**DOWN SYNDROME PARENTS’ SUPPORT NEEDS: A PARENTAL PERSPECTIVE**

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Individuals with DS display a unique behavioural and learning profile. As a result, parents of individuals with DS experience unique caregiving challenges. The support needs of this population have not been directly studied in research. Most previous research only includes caregivers of children with DS as control groups in studies exploring the needs of parents of children with other diagnoses. Previous research that has been conducted with caregivers of children with DS reveals that many support needs remain unmet. Objectives: The purpose of the study was to gain an understanding of caregivers’ needs from their perspective and to prioritize such needs to provide recommendations to services and advocacy agencies in the community. Method: The current study addressed the gap in the research field by using concept mapping techniques, a qualitative and quantitative methodology, to assess the needs of caregivers of individuals with DS. Participants were self-reported caregivers of at least one child with Down Syndrome. The researcher conducted individual interviews and participants completed follow up sorting and rating tasks. During the interview, caregivers were asked, “Are parents of individuals with Down Syndrome supported, why or why not?” Participants then sorted the generated statements into categories that made sense to them and rated their agreement that the statement was a support need. Interviews with 21 caregivers (18 women and 3 men) with a mean age of 44.10 years (SD = 5.44) were included in the study. Eighteen participants (16 women, 2 men) completed the sorting task and 24 participants (21 women and 3 men) completed the rating task. Data was analyzed using Trochim’s (1989) Concept Mapping procedures including multidimensional scaling and hierarchical cluster analysis. Results: Participants generated eight thematic clusters representing the support needs of caregivers of children with DS. The themes included online social support, community support gaps, areas where support is lacking, Down Syndrome Association support, financial support, advocacy needs, educational support needs and concerns for community programming. Concerns related to the lack of advocacy options for caregivers was highlighted and it was found that caregivers questioned the preparedness of professionals such as social service workers and medical professionals to discuss care options with families. Conclusions: Few studies have explored specific needs of parents of children with DS directly and none have employed the concept mapping procedures. The findings of the current study revealed caregiver support needs that have not yet been cited in the literature. Previous research does not cite caregiver concerns related to the lack of Down Syndrome Associations in smaller, more rural cities. The current research highlights the need for more local community organizations to offer support and programming that is affordable and accessible for families. Understanding the unmet support needs of caregivers is critical to improve the quality of support for caregivers. The current study will support future program planning for services for individuals supporting those with DS.

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