⊛ **Name of the study**: Help-seeking and personal growth among parents of children with intellectual disability

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Abstract

Parents of children with intellectual disability (ID) and of children with a dual diagnosis of intellectual disability and psychopathology (i.e., mental, emotional, or behavioral disorders) play an important role in providing support and maintaining a good quality of life for their children. Caring for a child with ID requires meeting a range of practical challenges: managing care, seeking help, and using services. All these require the investment of mental and physical inputs on their part (Faust & Scior, 2008; Griffith & Hastings, 2014). These challenges increase and are exaggerated when, in addition to the ID, the child is also diagnosed with a psychopathology (Douma et al., 2006a).

The literature on parenting a child with ID has also stressed the benefits, of caring for a child with ID including improved self-confidence, skillfulness, assertiveness, being able to focus on the important aspects of life, developing social relationships, empathy for others, and providing an opportunity for a process of personal development and growth (Beighton & Wills 2019; Findler 2011; Green 2007). Many studies have suggested the use of problem-focused strategies, including seeking help, as a factor that promotes growth among these parents (Byra et al., 2017).

Personal growth describes an experience of positive change that occurs as a result of psychological and cognitive struggle with highly challenging life crises (Calhoun & Tedeschi, 2001). Struggle or coping is a process that involves introspection, searching for meaning, and constructing new schemes or perceptions and beliefs about one's world (Calhoun & Tedeschi, 2006). Growth is manifested in acceptance and the creation of meaning around the challenging event, and in the achievement of new and positive basic assumptions of individuals toward themselves and their environment. Thus, one not only survives the crisis but experiences important and profound changes in one's life, which improved compared to its previous condition (Tedeschi & Calhoun, 1996; 2004). There are five main domains in which personal growth is manifested: higher appreciation for life, changes in interpersonal relationships, a sense of self-empowerment, seeing new possibilities in life, and spiritual development

(Tedeschi & Calhoun, 1996). Nevertheless, there is still a lack of understanding of the factors that encourage personal growth in parents of children with ID.

Previous research in the field of disability studies has dealt with patterns of personal growth (Tzur-Schwartz, 2013; Zimmerman, 2011) and the help-seeking practices of parents of children with ID and dual diagnosis (Douma et al., 2006a; Weiss & Lunsky, 2010). These studies suggest that personal growth and help-seeking are processes associated with a variety of areas in parents' lives, and therefore also related to their ability to support their children. Nevertheless, only a handful of studies have made a comprehensive examination of the relationship between help-seeking and personal growth. In a review article dealing with post-traumatic growth and the seeking help behavior among people who have survived cancer (Matsui & Taku, 2016), the authors argue that a close connection exist between the processes and that use of services predicts post-traumatic growth. Also, in order to expand the framework of the connection between post-traumatic growth and help-seeking behaviors, the cultural background and personal characteristics of the population being studied should be addressed (Matsui & Taku, 2016). A study conducted in the United States among students who experienced different types of trauma (Burrick, 2014), found a relationship between the nature and impact of the traumatic event and the degree of post-traumatic growth. Moreover, more help seeking intentions and more positive attitudes toward seeking help predicted higher personal growth (Burrick, 2014).

Finally, no studies have examined this relationship among parents of adolescents and young adults with ID or with dual diagnosis. By examining the connection between help-seeking and personal growth, the present study can guide researchers, professionals, and decision makers in assisting parents of adolescents and young adults with ID and dual diagnosis in the process of help-seeking and the use of services, enhancing the likelihood of these parents achieving personal growth.

 In the present study, I used a mixed methods design, suitable for research in the areas of clinical interventions and policy research. The combination of research methods helps deepen the understanding of existing processes, attitudes, and motivations in these domains (Creswell et al., 2007). The first study ("Unpublished"), using a qualitative approach, provides an initial glimpse of the phenomena under examination and the associated general concepts (Denzin & Lincoln, 1998).

The purpose of the study presented in the first chapter was to gain a deep understanding of the attitudes and experiences of parents of children with ID regarding help-seeking and using services, as background knowledge for the quantitative research I conducted afterward.

Specifically, the study focuses on factors that enable and hinder help-seeking and using services. Previous studies have already addressed help-seeking and the condition of services for people with ID, as well as the positive aspects of parenting a child with ID and dual diagnosis and their role as main caregivers for their children. Nevertheless, no studies have focused exclusively on the parents' help-seeking and use of services. Thus, I decided to focus on factors that enable and hinder the parents' help-seeking and using services for their children.

This study was based on three focus groups, in which 16 parents of 14 adolescents and young adults with ID or with dual diagnosis participated. Parents were asked about the factors that influenced their decision to use services, what helped them and what prevented them from receiving services, and what were their experiences and attitudes regarding the functioning of the various services and the professionals caring for their children. The data underwent qualitative content analysis. Ten key factors were found related to help-seeking and using services. The parents provided examples of how each factor enabled or hindered their help-seeking and their use of services, usually depending on whether this factor was present or absent from their lives. All the factors were divided between two main themes: "the parent as caregiver" and "professionals and services." The factors that enable help-seeking and using services were extracted from positive experiences and opinions expressed by the parents. They were used to achieve in-depth understanding of these positive aspects in their lives and of the parents as main caregivers for their children. The understanding served to support and enrich the subsequent quantitative findings.

The second chapter ("Submitted for publication") presents a model which examined the relations between the child's emotional, mental, or behavioral state (i.e., psychopathology), the parents' perception of the child's condition, and the parents' subjective distress vis-à-vis their personal growth. I also examined the role of social support in the parents' lives and their attitudes toward the use of services as mediating variables in this correlation. To the best of our knowledge, no study to date has examined how social support may mediate the association between the child's emotional, mental, or behavioral state and the parents' subjective distress as opposed to their personal growth. The present study sought to examine the role of social support as a measure of receiving informal help and of attitudes toward use of formal support services as a measure of their actual use. To this end, three goals were defined: (a) examine the connection between the emotional, mental, or behavioral state of the child (psychopathology), the parent's perception of the child's emotional state, and the parents' distress and their personal growth; (b) examine the connection between the parents' social support and attitudes toward the use of services and their personal growth; (c) examine how the

parents' social support and attitudes toward the use of services mediates between their child's condition based on the diagnoses (psychopathology), the parents' perception of the child's condition, and the parents' emotional distress on one hand, and personal growth on the other.

Participating in the study presented in chapters two and three were 195 parents of adolescents and young adults with ID or with dual diagnosis. The parents completed questionnaires used to collect information about the child's psychopathology, parental distress, attitudes toward use of services, parents' social support, and personal growth. Eight parents were excluded from the study because of missing data in the questionnaire. Social support has been found to play a key role in seeking help and in the personal growth of parents of children with ID and children with dual diagnosis, but attitudes toward seeking help have not played a significant part in these processes. Professionals working with people with ID and their parents should strive to increase the social support available to them. Following the quantitative model designed for this study and the results obtained, it was decided to incorporate a different research model, which appears in the third chapter, assessing the role of attitudes toward help-seeking and their relations with actual help-seeking and personal growth.

In the third chapter ("Unpublished"), based on the same sample and database, I examined the relationship between intentions to seek help, attitudes toward help-seeking, and actual help seeking vis-à-vis personal growth. I also examined the role of actual help-seeking as a mediating variable between intentions to seek help and attitudes toward help-seeking and personal growth, as well as the five dimensions of growth and their connections with the other variables.

The results revealed a connection between help-seeking and personal growth. The connection between intentions to seek help and personal growth was found to be indirect, mediated by the variable of "actual help-seeking." No connection was found between parent's attitudes toward help-seeking and actual help-seeking or personal growth. The child's psychopathology has been found to be related to greater intentions to seek help and actual help-seeking. Regarding the domains of personal growth, I found that more help-seeking is related to higher levels of personal growth and the existence of more interpersonal relationships.

The main conclusions that emerged from the study were that intentions to seek help and actual help-seeking contribute significantly to promoting personal growth in parents of children with ID or with dual diagnosis. Conversely, I found no connection between parents' attitudes toward help-seeking and actual help-seeking or personal growth. The findings attest to the fact that actual help-seeking is more important than preliminary attitudes toward help-seeking. The main

conclusion was that parents, as well as the professionals who help them, should be aware of the importance of actual help-seeking and focus on these actions. Focusing on actual help-seeking can promote feelings of parental self-efficacy and of greater control over their lives, aspects that are part of the dimensions of personal growth.

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