

The Experience of Stress and Personal Growth Among Grandparents of Children With and Without Intellectual Disability

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Abstract

The aim of this research was to examine the contribution of internal and external resources to stress and personal growth among grandparents of children with and without an intellectual disability. Ninety-four grandparents of children with intellectual disability and 105 grandparents of children without intellectual disability completed the following scales: Multidimensional Experience of Grandparenthood; Multidimensional Scale for Perceived Social Support, Level of Differentiation of Self Scale, Family Adaptability and Cohesion Evaluation Scale, Perceived Stress Scale, and Posttraumatic Growth Inventory. Results indicate that group differences are reflected in higher negative emotions among grandparents of children without intellectual disability. In addition, both stress and growth are related to better health, lower level of education, family cohesiveness, and negative emotions. However, whereas stress is associated with the internal resource of self-differentiation, the external resource of social support, and the cost of grandparenthood, growth is associated with gender and the symbolic and behavioral aspects of the grandparenting role. This study aimed to correct the nearly exclusive focus in the literature on negativity, stress, and the burden of grandparenting children with intellectual disability, as well as to test the pervasive assumption that the absence of disability results in an almost entirely positive grandparenting experience with nearly no negative affect.

Key Words: *grandparents; intellectual disability; stress; personal growth*

Raising children with intellectual disability entails numerous emotional and practical demands, pressures, and changes and often requires families to contend with extended stress (Patterson, Holm, & Gurney, 2004; Smith, Oliver, & Innoceti, 2001). Under these circumstances, grandparents are often a critical source of support that helps families deal with their stress. Although there is some recent research examining the grandparenting role as an important resource of the family support system (see, e.g., Findler, 2000; Margetts, Le Couteur, & Croom, 2006), the personal experience of grandparents of children with disabilities has been largely overlooked.

When faced with a grandchild with an illness or disability, grandparents can be expected to experience a two-pronged crisis: distress and pain both for their grandchild as well as for their own adult child (Vadasy, 1987). However, even though

grandparents may undergo a mourning process similar to that of the child's parents, they are not awarded the emotional and professional support typically offered to parents (Margetts et al., 2006). Many grandparents contend with these difficulties while simultaneously coping with the natural consequences of age, which include declining health, retirement, and the loss of friends and family members. The majority of existing literature on families of children with disabilities focuses on the negative implications of chronic stress, mourning, and sorrow (see, e.g., Best, Streisand, Catania, & Kazak, 2001; Marshak, Seligman, & Prezant, 1999). In stark contrast, the majority of literature addressing the experiences of families of children with typical development focuses on joy, benefit, happiness, and satisfaction (Findler, Taubman-Ben-Ari, Nuttman-Shwartz, & Lazar, 2013). This study sought to illuminate a more grounded and

nuanced picture of the experiences of grandparents of children with and without disabilities and to learn more about the similarities and differences between these groups. To achieve this aim, this study identified both the positive and negative aspects of the experiences of these grandparents. More specifically, it examined the contribution of the perceived role of grandparenthood, self-differentiation, social support, family cohesion and adaptability to stress, and personal growth of grandparents of children with and without intellectual disability.

Stress Among Grandparents of Children With Intellectual Disability

Despite increasing awareness of the impact of disabilities in children on the nuclear and extended family, little is known about their effects on intergenerational relations in general or on grandparents in particular (Hastings, Thomas, & Delwiche, 2002; Hillman, 2007; Miller, Buys & Woodbridge, 2012; Mitchell, 2007, 2008). The grandparenting role can be unique and meaningful, as grandparenthood can offer a symbolic sense of immortality, a link between history and the future, and compensation for past disappointments. Grandparents often regard their grandchildren as the agents of their continuity and take pride in the grandchildren's accomplishments (see, e.g., Findler et al., 2013; Kivnick, 1982; Neugarten & Weinstein, 1964). These meanings create a set of expectations in anticipation of the birth of a grandchild that are likely to be thwarted when a child is diagnosed with a disability (Miller et al., 2012; Seligman, 1991).

Grandparents of children with disabilities are often faced with a complex, multifaceted, and unexpected reality, and as noted previously, they may undergo a mourning process similar to that experienced by the child's parents (Hillman, 2007). However, whereas parents' feelings are often processed through active coping with the countless demands of the disability, grandparents remain remote from the practical implications of daily needs. This distance may leave them lacking a clear understanding of the short- and long-term consequences of the situation and thus heighten their stressors and prolong their sense of loss (Lee & Gardner, 2010).

Common reactions of grandparents to grandchildren's disabilities include distress, sadness,

depression, anxiety, shock, denial, disillusionment, and uncertainty. Moreover, grandparents often ignore the corporeality of their grandchild's condition, to the extent that they may develop fantasies or imagine unrealistic pictures of the disability (Seligman, 1991; Seligman Goodwin, Paschal, Applegate, & Lehman, 1997; Morton, 2000). These responses may be intensified by the lack of information and emotional support that is typically provided to the parents by professionals and others in their social network (Hillman, 2007; Morton, 2000; Scherman, Gardner, Brown, & Schutter, 1995; Shaw, 2005). Reactions to a child's disability, however, are not static. Rather, they tend to be fluid, with grandparents shifting between responses depending on the nature, prognosis, stage, and progress of the disability. These responses are also dependent on personal, familial, cultural, and environmental factors (Gardner, Scherman, Efthimiadis, & Shultz, 2004; Hastings et al., 2002; Hillman, 2007; Margetts et al., 2006).

After the initial diagnosis, grandparents who reconcile with and adapt to their grandchild's disability often respond by displaying a clear sense of responsibility to provide assistance to both their adult children and their grandchildren (see, e.g., Mitchell, 2008; Scherman et al., 1995; Schilmoeller & Baranowski, 1998). Furthermore, grandparents have reported that after their initial experience of anger and sadness, they made sense of and accepted the diagnosis and even took pride in their family's positive coping and adjustment with the unanticipated challenges (Woodbridge, Buys, & Miller, 2009). Nevertheless, the scarce literature addressing the experiences of these grandparents primarily describes their feelings and experiences in negative terms, overlooking the positive outcomes (see, e.g., Scherman et al., 1995) such as the potential for personal growth.

Personal Growth Among Grandparents of Children With Intellectual Disability

It has been argued that in stressful events and in the aftermath of adversity, people can show tenacious resilience and ultimately experience personal growth (Schaefer & Moos, 1992; Tedeschi & Calhoun, 1995). Studies of posttraumatic growth indicate that increased growth generally accompanies increased stress (Tedeschi & Calhoun, 2004). The potential for positive life changes in the wake of adversity has been examined in a variety of

populations contending with traumatic circumstances, such as bereaved spouses, parents (see, e.g., Davis, Nolen-Hoeksema, & Larson, 1998), and cancer patients (see, e.g., Manne et al., 2004). According to the literature, people often emerge from continuous stress experiences with new abilities, closer relationships with family and friends, broader priorities, and a richer appreciation of life (Schaefer & Moos, 1992). For many, life crises are catalysts for enhanced personal resources, social resources, coping skills, or spiritual insights (Schaefer & Moos, 1992; Tedeschi & Calhoun, 1995). However, the potential positive life-changing responses to the stress of having a grandchild with intellectual disability have yet to be addressed in the research literature.

Grandparents in general, and grandparents of children with disabilities in particular, may contend with significant and dramatic changes in their lives and thus may interpret the experience as an opportunity for personal growth. A recent study conducted with grandparents of childhood cancer survivors reported that with the cessation of active treatments, grandparents reassessed themselves and their family situation within the illness context (Findler, Dayan-Sharabi, & Yaniv, 2013). These grandparents indicated that despite the continual distress of the illness, they realized that they had found, developed, and displayed new strengths, positivity, and meaning. These grandparents noted their improved relationships with their children and grandchildren, and the pride they took in their role within the family, particularly throughout the difficulty of the illness and treatment.

The literature deals extensively with the negative implications of children's disabilities on their families, including on their grandparents (see, e.g. Hillman, 2007; Seligman, 1991). The current study sought to address the more positive aspects by exploring the potential growth experiences of these grandparents in light of this stressful and challenging situation. This study adopted the theoretical framework of Schaefer and Moos (1992), which relates to four factors that contribute to personal growth: (a) personal characteristics, operationalized in this research as self-differentiation, sociodemographic variables, and the perception of the grandparenting role; (b) environmental characteristics, defined here as social support and family cohesion and adaptability; (c) characteristics of the life event, represented in this study by the presence of a grandchild with intellectual disability; and (d)

coping responses, which, although part of the model, are beyond the scope of this investigation and consequently are not examined here.

Self-Differentiation

Self-differentiation is conceptualized by Bowen (1985) and refers to the extent to which individuals experience themselves as physically and cognitively distinct from others around them, namely, the degree to which they perceive their body, emotions, thoughts, desires, and actions to be their own. According to Bowen (1985), self-differentiation also relates to a person's ability to distinguish and integrate the emotional and intellectual aspects of their personality. Thus, self-differentiation contains both intra- and interpersonal dimensions. In a person with high self-differentiation, emotions and thoughts work in tandem; in a person with low self-differentiation, emotions overpower thoughts or thoughts displace emotions. People with high self-differentiation are able to feel and express their emotions, control their impulses, and respond to stress and crises with flexibility, self-control, and responsibility. Self-differentiation has been examined in the context of intergenerational relationships (Kerr, 2003; Miller-Day, 2004; O-Yang & Wu, 2012) and in unique circumstances of stress. Specifically, findings have shown that under greater stress, significant differences in psychological well-being were found between poorly and well-differentiated individuals (Murdock & Gore, 2004). Furthermore, self-differentiation has been found to be associated with personal growth among siblings, particularly those of children with intellectual disability. Findler and Vardi (2009) found that as soon as siblings were able to differentiate themselves from their family members and recognize that they were different and were not defined by their sibling's disability, they experienced increased personal growth.

Family Cohesion and Adaptability

Family cohesion refers to the level of emotional connection or separation among family members. Family cohesion is reflected in various aspects of the family relationship including the nature of emotional bonds, boundaries, coalitions within the family, amount of time spent together, extrafamily friendships, decision making, interest in each other's lives, and shared leisure activities. Adaptability refers to the flexibility of the family system

and its ability to modify itself in response to environmental and developmental pressures. Adaptability is expressed in features such as assertiveness, supervision, discipline, negotiation style, and division of roles (Olson, Russell, & Sprenkle, 1983). Baker, Mailick Seltzer, and Greenberg (2011) found that adaptability had longitudinal effects on depression among mothers of adolescents with autism. The authors suggest that within a family system, rigidity may foster negative feelings and depression, whereas fluidity and adaptability may promote well-being, particularly in the face of ongoing stress.

Social Support

Social support is defined as an interpersonal transaction involving both an emotional and an instrumental dimension (Wandersman, Wandersman, & Kahn, 1980). Research has shown social support to be one of the main resources of parents of children with disabilities (Dunst, Trivette, & Hanby, 1994; Florian & Findler, 2001). A growing body of evidence emphasizes the important role social support plays in the development of positive changes following adversity (McMillan & Cook, 2003) and as one of the crucial components which predict adjustment among mothers of children with disabilities (Findler, 2000; Mirfin-Veitch, Bray, & Watson, 1996). While grandparents are seen as the primary source of support for families of children with an illness or disability (see, e.g., Findler, 2000), their own need for support and its contribution to their adjustment has not been previously examined.

The Perception of the Grandparenting Role

Grandparenthood is often conceptualized as a multidimensional social role or developmental task of middle and late adulthood (Heiss, 1992). This social role comprises cognitive, affective, symbolic, and behavioral dimensions (Findler et al., 2013). The cognitive dimension relates to commitment to the grandparenting role, which is reflected in motivation to the investment of time and effort as well as in perceived personal cost, namely priorities, time, and money. The affective dimension refers to the positive feelings of joy, accomplishment, and pride and to the negative feelings of anger, guilt, and disappointment. The symbolic dimension refers to meaning, namely the sense that

grandparenthood is a uniquely enriching and challenging experience, that it is a compensation for parenthood and can be more rewarding and satisfying than parenthood, and that it serves as an intergenerational bond and link between the past and the future. The symbolic dimension also refers to the sense of burden and inconvenience of the grandparenting role. The behavioral dimension refers to the provision of emotional support to grandchildren—expressed in kissing, hugging, and encouragement—to contribution to the grandchild's upbringing and development, and to instrumental support such as babysitting, bathing, or cooking for the grandchildren (Findler et al., 2013). Although grandparents' support in families of children with disabilities has been extensively examined (see, e.g., Lee & Gardner, 2010; Schilmoeller & Baranovsky, 1998), their perspectives on their role within such unique circumstances have not been previously explored. It can be assumed that grandparents who perceive their role more positively and are therefore more engaged and committed to their role will experience less stress and more personal growth.

The current study examined both the levels of stress and personal growth among grandparents of children with intellectual disability, as well as the internal and external resources that contributed to these two outcome variables. These grandparents were compared with grandparents of children with typical development in order to learn more about the similarities and differences between both groups. It was hypothesized that grandparents of children with intellectual disability would display higher levels of stress and consequently greater personal growth than grandparents of children without disabilities. Additionally, it was expected that better self-differentiation, higher levels of cohesion and adaptability, social support, and perceived grandparenting role would contribute to lower levels of stress and higher personal growth among all grandparents.

Method

Participants

The sample consisted of 199 grandparents, 94 of whom (32 grandfathers and 62 grandmothers) had grandchildren with intellectual and developmental disabilities and 105 (45 grandfathers and 60 grandmothers) whose grandchildren did not have any disabilities.

All grandparents in the research group had grandchildren ages 3–12 learning in special-education kindergartens and primary schools. It is important to note that special education in Israel is anchored in legislation from 1988. According to this legislation, any child in Israel between the ages of 3 and 21 who is diagnosed with a disability has the right to special treatment which is paid for by the government. The kindergartens and schools offer established multidisciplinary personal learning plans for each child.

The comparison group included grandparents of children without a disability at the same age and from the same area of residence. Participants lived in different areas throughout Israel; 18.9% lived within walking distance; 47.5% lived within a 30-min drive, while 33.5% lived within a distance of more than half an hour drive of their grandchildren.

The personal and sociodemographic characteristics of each research group are presented in Tables 1 and 2. As shown in those tables, the only significant differences between the groups were found regarding grandparent’s age, number of grandchildren, and economic status.

Procedure

Following consent from the institutional scientific review board of the Ministry of Education in Israel, the national list of schools geared towards children with intellectual disability was provided by the ministry. Twenty-five educational institutions were initially approached; 11 were kindergartens and 14 were schools. Of the institutions initially contacted, 10 kindergartens and 9 schools agreed to participate in the research. Within these schools, 164 parents returned their parents’ (i.e., the grandparents) agreement to participate in the research. Of the initial sample, 94 grandparents ended up completing the questionnaires. Reasons for withdrawal from

the study included changes in health status and language difficulties. The comparison group consisted of grandparents of children of the same age who studied in the same geographical areas as the children in the research group. In the comparison group, 153 parents reported on grandparents who were willing to participate; however, only 105 grandparents completed the questionnaires. Many did not participate for the same reasons as in the group of grandparents with a child with a disability.

Research assistants contacted all grandparents by phone, explained the purpose of the study, and ensured the respondents’ anonymity. Questionnaires were mailed in a sealed envelope containing a self-addressed stamped envelope for the completed forms, which had to be returned. Grandparents of children with intellectual disability were instructed to focus upon their experience with the child with the disability. Grandparents in the comparison group were instructed to focus on their grandchild who was at a similar age as the child with the disability.

Participants were asked to complete the packet of questionnaires in the following order: the Multidimensional Experience of Grandparenthood set of inventories, Multidimensional Scale for Perceived Social Support, Level of Differentiation of Self Scale, Family Adaptability and Cohesion Evaluation Scale, Perceived Stress Scale, and finally sociodemographic data. Questionnaires took an average of 45–60 min to complete.

Instruments

Multidimensional Experience of Grandparenthood set of inventories (MEG). This instrument (Findler et al., 2013) contains four inventories reflecting the cognitive, affective, symbolic, and behavioral dimensions of grandparenthood. Each inventory is accompanied by a short introduction and instructions for completion. The

Table 1
Characteristics of Grandparents

Characteristic	Grandparents of children with intellectual disability (<i>n</i> = 94)		Grandparents of children without disability (<i>n</i> = 105)		<i>t</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
Age	66.90	6.95	63.76	6.34	3.32**
Number of children	3.49	1.93	3.35	1.00	.64
Number of grandchildren	9.78	10.30	5.63	3.90	3.83**

***p* < .01.

Table 2
Sociodemographic Characteristics of Grandparents

Characteristic	Grandparents of children with intellectual disability (<i>n</i> = 94)		Grandparents of children without a disability (<i>n</i> = 105)		χ^2
	<i>n</i>	%	<i>n</i>	%	
Gender					
Male	32	34.0	45	42.9	1.63
Female	62	66.0	60	57.1	
Marital status					
Married	75	81.5	87	82.9	0.06
Single	17	18.5	18	17.1	
Education					
Up to 8 years	12	13	5	4.8	5.77
Up to 12 years	29	31.5	32	30.8	
Up to 15 years nonacademic	29	31.5	31	29.8	
Academic degree	22	23.9	36	34.6	
Perceived health status					
Above average	28	30.1	58	28.4	2.33
Average	58	62.4	70	68.6	
Below average	7	7.5	3	2.9	
Perceived economic status					
Above average	25	27.2	31	29.8	6.05*
Average	53	57.6	68	65.4	
Below average	14	15.2	5	4.8	

**p* < .05.

cognitive dimension (14 items) consists of two factors relating to personal investment (e.g., “I have a strong sense of commitment to my role as grandparent”) and personal cost (e.g., “The role of grandparent requires a change in my priorities”). Respondents are asked to indicate the degree to which they agree or disagree with each statement on a 5-point Likert-type scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). In this study, Cronbach’s α was .89 for personal investment and .79 for personal cost. The affective dimension (21 items) relates to feelings aroused by the grandparenting role and consists of two factors: positive emotions (e.g., “joy,” “satisfaction,” “happiness”) and negative emotions (e.g., “guilt,” “sadness,” “inadequacy”). Respondents are asked to indicate the degree to which they experience the emotion indicated in each item on a 5-point Likert-type scale ranging from 1 (*not at all*) to 5 (*very much*). In this study, Cronbach’s α was .85 for positive

emotions and .91 for negative emotions. The symbolic dimension (19 items) relates to the level of significance the respondent attributes to being a grandparent. This dimension consists of four factors: meaning (e.g., “Being a grandparent gives more purpose to my life”), compensation for parenthood (e.g., “I feel I am a better grandparent than I was a parent”), continuity (e.g., “Being a grandparent gives me the opportunity to connect with my family history”), and burden (e.g., “Being a grandparent tires me out”). Respondents are asked to indicate the degree to which they agree or disagree with the statement in each item on a 5-point Likert-type scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). In the current study, Cronbach’s α was .84, .83, .78, and .52 for the four factors, respectively. Due to the low Cronbach’s α for burden, this factor was omitted. The behavioral dimension (23 items) relates to the grandparent’s interactions with their grandchildren and consists

of three factors: emotional support (e.g., “I encourage and praise my grandchildren”), contribution to upbringing (e.g., “I display an interest in my grandchildren’s hobbies”), and instrumental support (e.g., “I babysit my grandchildren when they are sick”). Respondents are asked to indicate the frequency of the activity described in each item on a 5-point Likert-type scale ranging from 1 (*never*) to 5 (*very often*). In the current research, Cronbach’s α was .85 for emotional support, .85 for contribution to upbringing, and .81 for instrumental support. Participants were assigned a score for each of the factors in the inventories by averaging their responses on all the relevant items.

Multidimensional Scale for Perceived Social Support (MSPSS). Developed by Zimet, Dahlem, Zimet, and Farley (1988), this is a 12-item scale assessing the respondent’s subjective perception of the social support he or she receives from family, friends, and a significant other (e.g., “I can talk with my friends about my problems”). Responses are marked on a 7-point Likert type scale ranging from 1 (*not appropriate*) to 7 (*very appropriate*). Cronbach’s α was .88 for family, .93 for friends, and .89 for a significant other. A social-support score for each participant was calculated by averaging the responses on the items in each subscale, with higher scores indicating greater social support.

Level of Differentiation of Self Scale (LDSS). Developed by Haber (1984), this instrument is based on Bowen’s conceptualization of self-differentiation (1985). The scale consists of 32 statements assessing two variables: emotional maturity and emotional dependency (e.g., “My actions and decisions are based on the agreement of other people”). Respondents are asked to indicate the degree to which they agree or disagree with each statement on a 4-point Likert-type scale ranging from 1 (*strongly disagree*) to 4 (*strongly agree*). The reliability coefficient in the current study was .88. A self-differentiation score was calculated for each participant by averaging his or her scores on all 32 items, with higher scores reflecting higher levels of self-differentiation.

Family Adaptability and Cohesion Evaluation Scale (FACES-III). This is a self-report instrument (Olson, Portner, & Lavee, 1985) consisting of 20 statements that describe family behaviors indicative of cohesion and adaptability (e.g., “Our family changes its way of handling day to day routines”). Respondents are asked to rate the frequency with which they engage in each behavior on a 5-point

scale from 1 (*almost never*) to 5 (*almost always*). In the current research, Cronbach’s α was .81 for family cohesion and .74 for adaptability. Respondents were assigned scores on each of the subscales by averaging their responses on all relevant items, with higher scores indicating higher cohesion or adaptability.

Perceived Stress Scale (PSS). This self-report instrument (S. Cohen, Kamarck, & Mermelstein, 1983) consists of 14 questions assessing the individual’s subjective perception of his or her level of stress in the last month (e.g., “How often have you been upset because of something that happened unexpectedly?”) Respondents are asked to indicate how frequently they felt each of the feelings in the previous month on a 5-point Likert-type scale ranging from 1 (*never*) to 5 (*very often*). A Cronbach’s α of .79 was found here for this instrument. A general stress score for each participant was calculated by averaging the responses on the 14 items, with higher scores indicative of greater stress.

Posttraumatic Growth Inventory (PTGI). This is a 22-item self-report scale (Tedeschi & Calhoun, 1996) used to measure personal growth; it relates to personal and spiritual strengths, appreciation of life and new possibilities, and relationships with others (e.g., “I am able to do better things with my life”). Participants are asked to indicate the degree to which the change expressed in each statement occurred in their life within the past 2 years. Responses are marked on a 6-point Likert scale ranging from 0 (*I did not experience this change*) to 5 (*I experienced this change to a very great degree*). In the present study, the scale yielded a Cronbach’s α of .96. Each participant was assigned a personal-growth score, computed by averaging his or her responses on all items; higher scores were indicative of greater personal growth.

Results

In the first stage of data analysis, one-way MANOVAs were conducted to examine the differences between grandparents of children with intellectual disability and grandparents of children without disabilities. The selection of MANOVAs was used in order to avoid random significant differences due to the large number of analyses (Tabachnick & Fidell, 2013). Since the dependent variables reflect different content from the predictors, two MANOVAs were conducted: one for the

dependent variables of stress and personal growth and one for the independent variables of self-differentiation, family adaptability and cohesion, social support, and perceived grandparenthood role.

No significant differences were found between the groups for the dependent variables of stress and personal growth, $F(2,189) = 1.46, p > .05$, or for levels of self-differentiation and family cohesion or adaptability and social support, $F(4,194) = 1.67, p > .05$. The MANOVA conducted on the dimensions of grandparenthood revealed significant differences between both groups, $F(11,187) = 2.86, p < .01$. However, a univariate ANOVA indicated differences only with regard to negative emotions, $F(2,197) = 12.32, p < .05, \mu = .06$, with grandparents of children without disabilities reporting more negative feelings ($M = 4.46, SD = 0.68$) than those with grandchildren with intellectual disability ($M = 4.76, SD = 0.50$).

In addition, differences between the two groups of grandparents were found regarding age, number of grandchildren (see Table 1), and economic status (See Table 2). More specifically, grandparents of children with intellectual disability were on average 3 years older, and they had more grandchildren and lower economic status. The correlations of these variables with stress and personal growth were not significant, indicating that there was no need to include them in the next analyses.

In the second stage of analysis, correlations between the independent variables and the outcome variables of stress and personal growth were calculated for the entire sample as a whole and for each group separately. The correlations for the entire sample are presented in Table 3. Correlations for each group in the case of differences between the groups, followed by Fisher's z test, are discussed below.

As Table 3 shows, significant negative correlations were found between stress and the levels of self-differentiation, social support, family cohesiveness, and negative feelings about grandparenthood; lower levels of each of these variables were associated with higher levels of stress. In addition, a significant positive correlation was found between stress and cost. Significant differences between the groups were found regarding the correlations between family cohesiveness and stress, $r = -.40, p < .001$ for the research group and $r = -.13, p > .05$ for the comparison group ($Z = 2.01, p < .05$). Another significant difference was found regarding the correlations between negative feelings and

Table 3
Correlations Between Stress and Personal Growth and the Study Variables

Variable	Stress	Personal growth
Level of differentiation	-.31***	-.09
Social support	-.19**	.06
Family cohesiveness	-.25***	.20**
Family adaptability	.02	.24***
Grandparent role		
Symbolic dimension		
Meaning	-.05	.30***
Continuity	.12	.34***
Compensation for parenthood	.06	.36*
Cognitive dimension		
Personal investment	-.06	.23***
Personal cost	.17*	.14
Affective dimension		
Positive emotions	-.11	.18*
Negative emotions	-.32***	-.18*
Behavioral dimension		
Emotional support	-.07	.24***
Instrumental support	.02	.31***
Contribution to upbringing	-.09	.35***

* $p < .05$, ** $p < .01$, *** $p < .001$.

stress ($Z = 2.08, p < .05$); correlation in the research group was $r = -.43, p < .001$, whereas the correlation in the comparison group was only $r = -.16, p > .05$.

In both groups, personal growth correlated positively with family adaptability, cohesiveness, and the grandparenthood aspects of meaning, continuity, compensation for parenthood, personal investment, positive emotions, emotional and instrumental support, and contribution to upbringing. In addition, lower levels of negative feelings were negatively associated with higher personal growth.

Fisher z analyses showed a significant difference between the groups only with regard to personal cost ($Z = 2.08, p < .05$). Personal growth was significantly and positively correlated with cost among grandparents of children with intellectual disability ($r = .34, p < .001$) and negatively and insignificantly among grandparents of children without disabilities ($r = -.03, p > .05$). Stress

and personal growth were moderately but significantly associated in both groups: $r = .17, p < .05$, for grandparents of children with disabilities, and $r = .12, p < .05$, for grandparents of children without disabilities.

In the third stage of analysis, two hierarchical regressions were conducted in order to examine the unique and combined contributions of the independent variables to the explained variance in the outcome variables of stress and personal growth. The predictors included sociodemographic characteristics, internal and external resources, and grandparenthood role dimensions, which were entered in seven steps in the following order:

The sociodemographic variables were entered in the first step in order to control for their contribution on the other predictors. Due to the large number of variables in this category, only those showing significant contribution in at least one of the analyses (i.e., gender, health, and education) were entered in the equation.

In the second step, group variable was entered (grandparents of children with intellectual disability vs. grandparents of children without disabilities).

Internal and external resources (self-differentiation, family adaptability and cohesiveness, and social support) were added in the third step.

The following three steps include the four dimensions of the role of grandparenthood, which were entered here according to the order of the original MEG (Findler et al., 2013). The symbolic dimension of grandparenthood was entered in Step 4; the cognitive and affective dimensions of grandparenthood in Step 5; and the behavioral dimension of grandparenthood in Step 6.

In these first six steps a forced method was used, while in the seventh and final step a stepwise method was used in which interactions of groups with independent variables were examined. The results of the hierarchical regressions appear in Table 4. None of the interactions in Step 7 reached a significance level of .05; therefore, only the results of the first six steps are presented.

As shown in Table 4, the independent variables contributed significantly to the explained variance of grandparents' stress (37.1%) and even more strongly to the variance of personal growth (40.2%). The sociodemographic variables in Step 1 accounted for 9.4% of the variance in stress, indicating that higher stress was reported among grandparents with better health and lower educa-

tion. The first step added 12.3% of the variance in personal growth. Women, and grandparents in better health and with lower education levels, reported more personal growth. In Step 2, the grandchild's intellectual disability did not contribute to the explanation of the variance in either outcome variable, showing that grandparents of children with intellectual disability did not indicate higher stress or personal growth than those of children without disabilities. The third step contributed 16.8% to the explained variance in stress and 6.9% to that in growth, with social support, self-differentiation, and family cohesiveness negatively related to stress. Only family cohesiveness was strongly and positively associated with personal growth. While the symbolic dimension of grandparenthood in Step 4 did not significantly contribute to explaining the variance in stress (2.8%), it added 15.4% to the explained variance in growth, revealing that a higher sense of both continuity and compensation for parenthood were associated with a higher level of personal growth. In the fifth step, the cognitive and affective dimensions of grandparenthood added 6.4% to the explained variance in stress and only an insignificant 2.2% to the variance in personal growth. Higher personal cost and lower negative emotions were associated with higher levels of stress. Negative emotions were also negatively associated with personal growth. Finally, the behavioral dimension of grandparenthood in Step 6 did not contribute to the explained variance in stress, but did contribute 3.3% to the explained variance in growth, indicating that when grandparents enriched their grandchildren by contributing to their upbringing, they also had a greater sense of personal growth.

Discussion

This study sought to examine the experience of grandparenting and the contributors to stress and personal growth among grandparents of children with intellectual disability in comparison with grandparents of children with typical development.

Differences Between Grandparents of Children With Disabilities and Grandparents of Children With Typical Development

The only difference found between grandparents of children with intellectual disability and those of children without disabilities was more negative

Table 4
Hierarchical Regression Coefficients (β Weights) for Grandparent's Stress and Personal Growth (N = 199)

Step and effect	Stress		Personal growth	
	β	ΔR^2	β	ΔR^2
Step 1				
Grandparent's gender	0.04	.094*	.21**	.123***
Grandparent's health status	.26***		.19**	
Grandparent's education	-.15*		-.18*	
Step 2				
Group (grandchild with/without intellectual disability)	-.12	0.014	-.04	0.001
Step 3				
Self-differentiation	-.29***	.168***	-.11	.069*
Family adaptability	0.09		0.04	
Family cohesiveness	-.20*		.30***	
Social support	-.17*		-.08	
Step 4				
Meaning	0.05	0.028	0.12	.154***
Continuity	0.06		.18**	
Compensation for parenthood	0.09		.22**	
Step 5				
Personal investment	-.04	.064**	0.03	0.022
Personal cost	.15*		0.06	
Positive emotions	-.10		0.07	
Negative emotions	-.22**		-.16*	
Step 6				
Emotional support	0.08	0.003	-.11	.033*
Instrumental support	-.08		0.04	
Contribution to upbringing	-.00		.27**	
R^2		0.371		0.402

* $p < .05$, ** $p < .01$, *** $p < .001$.

feelings among the latter group. It can be assumed that perhaps grandparents of children without disabilities would feel more comfortable expressing negative emotions or criticism of their own adult children. It can also be expected that grandparents of children with intellectual disability would feel a greater need to protect their adult children at a time when they are contending such demanding circumstances. It is reasonable to assume that these grandparents may therefore refrain from adding to their children's burden by expressing criticism or personal distress. This is in line with the study by Miller et al. (2012), who reported that a main

theme raised by grandparents was "holding their emotions." According to those authors, grandparents felt that the best way to help their children was to suppress their own emotions and to express positivity, regardless of their own distress and sorrow. Importantly, the present findings show that negative emotions were found to play a significant role in stress only among grandparents of children with disabilities but were negatively associated with growth among all grandparents.

The picture of grandparenthood is often painted in positive colors, leaving the difficulties and frustrations engendered by the role ignored and

silenced. However, in line with several previous studies which also sought to examine negative aspects of grandparenthood (see, e.g., Fingerma, 1998), the present findings indicate that negative emotions are associated not only with less growth but also with lower stress. This suggests that when grandparents of children with disabilities experience high levels of stress, they feel less legitimate in expressing their negative feelings, whereas when they experience low levels of stress, their negative feelings might hinder their ability to experience growth.

Stress and Personal Growth Among Grandparents

Contrary to expectations, findings reveal that levels of stress and personal growth were similar for grandparents of children with and without disabilities, with all grandparents reporting a relatively low level of stress (2.01 and 2.00, on a scale of 1–4, for grandparents of children with and without a disability, respectively) and a relatively high level of personal growth (3.87 and 3.70, on a scale of 1–5, for grandparents of children with and without a disability, respectively). The lack of difference between the two groups on these variables may be the result of many factors. Specifically, these findings may indicate that these grandparents have more in common than assumed. Moreover, research-group participants comprised grandparents of children with intellectual disability between the ages of 3 and 10. The diagnosis was not new, and they had therefore had several years to adapt. Thus, even if these grandparents did play an active role in supporting their adult child and caring for their grandchild with a disability, it did not appear to overshadow their lives and cause added stress or, alternatively, result in a greater sense of growth than that experienced by other grandparents. Additionally, perhaps with age these participants have learned to attend to their own well-being and maintain low stress levels.

Results indicate that even when grandparenthood is accompanied by increased concern and distress, the experience of helping raise a grandchild and watching him or her develop, and the accompanying sense of vitality, love, and joy, can significantly contribute to personal growth. Irrespective of disability, the grandparenting role and the intergenerational connections it can potentially involve can be invigorating and associated with

positive qualities. The lack of difference in stress and growth between these two groups in this study is in line with results obtained by Mirfin-Veitch et al. (1996, 1997), who found that personal resources and family-relationship history are more significant in a family's adaptation than is the presence or severity of a child's disability.

This study questioned the ways in which the link between stress and growth, found in other contexts (see, e.g., Tedeschi & Calhoun, 2004), would potentially apply and take shape among grandparents, and whether this link would be the same among grandparents of children with intellectual disability and those of children with typical development. Indeed, the results indicate an association between stress and growth in both groups. Numerous studies have reported a connection between these two variables in the wake of trauma (see, e.g., Calhoun & Tedeschi, 2001; Harvey, Barnett, & Rupe, 2006). However, recent investigations suggest that positive events and normative life transitions, such as parenthood and grandparenthood, may generate growth-enhancing stress as well (Ben-Shlomo, Taubman-Ben-Ari, Findler, Sivan, & Dolizki, 2010; Taubman-Ben-Ari, Ben-Shlomo, & Findler, 2012; Taubman-Ben-Ari, Findler, & Kuint, 2010). This might explain why a link between stress and growth was found among all the grandparents in the current study, not just grandparents of children with disabilities. In addition to the association that emerged between stress and growth, the patterns of contribution of internal and external resources to these outcomes provide further insight into the similarities and differences between the two groups in our study.

Patterns of Associations With Stress and Personal Growth Among Grandparents

In the current study, all grandparents with high self-differentiation experienced less stress. Apparently, individuals with high self-differentiation were not overwhelmed by emotions or by the pain and distress of other family members, and their routine was not disrupted. These grandparents were therefore less apt to experience stress even in the face of challenging circumstances such as a grandchild's disability. These findings are in line with previous studies which show that internal resources like self-esteem or self-mastery are associated with lower stress and better mental health among

mothers of children with physical disabilities (Florian & Findler, 2001). According to Bowen (1985), in unique circumstances well-differentiated people effectively regulate their anxiety and, therefore, cope better in stressful situations. Furthermore, self-differentiation has been found to be a significant predictor of psychological well-being (Murdock & Gore, 2004). Specifically, under greater stress, significant differences in psychological well-being were found between poorly and well-differentiated individuals.

Our results show that only among grandparents of children with intellectual disability was low family cohesiveness among the extended family related to higher levels of stress. It can be assumed that when there is low family cohesion, the demands posed by children with disabilities may further contribute to lack of unity, by serving as an added source of strain, problems, conflicts, accusations, and anger among family members. Grandparents of children with disabilities are often called upon by their children to display willingness to help out and a sense of caring and shared fate; they are expected to do this alongside peers who are not dealing with such demanding situations. Thus, family cohesion can be a particularly critical resource for them, as it can provide a climate of partnership, caring, and mutual concern and purpose. This correlation might also explain the rather surprising negative association found between stress and negative emotions among grandparents of children with intellectual disability. It is possible that the more comfortable and safe grandparents feel to express negative emotions and frustration in the family, the less stress they experience. Nevertheless, when the extended demands cost more for grandparents, the grandparents experienced increased stress.

Not surprisingly, and in line with the vast literature on the critical role of social support in reducing stress (see, e.g. L. H. Cohen, Hettler, & Park, 1997), the less social support grandparents had, the higher the stress they experienced. This finding was similar among all grandparents, regardless of whether or not their grandchildren had disabilities.

The pattern of associations for growth was similar between both groups of grandparents, highlighting the common characteristics that the birth and subsequent development of any child has on family members, including grandparents. The greater the sense of cohesion, flexibility, positive familial climate, expression of positive emotions,

and openness to change that grandparents display, the greater the growth and vitality they are likely to experience.

As expected, all symbolic aspects of grandparenthood were found to contribute to personal growth. This is primarily because these factors stress the uniqueness of the grandparenting role, which contrasts with the consequences of age that grandparents typically undergo, such as physical decline, loss of friends and family members, and retirement. Thus, we see that grandparenthood can spur growth by giving new meaning to life, offering a sense of continuity, and compensating for experiences grandparents may have missed out as parents. Along the same line of reasoning, the behavioral elements of providing instrumental support and contribution to their grandchild's upbringing afford grandparents a great sense of value and importance within the family and may therefore enhance personal growth.

Among all grandparents, personal growth was associated with high levels of personal investment in the grandparenting role. It appears that individuals who had a sense of purpose and motivation to extend themselves and help their children were also those who experienced personal growth. Interestingly, personal cost was associated with personal growth only among grandparents of children with intellectual disability, indicating that grandparents who were willing to sacrifice and contribute to the lives of their children and grandchildren were also those who reported personal growth. These findings are similar to results of a recent study on grandparents of childhood cancer survivors by Findler et al. (2013), who reported that along with distress and deteriorating health, grandparents took pride in the role they played during the illness and the resulting personal growth. Specifically, through their involvement in their grandchild's illness they became aware of their own strengths, evaluated their surroundings more positively, felt closer to their grandchild and his or her parents and siblings, and found new meaning in life—all signs of personal growth (Findler et al., 2013).

Unique and Combined Contributors to Stress and Personal Growth

Regression analyses added to the finding that among all participants, better health and lower education were associated with higher stress and personal growth. It is not surprising that the

grandparent's state of health was found to be a predictor of perceived growth, as this is a population at an age likely to be experiencing physical decline. It is, however, surprising that better health also predicted higher stress levels. This could potentially be because children may expect more help from healthier grandparents regardless of their age and physical stamina. A desire to fulfill these expectations and not let their children down may place a higher investment and consequently greater stress on grandparents. It is also unpredicted and worth further examination that lower levels of education were associated with both higher stress and greater personal growth.

Gender was associated only with growth. It is expected that grandmothers reported a higher level of personal growth than grandfathers, as women are generally more involved and committed to their role in the family and are more likely to view it as a means of self-fulfillment (Reitzes & Mutran, 2004; Silverstein & Marenco, 2001).

The regression analyses revealed that along with the common associations, each outcome is also predicted by different variables. Specifically, both stress and growth are related to better health, lower level of education, family cohesiveness, and negative emotions. However, whereas stress is associated with the internal resource of self-differentiation, the external resource of social support, and the cost of grandparenthood, growth is associated with gender and the symbolic and behavioral aspects of the grandparenting role. Thus, while lower levels of stress appear to be primarily related to personal and family resources, higher levels of growth are related to aspects of the family, but even more critically, to the perception of the grandparenting role as one that comprises vitality, self-worth, unique contributions, and abilities—all of which are essential features of personal growth.

In conclusion, the comparison between the groups made it possible to identify features common to grandparents in general as well as those more prevalent or unique among grandparents of children with disabilities. This comparison provides a fuller picture of what is undoubtedly a complex experience under any circumstances. Furthermore, this study aimed to correct the nearly exclusive focus in the literature on negativity, stress, and cost of grandparenting children with disabilities, as well as to test the pervasive assumption that the absence of disability results in an almost entirely positive grandparenting experience with nearly no negative affect.

Limitations and Suggestions for Future Research

This study has several limitations. First, it relied exclusively on self-reports. Future research would benefit from additional measures such as observational methods and data obtained from other relevant sources (e.g., family members, professionals). Second, although in many ways Israel is a Western society, it is possible that certain culture-specific factors, such as the great importance placed on intergenerational relationships and closeness, may have influenced the findings. It would therefore be interesting to examine stress and personal growth among grandparents of children with and without disabilities in diverse cultures and ethnic groups. Third, participation was voluntary, and thus the grandparents in our study are not representative of all grandparents. Additionally, a potential for social desirability lies in the self-reporting measures. Fourth, the outcome variables were only assessed at a single point in time. Future studies might adopt a longitudinal design, reassessing participants at additional intervals in order to gain insight into the trajectories of both stress and growth over time. Finally, it would be interesting to examine additional outcome variables relevant to grandparents, such as quality of life and well-being.

Practical Implications

Despite the meaningful familial role that grandparents of children both with and without disabilities play—which until recently was rarely considered by researchers or clinicians (see, e.g., Findler, 2000; Miller et al., 2012)—the present findings stress the need to investigate and address their experience more fully in order to help them cope with the costs and negative feelings that may be generated by their role. Accessing and enhancing behavioral, symbolic, and affective aspects of grandparenthood may mitigate the negative implications and help families benefit from this critical source of support.

Beyond the theoretical value, this study has practical implications. The contribution of grandparents' support to the family has been acknowledged by previous studies (Findler, 2000; White & Hastings, 2004). There is much literature addressing grandparents in terms of the role they take in providing support to their children and grandchildren. The uniqueness of this study is in the way in which it shines a light on grandparents themselves and on their own perceptions and experiences.

Based on these findings, it is recommended that resources should be allocated to increase professional awareness of grandparents' experiences, which in turn affects the grandparenting role in providing assistance and support to families of children in general, and to those with children with disabilities in particular. Interventions can be designed which encourage grandparents to recognize that alongside the physical and emotional toll of a child's condition, their experiences may also offer a positive opportunity for personal growth.

When creating these strategies, it is important to relate to the personal characteristics of grandparents, such as their level of education, health status, and family dynamics. In order to reduce the level of stress, it is important to focus on personal resources such as self-differentiation, as well as on external resources such as social support. In addition, it is important to allow grandparents to express negative feelings. In order to contribute to growth, efforts should be made to encourage the activities grandparents do with their grandchildren and to improve their skills in order to allow a sense of pleasure, vitality, and eventually growth.

Professionals should be made aware of the many possibilities for involving grandparents in individual or group activities run by educators and counselors. These programs should be specially designed for grandparents in order to provide them with information about the child's development and unique needs. These activities should provide grandparents with opportunities to receive emotional support in the process of adjusting to a grandchild with a disability. Emphasis should also be placed on helping grandparents gain the skills of play, guidance, and teaching, which will help them develop open communication and mutual expectations with their own children and thus enable them to provide more support to their grandchildren and adult children (C. A. Gardner, 1996; Hastings, 1997; Sandler, 1998; Scherman et al., 1995). These programs can take place only with policy makers' recognition of the importance of allocating resources to train educators to enhance such professional activities

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Résumés en Français

L'élaboration du cadre des politiques publiques de l'AAIDD

Rud Turnbull et Matthew J. Stowe

La 11e édition de l'AAIDD de « Déficience intellectuelle : définition, classification et systèmes de soutien » décrit un cadre permettant de comprendre la relation entre les politiques et les pratiques publiques en déficience intellectuelle. Ce cadre intègre trois éléments aux politiques et aux pratiques qui ont une influence sur la qualité de vie des individus et de leurs familles, de la société et des systèmes publics. Ces éléments sont représentés par des facteurs sociaux liés aux concepts de base de la politique du handicap et à l'évolution de sa conceptualisation. Les auteurs proposent des modifications pour rendre le cadre plus utile à l'élaboration du « contexte » (Schalock et al., 2010, p. 17) qui touche les personnes ayant une déficience intellectuelle et à la promotion des changements des politiques publiques qui mèneront à la réalisation des « résultats souhaités » (Schalock et al., 2010, p. 171).

Le lien entre le stress des mères d'enfants ayant une déficience intellectuelle et le partenariat famille-école

Meghan M. Burke et Robert M. Hodapp

Bien que les mères d'enfants ayant une déficience intellectuelle (DI) connaissent des niveaux élevés de stress et que les écoles constituent une ressource importante, la relation entre le stress maternel et les services éducatifs demeure inconnue. Lors d'une enquête nationale sur le Web, 965 mères d'élèves ayant un handicap ont répondu à un questionnaire de 163 items portant sur le stress parental. Le type d'enfants, de parents, et les caractéristiques parents-école en lien avec le stress maternel ont été étudiés. Les mères ayant un faible niveau de stress ont rapporté de meilleures relations parents-école et devoir moins défendre leurs intérêts. Cependant, de faibles niveaux de stress ont été principalement rapportés par les mères ayant des relations parents-école de bonnes à excellentes (versus partenariats pauvres à acceptables) et qui ne se livrent à pratiquement aucune (versus une) activité de défense de leurs intérêts. Des niveaux inférieurs

de stress maternel ont également été notés lorsque les enfants présentaient moins de problèmes de comportement, le syndrome de Down, et ne présentant pas d'autisme. Moins de stress a également été rapporté par les mères qui n'avaient pas adopté de garanties procédurales, faisaient partie de minorités, n'avaient pas de névrose et étaient plus extraverties, fiables et ouvertes à de nouvelles expériences. Cette étude a des implications importantes pour les cliniciens et les chercheurs.

Medicaid Personal Care Services pour les enfants ayant une déficience intellectuelle : Quelle aide est fournie? Quand est-elle fournie?

Timothy R. Elliott, Ashweeta Patnaik, Emily Naiser, Constance J. Fournier, Darcy K. McMaughan, James A. Dyer et Charles D. Phillips

L'étude examine la nature et le calendrier des services offerts aux enfants ayant une déficience intellectuelle (DI) identifiés par un nouvel outil d'évaluation et de planification des soins utilisé pour évaluer les besoins des enfants pour *Medicaid Personal Care Services* (PCS) au Texas. La nouvelle procédure d'évaluation résulte d'un règlement judiciaire avec la communauté de défense des droits des personnes. Les participants à l'étude étaient 1 109 enfants âgés de 4 à 20 ans avec un diagnostic de déficience intellectuelle, qui ont été évalués entre janvier et avril 2010. Le besoin d'aide est plus élevé le samedi et le dimanche, lorsque les services scolaires ne sont pas disponibles. Des différences dans les modèles de services pour les enfants qui varient en fonction de la gravité de la DI ont été rapportées. Les résultats de la présente étude ont des implications pour les politiques et les programmes qui desservent les familles avec des enfants ayant une DI.

L'expérience du stress et de la croissance personnelle chez les grands-parents d'enfants présentant ou non une déficience intellectuelle.

Liora Findler

L'objectif de cette recherche était d'étudier les contributions des ressources internes et externes au stress et à la croissance personnelle chez des grands-

parents d'enfants présentant ou non une déficience intellectuelle. Quarante-deux grands-parents d'enfants ayant une déficience intellectuelle et 105 grands-parents d'enfants n'ayant pas une déficience intellectuelle ont complété les échelles suivantes: *Multidimensional Experience of Grandparenthood*, *Multidimensional Scale for Perceived Social Support*, *Level of Differentiation of Self Scale*, *Family Adaptability and Cohesion Evaluation Scale*, *Perceived Stress Scale* et le *Posttraumatic Growth Inventory*. Les résultats indiquent que les différences parmi les groupes reposent sur une plus grande quantité d'émotions négatives chez les grands-parents d'enfants n'ayant pas de déficience intellectuelle. De plus, le stress et la croissance sont reliés au fait d'avoir une meilleure santé, un niveau d'éducation moindre, une cohésion familiale et des émotions négatives. Toutefois, tandis que le stress est associé à la ressource interne d'auto-différenciation, à la ressource externe du soutien social et au fait d'être grand-parent, la croissance, de son côté, est associée au genre et aux aspects symboliques et comportementaux du rôle de grand-parent. Cette étude avait pour but de corriger l'emphase presque exclusive dans la littérature sur l'aspect négatif, le stress et le fardeau que peuvent engendrer le fait d'être grands-parents d'enfants avec une déficience intellectuelle. Elle avait aussi pour but de rectifier l'hypothèse persistante selon laquelle l'absence de déficience intellectuelle chez les petits-enfants entraîne nécessairement une expérience presque toujours positive dans son ensemble, avec presque aucun affect négatif.

Peer-Mentored Preparedness (PM-Prep): un nouveau programme de préparation aux catastrophes naturelles pour les adultes vivant de façon autonome dans la communauté

David Paul Eisenman, Alicia Bazzano, Deborah Koniak-Griffin, Chi-hong Tseng, Mary-Ann Lewis, Kerry Lamb et Danise Lehrer

Les auteurs ont étudié un programme de promotion de la santé appelé PM-Prep (Peer-Mentored Preparedness), qui a été conçu pour améliorer la préparation aux catastrophes naturelles chez les adultes vivant de façon autonome dans la communauté. Le PM-Prep se compose de quatre classes de 2 heures co-animées par un éducateur de la santé et des pairs mentors. Les adultes ont été assignés aléatoirement à un groupe expérimental ou à une

liste d'attente. Les connaissances en matière de sécurité en cas de tremblement de terre et de préparation des fournitures ont été évaluées avant l'intervention ainsi qu'un mois après l'intervention (N = 82). Les adultes dans le groupe expérimental ont augmenté de manière significative leur préparation de 19%, passant de 56% à 75% ($p < 0,0001$), et amélioré leurs connaissances (réponses correctes) de 8%, passant de 79% à 87% ($p = 0,001$). Ceci est le premier programme de mentorat par les pairs, ciblé, ainsi que le premier programme de préparation aux catastrophes adapté et testé auprès de cette population.

Leçons apprises de nos aînés: comment étudier la polypharmacie chez les populations ayant une déficience intellectuelle

Jessica N. Stortz, Johanna K. Lake, Virginia Cobigo, Hélène M. J. Ouellette-Kuntz et Yona Lunskey

La polypharmacie est l'utilisation concomitante de multiples médicaments incluant à la fois des psychotropes et non-psychotropes. Bien que la polypharmacie soit parfois indiquée cliniquement, elle peut avoir bon nombre de conséquences négatives, incluant la non-adhésion à la médication, des effets nocifs ainsi que des interactions médicamenteuses indésirables. L'objectif de cet article était d'obtenir une meilleure compréhension de la façon d'étudier la polypharmacie chez les personnes ayant une déficience intellectuelle). Pour se faire, une revue de la littérature au sujet de la polypharmacie chez les aînés et les personnes ayant une DI a été effectuée afin de mettre en lumière les méthodes et approches de recherche à recommander pour de futures études de la polypharmacie chez les personnes ayant une DI. Les résultats ont identifié une variabilité significative dans les méthodes utilisées pour étudier la polypharmacie, autant sur le plan des définitions de la polypharmacie, des échantillons étudiés, des stratégies d'analyse, que des variables incluses dans ces dernières. Quatre leçons méthodologiques précieuses sont ressorties afin de solidifier la recherche future en matière de polypharmacie chez les personnes ayant une DI. Celles-ci comprennent l'utilisation de définitions cohérentes de la polypharmacie, l'implantation de stratégies d'échantillonnage basées sur la population, le développement de lignes directrices cliniques ainsi que l'importance d'étudier des variables associées.

Résumés en Español

Elaborando el Marco de Políticas Públicas de la AAIDD

Rud Turnbull and Matthew J. Stowe

La 11^a edición de Discapacidad Intelectual de la AAIDD: Definición, Clasificación y Sistemas de Apoyo describe un marco para comprender la relación entre las políticas públicas y la práctica. El marco incorpora tres aportes en las políticas públicas y la práctica con alcances en la calidad de vida de las personas y sus familias, la sociedad y los distintos sistemas. Los aportes son factores sociales, conceptos claves sobre política para la discapacidad y cambios en las conceptualizaciones sobre discapacidad. Aceptamos el marco de premisas básicas, pero proponemos mejoras para hacer el marco útil para lo propuesto en la elaboración del “contexto” (Schalock et al., 2010, p. 17), que afecta a las personas con discapacidad intelectual y “promociona las políticas públicas que conducirán a alcanzar los objetivos deseados en los resultados” (Schalock et al., 2010, p. 171).

Relacionando el Estrés de las Madres de Niños con discapacidades del Desarrollo asociada a la Familia y la Escuela

Meghan M. Burke and Robert M. Hodapp

Aunque las madres de niños con discapacidad intelectual y del desarrollo (DID) experimentan altos niveles de estrés constituyendo la escuela un importante recurso en esto, la relación entre el estrés materno y los servicios educacionales permanece aún desconocida. Respondiendo a una encuesta online realizada a nivel nacional, 965 madres de estudiantes con discapacidad completaron un cuestionario de 163 ítems sobre estrés en los padres. Examinamos qué característica de los niños, padres y padres-escuela se correlacionaron con el estrés materno. Las madres con menores niveles de estrés informaron de mejores relaciones entre padres-escuela y bajos niveles de apoyo a los padres. Sin embargo, los bajos niveles de estrés fueron predominantemente mostrados por madres con una excelente o buena relación entre padres-escuela (versus una pobre o adecuada relación) y quienes no se comprometieron prácticamente (vs. ninguna) en ninguna actividad. Los niveles de estrés maternal

fueron más bajos cuando los niños tuvieron menos problemas conductuales, síndrome de Down, y sin autismo. Un menor estrés fue también descrito por las madres que no habían promulgado las garantías procesales, ellas fueron minoría y promediaron un bajo puntaje en conductas neuróticas, se mostraron más extrovertidas, seguras y abiertas a nuevas experiencias. Este estudio tiene importantes implicancias para profesionales e investigadores.

Servicios de Cuidado Personal Medicaid para Niños con Discapacidad Intelectual: ¿Qué Asistencia es Entregada? ¿Cuándo esta Asistencia es Entregada?

Timothy R. Elliott, Ashweeta Patnaik, Emily Naiser, Constance J. Fournier, Darcy K. McMaughan, James A. Dyer and Charles D. Phillips

Describimos sobre la naturaleza y temporalidad de los servicios entregados a los niños con discapacidad intelectual (DI) identificados por una nueva y comprensiva herramienta de evaluación y cuidado utilizada para evaluar las necesidades de los niños en relación a los servicios de Cuidado Personal Medicaid (PCS) en Texas. El nuevo procedimiento evaluativo fue el resultado de un acuerdo legal con apoyo comunitario. Los participantes de este estudio fueron 1,109 niños de entre 4 y 20 años de edad con un diagnóstico de discapacidad intelectual, los cuales fueron evaluados entre enero y abril de 2010. La necesidad de asistencia es mayor los días sábados y domingos, cuando los servicios escolares no están disponibles. Informamos también diferencias en patrones de servicios para los niños, según varía la severidad de la DI. Finalmente, consideramos las implicancias de nuestros resultados para políticas y programas que atienden a familias con niños con alguna DI.

La Experiencia de Estrés y Crecimiento Personal entre Abuelos de Niños con y sin Discapacidad Intelectual.

Liora Findler

El objetivo de este estudio fue determinar el impacto de los recursos internos y externos en el estrés y el crecimiento personal de los abuelos de

niños con y sin discapacidad intelectual. Noventa y cuatro abuelos de niños con discapacidad intelectual y 105 abuelos de niños sin discapacidad intelectual completaron las siguientes escalas: Experiencia Multidimensional de los abuelos; Escala Multidimensional sobre Percepción de Apoyo Social; Escala personal de Nivel de Diferenciación, Escala de Evaluación de Adaptabilidad y Cohesión Familiar, Escala de Estrés Percibido y el Inventario de Crecimiento Postraumático. Los resultados indican que las diferencias de grupos se reflejan en altas emociones negativas entre los abuelos de niños sin discapacidad intelectual. Además, tanto el estrés como el crecimiento están relacionados con una mejor salud, menor nivel educacional, cohesión familiar y emociones negativas. Sin embargo, mientras el estrés es asociado con los recursos internos de autodiferenciación, los recursos externos son asociados al apoyo social y al costo de ser abuelo; el crecimiento es asociado con el género y los aspectos simbólicos y de la conducta propia del rol de abuelo. Este estudio intentó por una parte corregir el enfoque de la literatura existente casi exclusivamente centrado en la negatividad, el estrés y la carga del ser abuelo de niños con discapacidad intelectual y por otra parte evaluar la suposición generalizada de que la ausencia de discapacidad conlleva casi totalmente a una experiencia positiva de ser abuelo con escasos efectos negativos.

Preparación Tutelada de Pares (PM-Prep): Un nuevo Programa de Vigilancia ante Desastres para Adultos Viviendo Independientemente en la Comunidad

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Los autores estudiaron un programa de promoción de la salud llamado PM-Prep (Par- Tutelado Prep), el cual fue diseñado para mejorar el estado de alerta y vigilancia ante los desastres entre adultos que viven de forma independiente en la comunidad. PM-Prep consiste en cuatro clases de dos horas coenseñadas por un educador de salud y pares tutores. Los adultos fueron distribuidos aleatoriamente en un grupo experimental o un grupo de

control de lista de espera. El conocimiento de seguridad ante terremotos y manejo de útiles de alerta fueron evaluados antes de la intervención y un mes después de la intervención (N= 82). Los adultos en el grupo experimental incrementaron su capacidad de vigilancia en 19 puntos porcentuales, de un 56% hasta completar un 75% ($p < .0001$), y mejoraron su conocimiento en 8 puntos porcentuales desde 79% a 87% correcto ($p = .001$). Este es el primer programa de mejora de la vigilancia ante los desastres tutelado por pares focalizados y dirigido a esta población.

Lecciones aprendidas de nuestros mayores: Cómo estudiar la polifarmacia en poblaciones con discapacidad intelectual y del desarrollo.

Jessica N. Stortz, Johanna K. Lake, Virginie Cobigo, Hélène M. J. Ouellette-Kuntz and Yona Lunsky

La polifarmacia es el simultáneo uso de múltiples medicamentos, incluyendo drogas psicotrópicas y no psicotrópicas. Aunque esto puede ser a veces clínicamente indicado, la polifarmacia puede tener una serie de consecuencias negativas, incluyendo la falta de adherencia de medicamentos, reacciones adversas e interacciones no deseadas entre medicamentos. El objetivo de este artículo fue obtener una mejor comprensión de cómo estudiar la polifarmacia entre las personas con discapacidad intelectual y del desarrollo (DID). Para esto, revisamos la literatura sobre polifarmacia en adultos mayores y personas con DID para guiar abordajes de investigaciones futuras y métodos en polifarmacia en personas con DID. Los resultados indicaron significativa variabilidad en los métodos utilizados para estudiar la polifarmacia, incluyendo las definiciones de polifarmacia, las muestras estudiadas, las estrategias de análisis y las variables incluidas en aquellos análisis. Emergieron cuatro valiosas lecciones metodológicas para fortalecer las investigaciones futuras en la polifarmacia en personas con DID. Éstas incluían el uso de definiciones consistentes sobre polifarmacia, la implementación de estrategias de muestreo basadas en la población, el desarrollo de guías clínicas, y la importancia de estudiar las variables asociadas.

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