

Seven Brothers and Sisters of Severely Disabled Children Speak up about Their Everyday Challenges and Needs : A Multiple Case Study

Authors : Myriam Castonguay, Florence Vinit

Abstract : This study aims to gain a better understanding of the lived experience of seven children growing up in a family where another child is severely disabled, informed by family systems theory and the socio-ecological model of development. In depth semi-structured interviews were conducted with seven children who described their everyday life since their brother's or sister's diagnosis. Thematic analysis revealed four themes : struggling with loneliness inside the family, supporting the disabled child through its journey, accommodating to a changing routine and keeping a "bubble" for oneself. Brothers and sisters depict a family life characterized by much loneliness, with severe disabilities requiring ongoing care and prolonged hospitalizations. In the midst of adversity, siblings describe themselves as highly committed to supporting the disabled child and to preserve family cohesion, even if that means getting exposed to emotionally challenging situations and adjusting their daily routine frequently. Children recount that keeping up with schoolwork and leisure activities of their own is central to their well-being. Having a space where one can reconnect with his ordinary life as a kid is also deemed very important. This study reminds us that more needs to be done to counteract the loneliness experienced by siblings through the family experience of disability. Family members and clinicians need to be extra vigilant to ensure siblings' needs don't go unnoticed or dismissed, as it may be difficult for this population of children to voice their own experience and needs. Family, school and other actors in the community may help brothers and sisters pursue their personal dreams, goals and projects, to continue experiencing well-being despite adverse life circumstances.

Keywords : sibling's lived experience of disability, sibling's needs at various levels of the ecosystem, family adjustment to the disability experience, supporting family wellness through the disability experience

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