

TOPIC TITLE

Families of children with Down syndrome: What we know and what we need to know

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Abstract

From a family systems perspective, the relational life of families provides the central ecological context in which children are nurtured^[1]. The family system is influenced by the attributes each individual brings to family relationships as well as by family members' perceptions of those attributes. The birth of a child with Down syndrome is likely to affect the family system in many ways, from the micro level of dyadic interaction to the macro level of the cultural views guiding parent perceptions about a developmental disability.

Much research has indicated that a child with Down syndrome has effects on the family^[2]. Some effects relate to the likelihood that a child will display the cognitive and behavioural phenotypes considered to be typical of children with Down syndrome. These include specific patterns of strengths and weaknesses in information processing, social interaction, expressive language, receptive skills, motor skills, and motivation^[3,4,5]. Such patterns and/or the expectations of such patterns may influence the behaviour of caregivers in dyadic interaction with the child. Other effects may be due to increased difficulties and/or diminished satisfactions in the parental role and to parents' reduced opportunities in other spheres of life such as career success. In contrast, positive

effects are possible through the parents' identification of a particular purpose in life, or the development of particular talents that may not have been called upon in other circumstances^[6,7,8].

Parental adaptation to a child with Down syndrome has also been studied extensively in relation to parental well-being, especially the psychological reactions of parents. Many studies on parental adaptation to a child with Down syndrome have focused primarily on stress. The literature is often unclear about the precise meaning of stress. At least three interpretations have been applied to research on parental adaptation. Some authors use stress to refer to the emotional responses of parents to the demands of the parenting role (e.g., feeling isolated, entrapped, overwhelmed with responsibility). Others focus on the demands brought about by the child's temperament and behaviours (e.g., demandingness, soothability, activity level). A third approach focuses on parental mental health and psychological functioning (e.g., depression, anxiety, self-acceptance, mastery). This latter approach provides more useful data as it is possible for families to face increased demands but to meet these effectively (see, for example, REF 8). Clearly, however, parenting responsibilities, child demands and psychologi-

cal outcomes are related.

While there is some evidence that parents of children with Down syndrome experience similar levels of well-being to those experienced by parents of typically developing children^[9], most studies suggest that parents of children with Down syndrome experience lower levels of well-being than parents of typically developing children of similar age (see, for example, REFS 10,11). However, it should be noted that, in these studies, the majority of the parents fell into the non clinical range on instruments measuring psychological functioning (e.g., REFS 11,12). Nevertheless, as Singer pointed out, even mild levels of depression can have detrimental effects on individuals and on their families^[13].

Despite these increased difficulties in comparison to families where all children are developing typically, as a group, parents of a child with Down syndrome experience fewer negative effects and more positive effects than parents of children with other disabilities^[14-17]. Many studies compare parents of children with Down syndrome with those who have a child with autism (e.g., REFS 18,19), a comparison that may increase the likelihood of this outcome. There are also studies which use families of children with other conditions as a comparison group (e.g.,

