Administration and Policy in Mental Health and Mental Health Services Research (2019) 46:321–333
https://doi.org/10.1007/s10488-018-00915-w

ORIGINAL ARTICLE

Help-Seeking by Parental Caregivers of Individuals with Intellectual Disabilities and Dual Diagnosis

Shirli Werner[1] · **Ira Stern**[1] · **Dana Roth**[2] · **Ariel Tenenbaum**[3]

Abstract

This study examined the roles of stigma and of enabling factors in help-seeking by parental caregivers of individuals with intellectual disabilities and dual diagnosis. Questionnaires were completed by 195 family caregivers. Lower family stigma was related to higher personal enabling factors (e.g. knowledge about services and previous experience in seeking help), which in turn was related to higher help-seeking behaviors. Higher professional enabling factors (e.g. attitude of the professional, services in the vicinity) were related to higher intentions to seek help, which were related to higher help-seeking behaviors. Professionals can help families achieve a greater sense of self-efficacy in their own help-seeking process by providing them with knowledge about services and facilitating a more positive experience in the process.

Keywords Intellectual disabilities · Dual diagnosis · Help-seeking · Family caregivers

Introduction

Help-Seeking for Persons with Intellectual Disabilities and Dual Diagnosis

Intellectual disability (ID) denotes significant impairment of cognitive functioning (IQ below 70) and of adaptive behavior comprising three skill types: conceptual, social, and practical skills. Both of these must have their onset before the age of 18, usually during childhood (Schalock et al. 2010).

Studies have estimated the prevalence of ID to be between 2 and 3% of the general population (Szymanski and King 1999). Studies from Western countries have consistently found that the prevalence of psychopathology among persons with ID is higher than among the normal-intelligence population (Dekker et al. 2002), ranging between 17 and 56%, depending on study methodology and the population studied (Dekker et al. 2002; Lowe et al. 2007). Psychopathology denotes significant and persistent behavioral, emotional, or psychiatric disturbances not explained by the ID itself (Einfeld et al. 2006). Individuals in this condition are referred to as having a dual diagnosis.

Both individuals with ID and those with dual diagnosis may face cognitive, physical, psychiatric, communication, and social challenges. The needs of individuals with dual diagnosis are more complex than the needs of individuals with ID only (Morgan et al. 2008; Taua and Farrow 2009), and more services are needed to satisfy them (Davis et al. 2008). This reality may have serious implications for daily functioning, social inclusion, and psychological wellbeing (Morisse et al. 2013). It is therefore important to ensure that both populations receive appropriate and effective professional support (Williams and Heslop 2005).

The importance of providing accessible, high-quality services for people with disabilities is clearly stated in the UN Convention on the Rights of Persons with Disabilities (CRPD; UN General Assembly 2007) as well as in the UN Convention on the Rights of the Child (UN General Assembly 1989). Research indicates, however, that persons with ID frequently do not receive adequate or effective preventive

---

Preliminary findings related to this study were presented at the "Together against stigma" Conference, 20th–22nd September, 2017, Copenhagen, Denmark.

✉ Shirli Werner
Shirli.werner@mail.huji.ac.il

[1] Center for Disability Studies, Paul Baerwald School of Social Work & Social Welfare, Hebrew University of Jerusalem, Mount Scopus, 91905 Jerusalem, Israel

[2] Research and Evaluation Department, Beit Issie Shapiro, Ra'anana, Israel

[3] Down syndrome and the IDD Evaluation Centers, Hadassah-Hebrew University Medical Center, Mount Scopus, Jerusalem, Israel

and rehabilitative services (Douma et al. 2006b; Weiss and Lunsky 2010) given limited training and inadequate knowledge especially in specific areas related to the mental health needs of these individuals (Werner et al. 2013). This may lead to more severe problems (Turner 2012), reduced quality of life, and increased direct and indirect costs for both the individuals and their family. Seeking and obtaining suitable help may reduce these negative consequences. The current study focuses specifically on help-seeking in Israel, a country that is dominated mostly by Israeli Jews with Arabs constituting the main minority group, making up 20.1% of the general population (Israel Central Bureau of Statistics 2018).

Help-seeking refers to the search for assistance of both formal and informal sources of help (Gourash 1978). At a young aged it is the parents', especially mothers', role to assist individuals with ID and dual diagnosis in searching for appropriate services and sources of help (Weiss and Lunsky 2010). Studies have shown that although caregivers report high levels of service needs (Weiss and Lunsky 2010), many do not seek out services for their family member with an ID (Einfeld et al. 2006). Research examining the factors that influence these caregivers' decision to seek help is relatively scant (Douma et al. 2006b; Weiss and Lunsky 2010).

The socio-behavioral model (Andersen 1995) provides a useful framework for understanding help-seeking processes. The model assumes that use of services is dependent upon the individuals' intent to seek services (Godoy et al. 2014; Spoth et al. 1997), which in turn is dependent upon predisposing and enabling (Andersen 1995) factors. Predisposing factors are biological and social imperatives that include, among others, beliefs and attitudes toward health and help-seeking (e.g., fear of stigma) (Huỳnh et al. 2016). The roles played by enabling factors and stigma in the help-seeking of caregivers for individuals with ID and with dual diagnosis have rarely been examined (Douma et al. 2006a; Weiss and Lunsky 2010).

Enabling Factors and Help-Seeking

According to the socio-behavioral model (Andersen 1995), enabling factors predict intentions to seek help and help-seeking. Enabling factors can be attributes specific to the caregiver (personal) or to the community (Andersen and Davidson 1997), and they may encourage or discourage an individual from using services (Keysor et al. 1999). At the personal level, studies have considered the effect of the child's condition on the caregivers (Logan and King 2001), the parents' knowledge and understanding of the service system (Douma et al. 2006b; Kerkorian et al. 2006; Sayal et al. 2010; Weiss and Lunsky 2010), attitudinal and financial factors (MacNaughton and Rodrigue 2001), and previous experience seeking services (Cunningham and Freiman 1996; Owens et al. 2002).

Community level attributes include the availability of quality services and professionals in the vicinity, the cost of services, and good client-therapist relationships (Douma et al. 2006a; Iskra et al. 2015; Rawlinson and Williams 2000; Weiss and Lunsky 2010). Community level factors are important because they may be amenable to change, and may affect many families (Schraeder and Reid 2015).

The Role of Stigma in the Help-Seeking Process

The present study focuses on two types of stigma: family and help-seeking. Family stigma (also known as "courtesy stigma") refers to negative attitudes held by others toward families of someone with a disability (Ali et al. 2012; Struening et al. 2001). Research on family stigma with respect to ID has produced mixed findings. Some researchers have found that ID brings shame on families and fear that others would regard them negatively (Weiss 2008), especially in certain societies (McKonkey et al. 2016). The stigma is reinforced if the person with ID also has associated behavioral challenges (Ingstad 2001). Stigma may lead families to distance themselves from the extended family, the community, and potential services (Essop 2012; Haihambo and Lightfoot 2010; Foundation House & Centre for Multicultural Youth 2013; McCann et al. 2016). Other studies have found relatively low to moderate levels of internalized stigma in families, with variations according to disability type (Chiu et al. 2013; Mak and Cheung 2008; Mak and Kwok 2010; Werner and Shulman 2015).

The pathway to help-seeking may also be shaped by skepticism toward mental health service professionals and toward the treatment offered (Harrison et al. 2004; Lauber and Rössler 2007). Structural discrimination and paucity of governmental and public support systems within the mental health field were also recently found in a study conducted within the Czech Republic (Krupchanka et al. 2018). Thus, help-seeking stigma, or concern about the negative perception held by others regarding those who seek mental health services, may discourage individuals from seeking services (Corrigan 2004a; Mukolo et al. 2010). Additionally, individuals may also refrain from using help because of the fear of receiving a formal diagnosis, a phenomenon known as "label avoidance" (Corrigan 2004b).

Background Variables of the Help-Seeking Process

The socio-behavioral model identifies the recognition of a problem as yet another predictor of help-seeking. Studies have shown that parents are more likely to seek services for their child when they recognize a problem and when the problem is severe (Godoy et al. 2014; Haines et al. 2002; Thurston et al. 2015). Thus, we used the caregivers' appraisal of the child's problem (disability) as a background variable in the present study. We also used sociodemographic characteristics of parental age and parental education as background variables. Education was selected because studies have shown that parents with more education may be more aware of the potential benefits of using services, and may be less likely to attach stigma to help-seeking (Godoy et al. 2014). Furthermore, older parents were found to be more likely to seek services than younger ones (Thurston et al. 2015).

Study Aims and Model Examined

To the best of our knowledge, no prior study has examined predictors of help-seeking by family caregivers of individuals with ID and dual diagnosis based on the socio-behavioral model, and the roles of stigma and of enabling factors have not been previously examined from this perspective. Therefore, the general aim of the present study was to examine which variables predict help-seeking behaviors of parental caregivers of individuals with ID and dual diagnosis. The study sought to find answers to the following questions: (a) Do help-seeking intentions predict help-seeking among these caregivers? (b) Do family stigma, help-seeking stigma, and enabling factors predict help-seeking behaviors? (c) Which path best explains the association between these variables? Specifically, is the relationship between help-seeking intentions and behaviors better explained by a model in which stigma and enabling factors serve as moderators or as mediators?

Study Hypotheses

Figure 1 illustrates the model on which the study is based. We examined the following hypotheses:

1. A positive association exists between help-seeking intentions and behaviors.
2. A positive association exists between enabling factors and help-seeking behavior. This association is mediated by intentions to seek help.
3. A negative association exists between family and help-seeking stigma and help-seeking behaviors. This association is mediated by intentions to seek help.

No clear hypothesis can be formulated based on the literature regarding the moderating role of stigma and enabling factors in the relationship between intentions and help-seeking in practice, but we tested whether such moderation exists nevertheless.

Methods

Participants and Procedures

Participants were recruited through a convenience sample of family (mainly parental) caregivers of individuals with ID or dual diagnosis, aged 10–30 years (one caregiver for each individual). The age range was selected for two reasons: (a) to sample individuals whose parents are most likely beyond the preliminary stages of coping with a diagnosis of ID for their child; and (b) to sample parents who are still most likely caregivers for their child with ID. Additionally, this study was part of a larger research project in which we sought to achieve a heterogeneous sample, and therefore we oversampled individuals of Arab ethnicity. Differences in service use between these populations will be described in a separate paper.

Recruiting such a sample is a challenge, therefore we resorted to various means of recruitment, including a list provided by the National ID Registry in Israel, an Internet-based digital questionnaire distributed through family groups, newsletters, Facebook groups, special education schools, departments of social services, two specialized community clinics for the treatment of individuals with dual diagnosis, and we used the snow-ball technique. In total, 195 family caregivers responded: 156 were interviewed face-to-face, 31 answered the online version of the questionnaire, five completed the questionnaire and returned it by mail, and three were interviewed over the phone. Eight individuals were removed because of missing data.

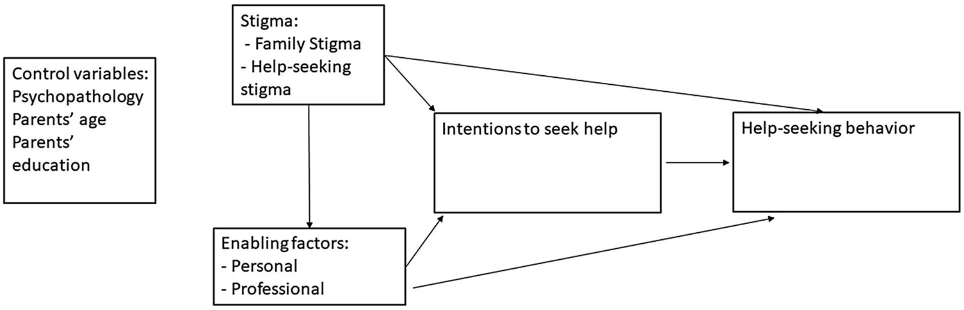

Fig. 1 Study model

Power analysis using G*Power (Faul et al. 2009) revealed that for a small-to-medium effect size of $f^2 = 0.10$, for nine predictors in a multiple regression, $\alpha = 0.05$, and power = 0.85, the required sample size is 184 participants.

The remaining 187 participants were parents, apart for one aunt with whom the individual with ID resided. Of the caregivers, 83.4% were female (n = 156), with a mean age of 48.1 (SD = 8.03; range 30–69); 55.6% (n = 104) were Jewish and 44.4% (n = 83) were Arab; mean years of education were 12.84 (SD = 3.35; range 1–24); 73.3% reported their level of income as below average, 10.7% as average, and 16.1% as above average, with average income defined as around 15,000 NIS (equivalent to approximately $4000) for the entire family.

Of the individuals with ID only, 55.1% (n = 103) were male, with a mean age of 17.10 (SD = 4.16; range 10–30). According to parental reports and based on the diagnosis levels used by the Israeli ID Diagnosis Committee, the level of ID was reported as mild in 17.6% of participants (n = 33), mild-moderate in 10.7% (n = 20), moderate in 25.1% (n = 47), moderate-severe in 2.7% (n = 5), and severe in 15.5% (n = 29). A further 28.3% [(n = 53)] reported on ID without specifying its level of severity. Mean age at the time of the diagnosis of ID was 2.41 years (SD = 3.01). According to parental reports, 111 individuals had a motor or physical difficulty in addition to ID, 31 had a sensory impairment, and 40 had autism spectrum disorders. Furthermore, 78.6% (n = 147) of individuals had dual diagnosis and 21.4% (n = 40) only ID, diagnosed mainly based on the Developmental Behavior Checklist, described below. No differences were found between the ID and dual diagnosis groups in gender, age, or level of ID.

Of the individuals, 90.9% (n = 170) lived with their parents, 8.0% (n = 15) lived in a supervised setting for less than one year, one lived on his own, and another with his aunt. Regarding their daily setting, 75.4% studied in a special education school or a special education class within a regular school, 13.4% were in a sheltered work setting or sheltered day center, and 3.7% had no structured daily setting. Only 5.3% were in non-segregated schools or work settings. A further 2.1% of caregivers did not specify their child's daily setting.

Ethics

The study protocol was approved by the Ethics Committee of the Paul Baerwald School of Social Work & Social Welfare within the Hebrew University of Jerusalem. All participants were asked to provide their consent before their participation.

Instruments

This article is based on the data collected in Israel as part of a larger binational (Israeli and German) study. Instruments were translated from English to Hebrew for the purpose of the current study. Structured questionnaires collected the following information.

Help-seeking behavior Caregivers were asked to answer either *yes* or *no* to questions about their past use of a series of 29 formal and informal services and sources of help (e.g., mental health professionals, general practitioners). Items were adapted from the relevant literature, as well as from the Actual Help Seeking Questionnaire (Rickwood et al. 2005), the Perceived Availability of Services Scale (Corrigan and Michaels 2012), from three preliminary focus groups conducted by the researchers, and from the researchers' own knowledge. Internal consistency of the present scale was good (Cronbach's $\alpha = 0.72$).

Help-seeking intentions were measured by adapting the above 29-item scale. Participants were asked to rate each of the 29 possible sources of help according to the likelihood that they would approach each one if their child had an emotional, behavioral, or psychiatric problem. Each item was rated on a 5-point Likert scale, ranging from 1 = Not at all likely to 5 = Very likely. Internal consistency of the overall scale was good (Cronbach's $\alpha = 0.90$).

Preliminary factor analyses of the actual help-seeking scale and of the help-seeking intentions scale revealed that, in addition to the overall score, help-resources may be classified into four types: (a) frequent resources, which include 10 frequently used services (e.g., physician, school, local social services); (b) mental health/ neurological resources, which include five services (e.g., neurologist, psychiatrist); (c) ID-specific resources, which include five services (e.g., ID diagnosis unit, sheltered workshop); and (d) informal supports, which include four sources (such as support provided by friend and spouse).

Family stigma was measured by adapting the seven-item Devaluation of Consumer Families Scale (Struening et al. 2001), which measures the extent to which caregivers believe that most people devalue families with an individual with mental illness. In the current study, items were adapted to relate to people with dual diagnosis. For example, "Most people in my community would rather not be friends with families that have a family member with ID and emotional, behavioral, or psychiatric difficulties." Items were rated on a 5-point Likert scale, ranging from 1 = Strongly disagree to 5 = Strongly agree, with higher scores indicating greater perception of family stigma. Internal consistency of the original (Cronbach's $\alpha = 0.71$; Struening et al. 2001) and current (Cronbach's $\alpha = 0.75$) scales was good.

Help-seeking stigma was measured using eight items derived from the Stigmatization subscale of the Parental

Attitudes Toward Psychological Services Inventory (PATPSI; Turner 2012). These items rate the degree to which the participants feel that stigma is attached to services or service providers. For example, "I would not want to take the person with an ID to a professional because of what people might think." Items were rated on a 5-point Likert scale, ranging from 1 = Strongly disagree to 5 = Strongly agree, with higher scores indicating greater perception of stigma. Internal consistency in the previous (Cronbach's α = 0.88; Turner 2012) and the current study (Cronbach's α = 0.80) was good.

Enabling factors This scale was developed for the present study, based on the literature and on insights gained from preliminary focus groups. Participants were asked to rate the degree to which each of 14 possible enabling factors enabled them to seek services. Items are rated on a 5-point Likert scale, ranging from 1 = Did not help at all to 5 = It helped very much, with higher scores indicating a greater degree of enabling help seeking. Factor analysis revealed that the items represented two distinct factors. "Personal" enabling factors included six items (e.g., knowledge about services, previous experience in seeking help), and "professional" enabling factors included seven items at the level of the professional or the system (e.g., attitude of the professional, services in the vicinity). Cronbach's alphas were good for the overall, personal, and professional scales (Cronbach's α = 0.86, α = 0.81, α = 0.85, respectively).

Recognition of psychopathology The existence of psychopathology was ascertained with the Short Form of the Developmental Behavior Checklist (DBC-P, Taffe et al. 2007). This 24-item scale provides a brief measure of behavioral and emotional problems of people with ID. Problems observed in the preceding six months (e.g., bangs head) are scored on a 3-point scale (0 = Not true, 1 = Somewhat or sometimes true, and 2 = Very true or often true). The instrument has been found to have high inter-rater reliability, test re-test reliability, and internal consistency (Cronbach's α = 0.94) (Einfeld and Tonge 2002). The total behavior problem score was calculated as a mean score for the 24 items. The cut-off score for psychopathology was set at 0.48 (Taffe et al. 2007). Internal consistency in the preset study was found to be good (Cronbach's α = 0.87).

Sociodemographic background included parental age and parental years of education.

Data Analysis

Data were analyzed with SPSS (ver 24.0) and AMOS (ver 24). Intercorrelations were examined between the study variables, and multiple regressions were calculated for the various dimensions of help-seeking behaviors. The research model was examined with path analysis (AMOS ver 24), controlling for psychopathology, parents' age, and parents' education. Control variables, independent variables, and mediating variables were allowed to intercorrelate within their own category. Control variables were allowed to intercorrelate with all other variables as well. Selig and Preacher's procedure with bootstrapping (Selig and Preacher 2008) was used to examine possible mediated relationships. Moderation was examined within the path analysis, and interpreted with simple slopes (Aiken and West 1991; Dawson 2014).

Results

Means, Standard Deviations, and Correlations of Main Study Variables

Table 1 presents the means, standard deviations, and correlations between the main study variables. Participants reported very low levels of help-seeking stigma (M = 1.32; SD = 0.48) and higher levels of family stigma (M = 2.32; SD = 0.85), although these were still below the midpoint of the scale ranging from 1 to 5. Rating of the enabling factors was relatively high, with higher scores attributed to professional (M = 3.90; SD = 0.88) than to the personal enabling factors (M = 3.59; SD = 0.98; t = 4.19, p < .001). Help-seeking intentions (M = 3.81; SD = 0.79) and help-seeking behaviors (M = 0.65; SD = 0.14) were also rated above the mid-point of the scale.

Family stigma was negatively associated with personal enabling factors (r = − .22, p < .01) and with professional enabling factors (r = − .17, p < .01), and help-seeking stigma was negatively associated with both personal enabling factors (r = − .21, p < .01) and help-seeking behaviors (r = − .23, p < .01). Both personal and professional enabling factors were found to be related to help-seeking behaviors (r = .30, p < .001; r = .15, p < .05).

Higher levels of psychopathology (DBC scores) were related to greater levels of family stigma (r = .29, p < .001), lower levels of personal (r = − .34, p < .001) and professional enabling factors (r = − .17, p < .05), and higher levels of help-seeking intentions (r = .24, p < .001). Parents' age was negatively related to family stigma (r = − .25, p < .001) and help-seeking intentions (r = − .30, p < .001). Parents' years of education were positively related to personal enabling factors (r = .30, p < .001) and help-seeking behaviors (r = .19, p < .01), and negatively associated with family stigma (r = − .17, p < .05) and help-seeking intentions (r = − .33, p < .001).

Table 2 shows the means and standard deviations of each of the help-seeking behavior factors, and the correlations between the factors. The highest degree of help-seeking behavior was found for frequent services (M = 0.87; SD = 0.14), followed by informal supports (M = 0.68; SD = 0.25), and mental health/neurological services

Table 1 Means, standard-deviations, range, and correlations between main study variables

	DBC	Parents' age	Parents' education	Family stigma	Help-seeking stigma	Enabling factors (personal)	Enabling factors (professional)	Help-seeking intention	Help-seeking behavior	Mean (SD)	Range
Psychopathology—DBC (0–2)	1	−0.28***	−0.36***	0.29***	0.10	−0.34***	−0.17*	0.24***	−0.01	0.74 (0.40)	0–1.67
Parents' age		1	0.20**	−0.25***	−0.02	0.14	0.13	−0.30***	0.11	48.10 (8.03)	30–69
Parents' education			1	−0.17*	−0.08	0.30***	0.11	−0.33***	0.19**	12.84 (3.35)	1–24
Stigma				1	0.11	−0.22**	−0.17*	0.07	−0.02	2.32 (0.85)	1.00–4.00
Family stigma (1–5)					1	−0.21**	−0.06	−0.10	−0.23**	1.32 (0.48)	1.00–3.50
Help seeking stigma (1–5)											
Enabling factors (total)						1	1	−0.05	0.30***	3.59 (0.98)	1.00–5.00
Personal (1–5)								0.11	0.15*	3.90 (0.88)	1.00–5.00
Professional (1–5)											
Help-seeking intention (total; 1–5)								1	0.09	3.81 (0.79)	1.88–5.00
Actual help seeking (total; 0–1)									1	0.65 (0.14)	0.32–1.00

*p < .05; **p < .01; ***p < .001

(M = 0.53; SD = 30); the lowest degree of utilization was for ID-specific sources (M = 0.34; SD = 0.26; F(5) = 314.82; p < .001). Low-to-moderate associations were found between all but one of the factors, ranging between 0.14 and 0.74.

Testing of the Research Model

The research model was tested using path analysis (AMOS ver 24), as shown in Fig. 2 and Tables 3 and 4, controlling for psychopathology, parents' age, and parents' education. The study model was found to fit the data well: χ^2 (26) = 27.67, p = .375, *NFI* = 0.894, *NNFI* = 0.983, *CFI* = 0.992, *RMSEA* = 0.019. As shown in Table 3 and Fig. 2, help-seeking behavior was positively related with intentions to seek help and with personal support, and negatively related with help-seeking stigma. The intention to seek help was positively related with professional support, and negatively related with help-seeking stigma. Family and help-seeking stigma were negatively related with personal support, and family stigma was negatively related with professional support as well.

The model involving the significant relationships was found to fit the data as well: χ^2 (31) = 27.67, p = .384, *NFI* = 0.875, *NNFI* = 0.985, *CFI* = 0.992, *RMSEA* = 0.017. As shown in Table 4, several indirect relationships involving help-seeking behavior and intentions to seek help on one hand, and stigma and social support, on the other hand, were significant.

Table 3 and Fig. 2 suggest that professional enabling factors may mediate the relationship between family stigma and the intention to seek help, that personal enabling factors may mediate the relationship between family stigma and help-seeking behaviors, and that personal enabling factors may mediate the relationship between help-seeking stigma and help-seeking behaviors. Intentions to seek help may mediate the relationship between help-seeking stigma and help-seeking behaviors, as well as the relationship between professional enabling factors and help-seeking behavior.

We examined these possible mediations with Selig and Preacher's Monte Carlo method for assessing mediation with bootstrapping (Selig and Preacher 2008). Table 5 shows all the significant mediated relationships found. Note that lower family stigma was related to higher professional enabling factors, which in turn was related to higher intention to seek help. Similarly, lower family stigma was related with higher personal enabling factors, which in turn was related with higher help-seeking behaviors. Lower help-seeking stigma was related with higher personal enabling factors as well as with higher intention to seek help, which in turn were related with higher help-seeking behaviors. Finally, higher professional enabling factors were related with higher intention to seek help, which in turn was related with higher help-seeking behaviors.

Table 2 Correlations between help-seeking behavior factors (n = 187)

Help-seeking behaviors						
	Frequent sources	Mental health/neurological sources	ID-specific sources	Informal sources	Overall help seeking	Mean (SD)
Frequent	1	0.20**	0.38***	0.14*	0.69***	0.87 (0.14)
Mental health/neurological		1	0.20**	0.09	0.60***	0.53 (0.30)
ID-specific			1	0.34***	0.74***	0.34 (0.26)
Informal				1	0.52***	0.68 (0.25)
Overall					1	0.65 (0.14)

*p < .05; **p < .01; ***p < .001

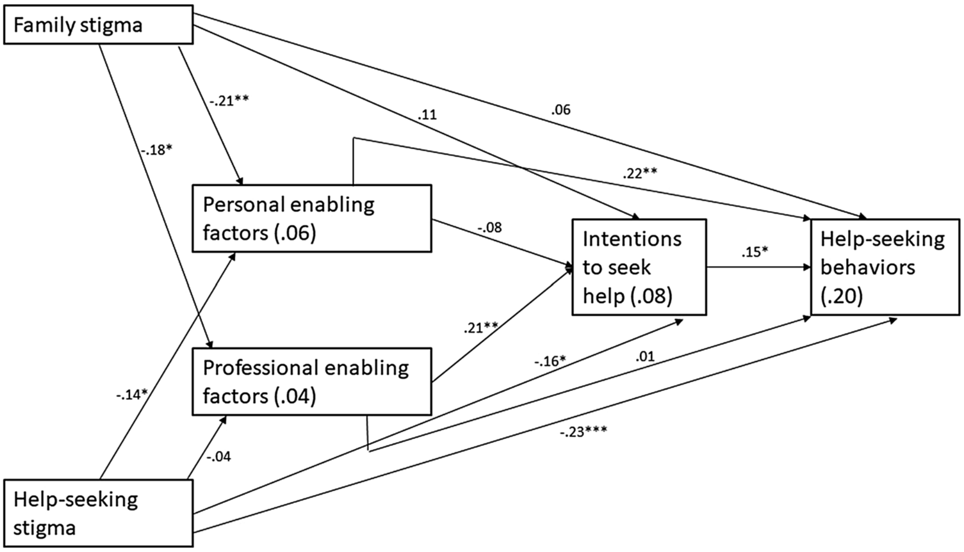

Fig. 2 Path analysis for the research model. *p < .05; **p < .01; ***p < .001. Psychopathology, parents' age, and parents' education served as control variables, which are excluded from the figure for reasons of clarity. Values on arrows are β values; values within the parenthesis are R^2

Table 3 Direct relationships between stigma, social support, intention to seek help, and help-seeking behavior ($N = 187$)

DV (R^2)	IV	β	SE	p
Personal enabling factors (0.06)	HS stigma	−0.138	0.069	0.047
	Family stigma	−0.206	0.070	0.004
Professional enabling factors (0.04)	HS stigma	−0.044	0.076	0.549
	Family stigma	−0.183	0.074	0.013
Intention to seek help (0.08)	HS stigma	−0.157	0.066	0.014
	Family stigma	0.109	0.073	0.131
	Personal enabling	−0.081	0.076	0.269
	Professional enabling	0.207	0.069	0.003
	HS stigma × professional enabling	−0.129	0.070	0.049
HS behavior (0.20)	HS stigma	−0.225	0.009	0.001
	Family stigma	0.060	0.009	0.388
	Personal enabling	0.218	0.010	0.003
	Professional enabling	0.014	0.010	0.854
	Intention to seek help	0.149	0.009	0.034
	Personal support × Intentions to seek help	0.206	0.010	0.002

DV dependent variable, *IV* independent variable, *HS* help seeking, R^2 percent of explained variance

Table 4 Indirect relationships between stigma and enabling factors, and between intention to seek help and help-seeking behavior ($N = 187$)

DV (R^2)	IV	Standardized indirect effect	SE	p
Intention to seek help (0.08)	Family stigma	−0.030	0.017	0.015
HS behavior (0.20)	Family stigma	−0.049	0.021	0.005
	HS stigma	−0.048	0.023	0.014
	Professional support	0.025	0.018	0.023

DV dependent variable, *IV* independent variable, *HS* help seeking, R^2 percent of explained variance

Table 5 Indirect effects of stigma and social support on intention to seek help and help-seeking behavior ($N = 187$)

DV (R^2)	Mediator	IV	95% CI
Intention to seek help (0.08)	Professional support	Family stigma	−0.068, −0.0035
HS behavior (0.20)	Personal support	Family stigma	−0.013, −0.0012
	Personal support	HS stigma	−0.0092, −0.0001
	Intention to seek help	HS stigma	−0.0074, −0.00006
	Intention to seek help	Professional support	0.00006, 0.0081

DV dependent variable, *IV* independent variable, *HS* help seeking, R^2 percent of explained variance

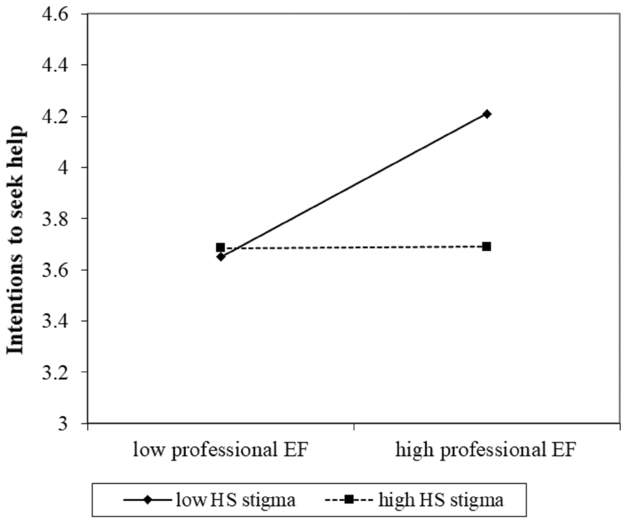

Fig. 3 Help-seeking stigma as a moderator between professional support and intention to seek help. *EF* enabling factor

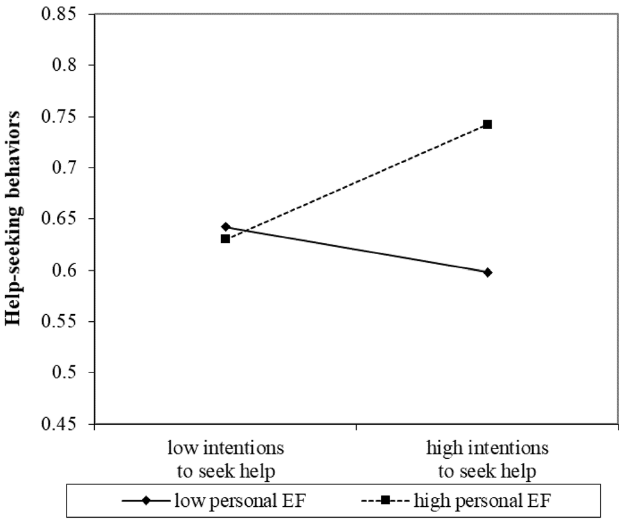

Fig. 4 Personal support as a moderator between intention to seek help and help-seeking behavior

In the final step, two moderated relationships were found to be significant. First, help-seeking stigma was found to moderate the relationship between professional enabling factors and intentions to seek help. Interpreting it with simple slopes (Aiken and West 1991; Dawson 2014) revealed that the slope for low stigma was significant (coefficient = 0.28, $t = 3.59$, $p < .001$), whereas the slope for high stigma was non-significant (coefficient = 0.003, $t = 0.03$, $p = .972$), as shown in Fig. 3. In other words, higher professional support is related to higher intention to seek help for low help-seeking stigma.

Second, personal support was found to moderate the relationship between intention to seek help and help-seeking behavior. Interpreting it with simple slopes (Aiken and West 1991; Dawson 2014) revealed that the slope for high personal support was positive and significant (coefficient = 0.06, $t = 4.02$, $p < .001$), whereas the slope for low personal support was non-significant (coefficient = −0.02, $t = -1.43$, $p = .156$), as shown in Fig. 4. In other words, higher intention to seek help is related to higher help-seeking behaviors for high personal support.

Discussion

The study adapted the socio-behavioral model to examine help-seeking behavior of family caregivers of individuals with ID and of those with dual diagnosis. We examined the association between the intention to seek help and help-seeking behavior, as well as the role of family and help-seeking stigma, and of personal and professional enabling factors in the help-seeking process.

Findings show that the conceptualization of the socio-behavioral model is useful for understanding this area of help-seeking, which has not been previously examined using this model. Specifically, (a) intentions to seek help predicted help-seeking behavior; (b) help-seeking stigma, but not family stigma, predicted help-seeking; (c) personal enabling factors, and to a lesser degree professional enabling factors, predicted help-seeking; (d) personal enabling factors mediated the relationship between both family stigma and help-seeking stigma on one hand, and help-seeking behavior on the other; (e) intentions mediated the association between both help-seeking stigma and professional enabling factors on one hand, and help-seeking behavior on the other; (6) personal enabling factors moderated the relationship between help-seeking intention and behavior.

We discuss three main issues based on these findings: the roles of intentions, enabling factors, and stigma in the help-seeking process.

The Role of Intentions in the Help-Seeking Process

Consistent with Andersen's socio-behavioral model (Andersen 1995) and with studies conducted in other fields (Godoy et al. 2014; Spoth et al. 1997), our findings show that intention to seek help of family caregivers of individuals with ID and dual diagnosis predicted help-seeking behaviors. The intention to seek help was found to mediate the association between help-seeking stigma and help-seeking behaviors, such that higher help-seeking stigma predicted lower intention, which in turn predicted lower help-seeking behaviors. Finally, intention to seek help was found to mediate the association between professional enabling factors and help-seeking behaviors. These findings provide support for the conceptualization of the help-seeking process whereby the intention to seek help is a predictor of help-seeking. Nevertheless, it is also important to note that the association between intentions and help-seeking behaviors was not very strong, pointing towards the greater importance of other variables, such as personal enabling factors and help-seeking stigma as well as, possibly, additional variables that were not examined in the present study.

The Role of Enabling Factors in the Help-Seeking Process

Although a slightly higher mean was reported for professional than for personal enabling factors, the latter appeared to be a more important predictor of help-seeking behavior. Professional enabling factors did predict help-seeking intent, but not help-seeking behaviors. Put differently, although personal enabling factors did not directly predict intention to seek help, they did predict help-seeking behaviors. Personal enabling factors moderated the relationship between intention and help-seeking, such that for higher (but not lower) personal enabling factors, a relationship existed between intention and help-seeking. Personal enabling factors also acted as a mediating variable in the relationship between help-seeking stigma and help-seeking, such that lower levels of help-seeking stigma predicted more personal enabling factors, which in turn predicted more help seeking. Finally, personal enabling factors acted as a mediating variable in the relationship between family stigma and help-seeking behaviors, such that lower family stigma predicted greater personal enabling factors, which in turn predicted greater help-seeking behaviors.

Two complimentary explanations are possible for these results. First, family caregivers appear to rely on their own strengths and previous personal experiences with help-seeking as factors that enable them to seek services, more than they rely on the professional's attitudes and knowledge. This explanation is consistent with the theory of planned behavior (Ajzen 2002), according to which one of the main predictors of behavioral intention is self-efficacy or the confidence that one feels about engaging in a particular behavior (Bandura 1986). Self-efficacy has been found to be a more significant predictor of behavior than professional support (Twyford and Lusher 2016), suggesting that individuals seek help if they have confidence and feel that they have internal control over the help-seeking behavior (Twyford and Lusher 2016). Thus, internal control appears to be more important for help-seeking rather than external control, such as close-by services or knowledge and attitude of the professional.

A second associated explanation is that external professional enabling factors may be considered to be characteristics that are beyond the individuals' ability to control or change. This is especially true of public services over which individuals have no personal control as they, usually, can not chose the specific professional to turn to. Thus, families may seek help regardless of how they perceive these professionals and their abilities because they cannot see an alternative to a professional or to certain services.

The Role of Stigma in the Help-Seeking Process

Although participants reported higher levels of family stigma than help-seeing stigma, and although a higher degree of psychopathology was found to correlate with greater family stigma, the latter nevertheless seemed a more important predictor in the help-seeking process. Family stigma was not found to be directly related to intention to seek help or to help-seeking behaviors, whereas help-seeking stigma was related to both intention to seek help and help-seeking behaviors. Help-seeking stigma also acted as a moderating variable in the relationship between professional enabling factors and intent to use services, such that when stigma was low, a positive association was found between professional enabling factors and intention to seek help.

These findings show that family stigma was less important for help-seeking than the additional stigma associated with seeking mental health services. The finding may be related to the notion of "double stigma" (Mizock 2012), according to which families may fear that greater stigma will attach to them if they seek services. Families may feel that stigma associated with services is an additional type, above and beyond the family stigma. The fear of exposing the individual and the family to a double stigma is not unrealistic, studies having shown that even professionals held a higher degree of stigmatic attitudes toward individuals with greater psychopathology (Werner and Araten-Bergman 2017).

Study Limitations and Future Studies

First, the study was based on a convenience sample. Although we used various techniques of recruitment, convenience samples risk missing individuals who are not in contact with any kind of service. Second, the study focused solely on Jewish and Arab participants living in Israel which may not be representative of stigma and help-seeking across other cultures. Third, the study was based on a measure of current psychopathology. Thus, it is not inclusive of individuals that may have faced psychopathology and sought services in their past. Fourth, we measured help-seeking stigma as an overall construct. Future studies should examine stigma attached to specific services and inquire which services are perceived as more stigmatic by families. Fifth, the study did not investigate the objective usefulness of the services provided. This is an aim for future studies that could also conduct in-depth interviews regarding service use. Finally, some of the measures utilized were modified by the research team for the purpose of the current study. Thus, the extent to which reliability and validity of these measures was affected may bias the results in unknown ways.

Conclusions and Implications

The study has several important theoretical and practical implications. Theoretically, it extends the use of the socio-behavioral model to a field of research in which it has not been previously applied. The study also introduces both family and help-seeking stigma as constructs that require attention in the help-seeking process.

The results of the study stress the importance of continuing the engagement of families in the course of the help-seeking process. As families do not always seek for services, it is important that professionals that are currently involved with the families, such as the social worker or the general practitioner help enhance the families' sense of self-efficacy in their help-seeking process, and empower families to feel that the help-seeking process is under their control. This is possible to achieve by providing families with knowledge about various services and about how to find them, and by making the process a positive experience. By meeting with other family caregivers and professionals, family caregivers can gain a stronger feeling that they are taking the lead in these processes, which allow for their autonomous decisions. At the same time, there is a need to strengthen the relationship between family members and professionals. Even public services should provide family members the opportunity to meet various professionals and select those with whom they feel most comfortable. This would enable family members to gain a sense of positive team work rather than a feeling that professional attributes are beyond their control. At the same time it should be acknowledged that professionals working with individuals with ID and psychopathology are relatively few. Therefore, families should be clearly advised as to those professionals that are experts in the fields. At the same time, more should be done to train more knowledgeable professionals. Specifically, more training and knowledge should be provided to professionals working with individuals with ID and their families in assisting them to meet their needs. Finally, professionals working with families should be aware of the factors that facilitate families' help-seeking processes. This would make professionals aware of the important role they play in helping families understand this process from the early stages, when the children are still young, and throughout their lives. Specifically, it is important that professionals understand that stigma and especially structural discrimination evident within the current service system may deter families from seeking services.

Acknowledgements This research was supported financially by the State of Lower-Saxony, Hannover, Germany (ZN 2918). We warmly thank the families who participated in the study. We also thank the Ministry of Education, the Disabilities' Administration of the Ministry of Labour, Social Affairs and Social Services, The Outpatient Unit for Neurodevelopmental Psychiatry at Schneider Children's Medical Center and Beit Issie Shapiro for their help in recruitment. Finally, we thank all the research assistants who made this study possible.

Funding This study was funded by the State of Lower-Saxony, Hannover, Germany (Grant Number ZN 2918).

Compliance with Ethical Standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent Informed consent was obtained from all individual participants included in the study.

References

Aiken, L. S., & West, S. G. (1991). *Multiple regression: Testing and interpreting interactions*. Newbury Park: Sage.

Ajzen, I. (2002). Perceived behavioral control, self-efficacy, locus of control, and the theory of planned behavior. *Journal of Applied Social Psychology, 32*(4), 665–683.

Ali, A., Hassiotis, A., Strydom, A., & King, M. (2012). Self stigma in people with intellectual disabilities and courtesy stigma in family carers: A systematic review. *Research in Developmental Disabilities, 33*(6), 2122–2140. https://doi.org/10.1016/j.ridd.2012.06.013.

Andersen, R. M. (1995). Revisiting the behavioral model and access to medical care: Does it matter? *Journal of Health and Social Behavior, 36*(1), 1–10. https://doi.org/10.2307/2137284.

Andersen, R. M., & Davidson, P. L. (1997). Ethnicity, aging, and oral health outcomes: A conceptual framework. *Advances in Dental Research, 11*(2), 203–209.

Bandura, A. (1986). *Social foundations of thought and action*. Englewood Cliffs: Prentice Hall.

Chiu, M. Y., Yang, X., Wong, F. H. T., Li, J. H., & Li, J. (2013). Caregiving of children with intellectual disabilities in China—An examination of affiliate stigma and the cultural thesis. *Journal of Intellectual Disability Research, 57*(12), 1117–1129. https://doi.org/10.1111/j.1365-2788.2012.01624.x.

Corrigan, P. (2004a). Target-specific stigma change: A strategy for impacting mental illness stigma. *Psychiatric Rehabilitation Journal, 28*(2), 113–121. https://doi.org/10.2975/28.2004.113.121.

Corrigan, P. W. (2004b). How stigma interferes with mental health care. *American Psychologist, 59*(7), 614–625. https://doi.org/10.1037/0003-066X.59.7.614.

Corrigan, P. W., & Michaels, P. J. (2012). *Perceived availability of services scale*. Chicago: CASD.

Cunningham, P. J., & Freiman, M. P. (1996). Determinants of ambulatory mental health services use for school-age children and adolescents. *Health Services Research, 31*(4), 409.

Davis, E. L., Barnhill, J., & Saeed, S. Y. A. (2008). Treatment models for treating patients with combined mental illness and developmental disability. *Psychiatric Quarterly, 79*, 205–223. https://doi.org/10.1007/s11126-008-9082-2.

Dawson, J. F. (2014). Moderation in management research: What, why, when and how. *Journal of Business and Psychology, 29*(1), 1–19. https://doi.org/10.1007/s10869-013-9308-7.

Dekker, M. C., Koot, H. M., Van der Ende, J., & Verhulst, F. C. (2002). Emotional and behavioral problems in children and adolescents with and without intellectual disability. *Journal of Child Psychology Psychiatry, 43*(8), 1087–1098. https://doi.org/10.1111/1469-7610.00235.

Douma, J. C. H., Dekker, M. C., & Koot, H. M. (2006a). Supporting parents of youths with intellectual disabilities and psychopathology. *Journal of Intellectual Disability Research, 50*(8), 570–581. https://doi.org/10.1111/j.1365-2788.2006.00825.x.

Douma, J. C. H., Dekker, M. C., Ruiter, K. P., Verhulst, F. C., & Koot, H. M. (2006b). Help-seeking process of parents for psychopathology in youth with moderate to borderline intellectual disabilities. *Journal of the American Academy of Child and Adolescent Psychiatry, 45*(10), 1232–1242. https://doi.org/10.1097/01.chi.0000230167.31246.db.

Einfeld, S. L., Piccinin, A. M., Mackinnon, A., Hofer, S., Taffe, M., Gray, J., Bontempo, K. E., Hoffman, D. E., Parmenter, L. R.T., & Tonge, B. J. (2006). Psychopathology in young people with intellectual disability. *Journal of the American Medical Association, 296*(16), 1981–1989. https://doi.org/10.1001/jama.296.16.1981.

Einfeld, S. L., & Tonge, B. T. (2002). *Manual for the developmental behaviour checklist (second edition)—primary carer version (DBC-P-P) and teacher version (DBC-P-T)*. Melbourne: Monash University Centre for Developmental Psychiatry and Psychology and School of Psychiatry, University of New South Wales.

Essop, F. (2012). Parents' and special care workers understanding of "acceptance" and "denial" in relation to a child's intellectual disability. In *unpublished master's thesis*. Disability studies division: University of Cape Town, South Africa.

Faul, F., Erdfelder, E., Buchner, A., & Lang, A. G. (2009). Statistical power analyses using G* Power 3.1: Tests for correlation and regression analyses. *Behavior Research Methods, 41*(4), 1149–1160.

Foundation House & Centre for Multicultural Youth. (2013). *Responding to challenges of misuse of alcohol and other drugs by young people of refugee backgrounds*. Melbourne: Authors.

Godoy, L., Mian, N. D., Eisenhower, A. S., & Carter, A. S. (2014). Pathways to service receipt: Modeling parent help-seeking for childhood mental health problems. *Administration and Policy in Mental Health and Mental Health Services Research, 41*(4), 469–479. https://doi.org/10.1007/s10488-013-0484-6&%23x200F;.

Gourash, N. (1978). Help-seeking: A review of the literature. *American Journal of Community Psychology, 6*(5), 413–422. https://doi.org/10.1007/BF00941418.

Grue, J., Johannessen, L. E., & Rasmussen, E. F. (2015). Prestige rankings of chronic diseases and disabilities. A survey among professionals in the disability field. *Social Science & Medicine, 124*, 180–186. https://doi.org/10.1016/j.socscimed.2014.11.044.

Haihambo, C., & Lightfoot, E. (2010). Cultural beliefs regarding people with disabilities in Namibia: Implications for inclusion of people with disabilities. *International Journal of Education, 25*, 76–87.

Haines, M. M., McMunn, A., Nazroo, J. Y., & Kelly, Y. J. (2002). Social and demographic predictors of parental consultation for child psychological difficulties. *Journal of Public Health, 24*(4), 276–284. https://doi.org/10.1093/pubmed/24.4.276&%23x200F;.

Harrison, M., McKay, M., & Bannon, W. (2004). Inner-city child mental health service use: The real question is why youth and families do not use services. *Community Mental Health Journal, 40*(2), 119–131. https://doi.org/10.1023/B:COMH.0000022732.80714.8b.

Huỳnh, C., Caron, J., & Fleury, M. J. (2016). Mental health services use among adults with or without mental disorders: Do development stages matter? *International Journal of Social Psychiatry, 62*(5), 434–451.

Ingstad, B. (2001). Disability in the developing world. In G. L. Albrecht, K. D. Seelman & M. Bury (Eds.), *Handbook of disability studies* (pp. 772–792). Thousand Oaks: Sage

Iskra, W., Deane, F. P., Wahlin, T., & Davis, E. L. (2015). Parental perceptions of barriers to mental health services for young people. *Early Intervention in Psychiatry*. https://doi.org/10.1111/eip.12281.

Israel Central Bureau of Statistics. (2018). Population: Table B1. Retrieved from: http://www.cbs.gov.il/publications18/yarhon0718/pdf/b1.pdf.

Kerkorian, D., McKay, M., & Bannon, W. M. Jr. (2006). Seeking help a second time: Parents'/caregivers' characterizations of previous experiences with mental health services for their children and perceptions of barriers to future use. *American Journal of Orthopsychiatry, 76*(2), 161. https://doi.org/10.1037/0002-9432.76.2.161.

Keysor, J. J., Desai, T., & Mutran, E. J. (1999). Elders' preferences for care setting in short-and long-term disability scenarios. *The Gerontologist*, *39*(3), 334–344.

Krupchanka, D., Chrtková, D., Vítková, M., Munzel, D., Čihařová, M., Růžičková, T., Winkler, P., Janoušková, M., Albanese, E., & Sartorius, N. (2018). Experience of stigma and discrimination in families of persons with schizophrenia in the Czech Republic. *Social Science & Medicine, 212*, 129–135. https://doi.org/10.1016/j.socscimed.2018.07.015.

Lauber, C., & Rössler, W. (2007). Stigma towards people with mental illness in developing countries in Asia. *International Review of Psychiatry, 19*(2), 157–178. https://doi.org/10.1080/09540260701278903.

Logan, D. E., & King, C. A. (2001). Parental facilitation of adolescent mental health service utilization: A conceptual and empirical review. *Clinical Psychology: Science and Practice, 8*(3), 319–333.

Lowe, K., Allen, D., Jones, E., Brophy, S., Moore, K., & James, W. (2007). Challenging behaviours: Prevalence and topographies. *Journal of Intellectual Disability Research, 51*(8), 625–636. https://doi.org/10.1111/j.1365-2788.2006.00948.x.

MacNaughton, K. L., & Rodrigue, J. R. (2001). Predicting adherence to recommendations by parents of clinic-referred children. *Journal of Consulting and Clinical Psychology, 69*(2), 262. https://doi.org/10.1037/0022-006X.69.2.262&%23x200F;.

Mak, W. W., & Kwok, Y. T. (2010). Internalization of stigma for parents of children with autism spectrum disorder in Hong Kong. *Social Science & Medicine, 70*(12), 2045–2051. https://doi.org/10.1016/j.socscimed.2010.02.023.

Mak, W. W.,S., & Cheung, R. Y. M. (2008). Affiliate stigma among caregivers of people with intellectual disability or mental illness. *Journal of Applied Research in Intellectual Disabilities, 21*, 532–545. https://doi.org/10.1111/j.1468-3148.2008.00426.x.

McCann, T. V., Mugavin, J., Renzaho, A., & Lubman, D. I. (2016). Sub-Saharan African migrant youths' help-seeking barriers and facilitators for mental health and substance use problems: A qualitative study. *BMC Psychiatry, 16*(1), 275. https://doi.org/10.1186/s12888-016-0984-5&%23x200F;.

McConkey, R., Kahonde, C., & McKenzie, J. (2016). Tackling stigma in developing countries: The key role of families. In *Intellectual Disability and Stigma* (pp. 179–194). London: Palgrave Macmillan.

Mizock, L. (2012). The double stigma of obesity and serious mental illnesses: Promoting health and recovery. *Psychiatric Rehabilitation Journal, 35*(6), 466.

Morgan, V. A., Leonard, H., Bourke, J., & Jablensky, A. (2008). Intellectual disability co-occurring with schizophrenia and other psychiatric illness: Population-based study. *The British Journal of Psychiatry, 193*(5), 364–372. https://doi.org/10.1192/bjp.bp.107.044461.

Morisse, F., Vandemaele, E., Claes, C., Claes, L., & Vandevelde, S. (2013). Quality of life in persons with intellectual disabilities and mental health problems: An explorative study. The Scientific World Journal. https://doi.org/10.1155/2013/491918.

Mukolo, A., Heflinger, C. A., & Wallston, K. A. (2010). The stigma of childhood mental disorders: A conceptual framework. *Journal of the American Academy of Child and Adolescent Psychiatry, 49*(2), 92–103. https://doi.org/10.1016/j.jaac.2009.10.011.

Owens, P. L., Hoagwood, K., Horwitz, S. M., Leaf, P. J., Poduska, J. M., Kellam, S. G., & Ialongo, N. S. (2002). Barriers to children's mental health services. *Journal of the American Academy of Child & Adolescent Psychiatry, 41*(6), 731–738. https://doi.org/10.1097/00004583-200206000-00013.

Rawlinson, S., & Williams, R. (2000). The primary/secondary care interface in child and adolescent mental health services: The relevance of burden. *Current Opinion in Psychiatry, 13*(4), 389–395. https://doi.org/10.1097/00001504-200007000-00005.

Rickwood, D., Deane, F. P., Wilson, C. J., & Ciarrochi, J. (2005). Young people's help-seeking for mental health problems. *Australian e-Journal for the Advancement of Mental health, 4*(3), 218–251. https://doi.org/10.5172/jamh.4.3.218.

Sayal, K., Tischler, V., Coope, C., Robotham, S., Ashworth, M., Day, C., Tylee, A., & Simonoff, E. (2010). Parental help-seeking in primary care for child and adolescent mental health concerns: Qualitative study. *The British Journal of Psychiatry, 197*(6), 476–481. https://doi.org/10.1192/bjp.bp.110.081448.

Schalock, R. L., Borthwick-Duffy, S. A., Bradley, V. J., Buntinx, W. H. E., Coulter, D. L., Craig, E. M., Gomez, S. C., Lachapelle, T., Luck-asson, R., Reeve, A., Shoren, K. A., Snell, M. E., Spreat, S., Tasse, M. J., Thompson, J. R., Verdugo-Alonso, M. A., Wehmeyer, M. l., & Yeager, M. H. (2010). *Intellectual disability: Definition, Classification, and systems of supports* (11th ed.). Washington, DC: American Association on intellectual and Developmental Disabilities.

Schraeder, K. E., & Reid, G. J. (2015). Why wait? The effect of wait-times on subsequent help-seeking among families looking for children's mental health services. *Journal of Abnormal Child Psychology, 43*(3), 553–565. https://doi.org/10.1007/s10802-014-9928-z.&%23x200F;.

Selig, J. P., & Preacher, K. J. (2008). Monte Carlo method for assessing mediation: An interactive tool for creating confidence intervals for indirect effects [Computer software]. http://quantpsy.org/.

Spassiani, N., Chacra, A., & Lunsky, Y. (2017). "Why are you here? Can't you cope at home?" The Psychiatric crisis of people with intellectual disabilities and the community's response. *Journal of Mental Health Research in Intellectual Disabilities, 10*(2), 74–92. https://doi.org/10.1080/19315864.2016.1278290.

Spoth, R. L., Redmond, C., Kahn, J. H., & Shin, C. (1997). A prospective validation study of inclination, belief, and context predictors of family-focused prevention involvement. *Family Process, 36*(4), 403–429.

Struening, E. L., Perlick, D. A., Link, B. G., Hellman, F., Herman, D., & Sirey, J. A. (2001). The extent to which caregivers believe most people devalue consumers and their families. *Psychiatric Services, 52*(12), 1633–1638. https://doi.org/10.1176/appi.ps.52.12.1633.

Szymanski, L. S., & King, B. H. (1999). Summary of the practice parameters for the assessment and treatment of children, adolescents, and adults with mental retardation and comorbid mental disorders. *Journal of the American academy of child and adolescent psychiatry, 38*(12), 1606–1610.

Taffe, J. R., Gray, K. M., Einfeld, S. L., Dekker, M. C., Koot, H. M., Emerson, E., Koskentausta, T., & Tonge, B. J. (2007). Short form of the developmental behaviour checklist. *American Journal on Mental Retardation, 112*(1), 31–39. https://doi.org/10.1352/0895-8017(2007)112%5B31:SFOTDB%5D2.0.CO;2.

Taua, C., & Farrow, T. (2009). Negotiating complexities: An ethnographic study of intellectual and mental health nursing in New Zealand. *International Journal of Mental Health Nursing, 18*(4), 274–284. https://doi.org/10.1111/j.1447-0349.2009.00610.x.

Thurston, I. B., Phares, V., Coates, E. E., & Bogart, L. M. (2015). Child problem recognition and help-seeking intentions among black and white parents. *Journal of Clinical Child & Adolescent Psychology, 44*(4), 604–615. https://doi.org/10.1080/15374416.2014.883929.

Turner, E. A. (2012). The parental attitudes toward psychological services inventory: Adaptation and development of an attitude scale. *Community Mental Health Journal, 48*(4), 436–449. https://doi.org/10.1007/s10597-011-9432-7.

Twyford, J., & Lusher, J. (2016). Determinants of exercise intention and behaviour among individuals diagnosed with schizophrenia. *Journal of Mental Health, 25*(4), 303–309. https://doi.org/10.3109/09638237.2015.1124399.

UN General Assembly. (1989) Convention on the rights of the child. United Nations, Treaty Series, vol. 1577, p. 3. Accessed Dec 8, 2018, from https://www.refworld.org/docid/3ae6b38f0.html.

UN General Assembly. (2007) Convention on the rights of persons with disabilities: Resolution. Adopted by the General Assembly. 24 January 2007.

Weiss, J., & Lunsky, Y. (2010). Service utilization patterns in parents of youth and adults with intellectual disability who experienced behavioral crisis. *Journal of Mental Health Research in Intellectual Disabilities, 3*(3), 145–163. https://doi.org/10.1080/19315864.2010.490617.

Weiss, M. G. (2008). Stigma and the social burden of neglected tropical diseases. *PLoS Neglected Tropical Diseases, 2*(5), e237. https://doi.org/10.1371/journal.pntd.0000237.

Werner, S., & Araten-Bergman, T. (2017). Social workers' stigmatic perceptions of individuals with disabilities: A focus on three disabilities. *Journal of Mental Health Research in Intellectual Disabilities, 10*(2), 93–107. https://doi.org/10.1080/19315864.2017.1284288.

Werner, S., & Shulman, C. (2015). Does type of disability make a difference in affiliate stigma among family caregivers of individuals with autism, intellectual disability or physical disability? *Journal of Intellectual Disability Research, 59*(3), 272–283. https://doi.org/10.1111/jir.12136.

Werner, S., Stawski, M., Polakiewicz, Y., & Levav, I. (2013). Psychiatrists' knowledge, training and attitudes regarding the care of individuals with intellectual disability. *Journal of Intellectual Disability Research, 57*, 774–782. https://doi.org/10.1111/j.1365-2788.2012.01604.x.

Williams, V., & Heslop, P. (2005). Mental health support needs of people with a learning difficulty: A medical or a social model? *Disability & Society, 20*(3), 231–245. https://doi.org/10.1080/09687590500060554.

Wilson,C. J., Deane, F. P., Ciarrochi, J., & Rickwood, D. (2005). Measuring help-seeking intentions: Properties of the General Help-Seeking Questionnaire. *Canadian Journal of Counselling, 39*(1),15–28.