sub-groups (Corrigan, 2000; Corrigan & Watson, 2002). One way to approach stigma is to discern it as negative postures optically. In developing a public health-oriented model of the process of stigma, Sartorius (1999) suggests that stigma is a cycle of disadvantage. It commences the condition that manifests impairment within society, such that stigma is linked to the situation as an impairment. This situation leads to discrimination which can truncate an individual's facility and opportunity for rehabilitation. In turn, such barriers can engender a malfunction in the individual's social role, such that the child's condition and its impairment are more pronounced, and the cycle commences again. The public health perspective on stigma is predicated on an ecological view that includes individual-level cognitive and emotional determinants and the broader psycho-social-political determinants of stigma. Stigma affects individuals who carry the stigmatizing label and others who conventionally associate with them (Ostman & Kjellin, 2002; Goffman, 1963). For individuals with perspicacious incapacitation, Social support most often emanates from members of family who may themselves become targets for stigma and who are active participants in their lives (Phelan, Bromet & Link, 1998; Struening, Perlick, Link, Hellman, Herman, & Sirey, 2001). Incapacitation is often associated with stigma

and discrimination. The child's lack of facilities, unique needs, and special treatment makes him and his family prone to gregarious bias because of the misconceptions and ignorance related to the disability.

Stigma is pervasive. It affects individuals who carry the stigmatizing label and others who regularly associate with them (Ostman & Kjellin, 2002; Goffman, 1963). For individuals with Special needs, social support mainly comes from family members who are active in their lives and may themselves feel stigma (Lefley, 1987; Phelan et al., 1998; Struening et al., 2001). Thus, as previously mentioned, this process whereby an individual is stigmatized due to their association with a stigmatized individual is referred to as 'courtesy stigma' (Goffman, 1963) or 'stigma by association' (Mehta & Farina, 1988). For example, Mehta & Farina (1988) found that family members of individuals with Special Needs felt that they could not disassociate with the stigmatizing situation because they, themselves, were not only the 'marker' but also the 'marked'. By labelling their family member's disability, they became the 'marker', and by the association to that family member, they were also 'marked' by society.

Parents of children with Special Needs worldwide experience stigma that can constrain gregarious inclusion and increment disparities with the general population. Stigma involves discrimination, prejudice, and omission of people in sundry forms and often affects how one can participate or is accepted within a community. It is intricate, and individual experiences can be highly varied and diverse, depending on the circumstances. The literature describes sundry forms of stigma, including public stigma, self-stigma, courtesy stigma, and affiliate stigma. As betokened by its denomination and most prominent, public stigma incorporates prejudicial, discriminatory, and stereotypical perceptions and comportments towards people with Special Needs from the broader society. When individuals with Special Needs internalize these harmful postures and comportments towards them and believe they are de-valued, this is referred to as self-stigma. Contrarily, courtesy stigma describes the prejudice or discrimination experienced by others associated with the person with Special Needs (i.e. family, friends). Affiliate stigma occurs when they internalize these negative attributes and endorse such stereotypes in society. Stigma and omission can have grave consequences for people's participation, noetic wellbeing and overall quality of life. Hence, the importance of implementing and developing interventions to promote community acceptance and participation of people with Special Needs.

Some theorists (e.g., Corrigan, 2004) have suggested that adverse reactions to stigmatized persons such as people with mental illnesses essentially represent a form of prejudice. An examination of the research literature indicates that although there is considerable overlap, stigma can be differentiated from prejudice because stigma necessarily involves reactions to perceived negative deviance. Discrimination does not necessarily connote a reaction to deviance. For example, prejudice can occur between two social groups that are similarly common in a society where either "sticks out" or appears deviant.

Stigmatization occurs on interpersonal, individual and societal levels. Pryor and Reeder (2011) stated a conceptual model to stigma, that depicts four dynamically interrelated manifestations of stigma (Corrigan, 2004; Herek, 2007). *Public stigma* is at the core of this model and represents people's psychological and social reactions to some person, they perceive to have a stigmatized condition. Stigma is comprised of cognitive, affective, and behavioural responses of those who stigmatize. The second type of stigma in Pryor and Reeder's model is *Self-stigma* reflects the social and psychological impact of possessing a stigma. It includes the apprehension of being exposed to stigmatization and the potential to internalise negative beliefs and feelings associated with the stigmatized condition. The third type of stigma is *stigma by association*. *Stigma by association* is analogous to Goffman's (1963) courtesy stigma. It entails psychological and social reactions to people associated with a stigmatized individual (e.g., family and friends) and people's responses to stigmatised individuals. Finally, *structural stigma* defined as the "legitimization and perpetuation of a stigmatized status by society's institutions and ideological systems" (Pryor & Reeder, 2011). The four manifestations of stigma are interrelated. However, public stigma—the consensual understanding that a social attribute devalued—is considered at the core of the other three manifestations.

Researchers recognise that in many cases, cultural values, credences, and practices influence how stigma is expressed and experienced for people with Special Needs and approaches for incrementing community acceptance and belonging. Ditchman et al. discuss Triandis four-factor conceptualization of culture concerning stigma towards people with Special Needs, including horizontal individualism-collectivism, and vertical individualism-collectivism, where vertical cultures value hierarchy whereas horizontal cultures value parity. Historically, Western values of individualism and promoting productivity and independence have predominated the framing of stigma and inclusion interventions; however, several authors critique this approach as perpetuating implicit prejudice against people with Special Needs. Now, there appears to be incrementing discussion about the influence of adapting anti-stigma interventions to be appropriate within the categorical cultural context.

Consequently, for support providers from outside of the given cultural context of the individuals or communities they are accommodating, cultural training is critical to ascertain their relevant and appropriate approaches.

Finally, the impact of stigma on family members may vary (Gray, 2002; Sigelman et al., 1991) though the factors that might predict this have not been systematically studied. Research into coping strategies has shown that family members may use different tactics such as concealment to avoid shame and stigma (Phelan et al., 1998; Angermeyer et al., 2003; Ohaeri & Fido, 2001; Shibre et al., 2001; Stengler-Wenzke et al., 2004). These studies show that family members can experience considerable social isolation and emotional distress because of stigma (Ablon, 1990; Blum, 1991; MacRae, 1999).

Conclusion:

An area of research that incorporates the effects of stigma by association has been researched on the caregivers' experiences (burden). Through such research, initial attempts can be made at measuring some aspects of stigma by the association in parents of individuals with mental health-related disabilities. Research on the interrelatedness of different manifestations of stigma would likely benefit from collaboration between other disciplines within psychology. Psychologists should also work together with experts in neuroscience to examine research questions about the brain and stigmatizing responses.

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