Social worker perception of grandparent involvement where a parent has an intellectual disability

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ABSTRACT

Background: Family members of parents with intellectual disabilities (ID) are viewed as their main source of support. However, the existence of family involvement itself does not guarantee that such support will be beneficial.
Aims: This study draws on the perspectives of social workers to describe and evaluate involvement by Israeli family members (grandparents) in the lives of their adult children with ID (parents with ID) who themselves have become parents.
Method: A thematic analysis was conducted in 21 semi-structured interviews with social workers serving parents with ID through social service departments.
Results: From the social workers' perspectives, grandparent attitudes regarding their adult children with ID procreating and parenting ranged from strong resistance to active encouragement. Two sub-themes of grandparent involvement were identified from the social workers' perspectives: the critical role of grandparent support, and the complex relationships between grandparents and the parents with ID. Two further and interrelated subthemes emerged on the role of social worker engagement with grandparents.
Conclusions: Professionals should be aware that grandparent involvement can either support or undermine the parenting function of parents with ID. Social service professionals need to promote family involvement that empowers parents with ID by supporting their needs and roles, but without supplanting their primary parenting activities.

What this paper adds?

Support systems are vital to the well-being and parental capacity of parents with ID. The International Classification of Functioning, Disability, and Health emphasizes that environmental factors, such as family support, can act either as facilitators or barriers. This study endeavors to understand the impact of support provided to parents with ID by grandparents from the perspective of social workers. This paper adds to the scarce knowledge on this unique issue.

Findings show that from the social workers' perspectives, grandparents expressed interest in the intimate relationships and parenting of their children, the parents with ID. The attitudes of these grandparents ranged from active resistance to their adult children with ID procreating to actively encouraging procreation.

According to social workers, grandparents are highly involved in most cases and comprise the most significant part of these families' support systems. However, in some families, social workers described excessive involvement. Those families usually

exhibited complex relationships between the grandparents and the parents with ID. The complications usually arose from the very close bond between the grandparents and their grandchildren, causing the parents with ID to feel excluded.

Social workers viewed their role as encouraging grandparent involvement with the family while also striving to warrant that such interaction was not excessive.

1. Introduction

Support is crucial for all parents, and in particular parents with disabilities who may require added interventions and services (World Health Organization, 2011). Amongst that population, parents with intellectual disabilities (ID) are considered especially vulnerable (Llewellyn & McConnell, 2002; McGaw, Ball, & Clark, 2002). Evidence suggests that relative to the general parenting population, parents with ID experience poorer psychological well-being, face greater daily challenges, and require increased assistance to enable their functioning (Aunos, Feldman, & Goupil, 2008; Darbyshire & Kroese, 2012). However, even when state-based services and interventions are increased, parents with ID remain largely dependent upon and empowered by support from extended family networks (Traustadóttir & Sigurjónsdóttir, 2008).

The present investigation focuses on involvement by Israeli grandparents (grandparents) in the lives of their adult children with ID who themselves have become parents (parents with ID), and with the children of those parents with ID (grandchildren), from the perspective of social workers.

1.1. Conceptual framework

We utilized the International Classification of Functioning, Disability, and Health (ICF), promulgated by the World Health Organization, as the conceptual framework for this study. The ICF is a bio-psycho-social model that reflects a workable compromise between the medical and social models of disability. The ICF achieves this balance by understanding functioning and disability as a dynamic interaction between health impairments on the one hand, and personal and environmental socio-contextual factors, on the other. Specifically, the ICF views functionality within the specific ecosystems in which people with different levels of impairment must live and act (Bickenbach, Cieza, Rauch, & Stucki, 2012). Support, relationships, services, and policies are each examples of environmental factors that can act either as facilitators or barriers (World Health Organization, 2002, 2011). Support is defined as "resources and strategies that aim to promote the development, education, interests, and personal well-being of a person and that enhance individual functioning" (Schalock et al., 2010, p.105). Support for the existentially crucial social role of parenting has received little attention (Lightfoot & LaLiberte, 2011).

1.2. Support network of parents with ID

Parents with ID are among the most socially excluded parents within their communities (Llewellyn & McConnell, 2002; McGaw et al., 2002). Hence, the ambient social network surrounding these individuals has a vast impact on their well-being and that of their children (Darbyshire & Kroese, 2012; Kroese, Hussein, Clifford, & Ahmed, 2002; Wade, Llewellyn, & Matthews, 2011). Accordingly, extensive research has investigated how social networks function as a support system for persons with ID generally, as well as specifically for parents with ID. Kroese et al. (2002), for instance, found significant associations between social networks and positive improvement in the self-esteem of mothers with ID. They also noted that the social networks of mothers with ID included very few non-family members (Kroese et al., 2002).

Llewellyn (1995) found that social support for parents with ID was largely received from their spouses and other family members. Llewellyn and McConnell (2002) explored the support networks of mothers with ID and determined that family members were most frequently cited as the individuals who were "there for them;" further, that these mothers felt most comfortable in asking for help from family members (Llewellyn & McConnell, 2002). The next most frequently cited source of support were service providers. Llewellyn and McConnell (2002) concluded that, because few mothers with ID could identify supportive ties with friends and neighbors, these mothers were isolated from their local communities and potentially vulnerable if a breakdown occurred in the support provided by their families (Llewellyn & McConnell, 2002).

Traustadóttir and Sigurjónsdóttir (2008) examined the role of extended family members in assisting mothers with ID to parent their children. Notably, they identified female relatives as playing a crucial role—and were even referred to by the biological mothers with ID as 'mothers.' These 'mothers' were non-disabled woman who provided practical and emotional assistance and advocated on behalf of the mothers with ID and their families (Traustadóttir & Sigurjónsdóttir, 2008). Along similar lines, Traustadóttir and Sigurjónsdóttir (2008) emphasized the advocacy role provided by family members as part of their support function. Their activities included negotiating with service professionals and protecting the mothers with ID from the impact of negative attitudes held by professionals and support workers within the health, social, and child protection services (Traustadóttir & Sigurjónsdóttir, 2008).

Despite this generally positive picture, research indicates that the level of support from families varies widely; that some parents with ID receive extensive assistance while others receive little or no help from their extended families (Llewellyn & McConnell, 2002; Sigurjonsdottir & Traustadóttir, 2010). Further, not all support provided by family members was seen as helpful by mothers with ID (Llewellyn, 1995). Kroese et al. (2002), for example, indicated that just over half of the support was seen as very helpful by their interviewees. They concluded that the very presence of social contacts do not guarantee that the received support will be beneficial (Kroese et al., 2002).

Indeed, Tucker and Johnson (1989) posit that social support may have a negative influence that can seriously inhibit effective

parenting. When so averring, they distinguish between competence-promoting support and competence-inhibiting support. Competence-promoting support enhances a mother's sense of her parental competence and recognizes the important role she plays in her child's life. Competence-inhibiting support assumes maternal incompetence and assumes that extensive support is necessary for the sake of the respective children (Tucker & Johnson, 1989). Tucker and Johnson further found that mothers with ID were more effective parents when they were supported by someone who believed they could become more competent, and consequently provided more training. This was in contrast to situations where they were 'supported' by someone who belittled their efforts and did not attempt to develop their skills (Tucker & Johnson, 1989).The majority of participants indicated that the grandparents were mostly helpful, both practically and financially, but that a minority of them usurped parental functions from the mothers with ID and thereby fostered poor relationships.

Booth and Booth (1998) proposed a third notion of competence which they term 'distributed competence.' The term suggests that parenting is mostly a shared activity consisting of interdependent relationships that comprise the actual parenting tasks and provide support to parents with ID in performing their parental roles (Booth & Booth, 1998). From this perspective, parental competence or incompetence is highly linked to the properties and attitudes of social networks encompassing individual parents with ID.

1.3. Study's rationale

Llewellyn, Mayes, and McConnell (2008) suggested that, in contrast to prior research that focused on autonomous experiences of parents with ID, current research ought to be characterized by greater emphasis on the effect of the family, community, and general social context on the lives of parents with ID and their children (Darbyshire & Kroese, 2012; Kroese et al., 2002; Mayes, Llewellyn, & McConnell, 2008). Because we agree with Tucker and Johnson (1989) that the mere existence of a support network is insufficient to predict or bolster parental coping and competence, this study endeavors to understand the impact of support provided by grandparents from the perspective of social workers.

This is the first Israeli study that explores the characteristics of families with parents with ID, their treatment and services, and familial support systems. Hence, the current investigation is exploratory. The first author is a social worker who worked with adults with ID and their families. We believed that social worker perspective provides a wide range and rich data regarding these families. We also acknowledge that this is the first step in exploring the life experience and needs of these families.

This paper also is part of a larger study investigating the attitudes and experiences of Jewish and Muslim Israeli social workers toward parenting with ID among their respective Jewish and Muslim clients. Because of the deep significance of culture in explaining research findings, this study focuses only on Jewish social workers' perspectives working with Jewish parents with ID and their families.

2. Materials and methods

2.1. Design

A qualitative method using semi-structured interviews was chosen to enable the participants to freely relate their experiences and perspectives. Qualitative methods are routinely chosen for studying social and public policy issues when complex needs, behaviors, systems, and cultures need to be analyzed (Ritchie & Spencer, 2002). Qualitative methods are also particularly apt for identifying and understanding underlying attitudes and perceptions among participants and the cultural mores of their societies (Ulin, Robinson, & Tolley, 2004).

2.2. Setting

All interviews were conducted at social service departments operating under Israel's Ministry of Labor, Social Affairs and Social Services. Pursuant to the 1958 Social Welfare Law, municipalities and local authorities are required to maintain social services departments under the auspices of the Ministry. In turn, the Ministry determines policy, initiates legislation, enacts regulations for the operation of social services, supervises services offered by public and private organizations, and supports those service departments.

Social workers rendering services to clients with ID are typically organized into three thematic areas: ID and/or special needs coordinators (ID/SN social workers); social workers assigned to implement the youth law (Youth social workers) or the welfare law (Welfare social workers); and Family social workers. Within smaller social service departments, social workers are characterized as Family social workers (Hovav, Leventhal, & Katan, 2012). Each social services department has management and coordination positions, with the number of staffed positions depending on department size. When regional departments lack a designated ID/SN social worker, Family social workers are assigned to manage cases involving those clients (Social work regulations, article 2, no. 4). Social service departments are also organized to reflect the population and geography of their cliental. This investigation focuses on social workers serving Jewish clients; other research investigates social workers serving Muslim clients.

2.3. Sample

Our opportunity sample, based on convenience, included 21 social workers from across 17 of Israel's social services departments serving primarily Jewish population areas. Table 1 presents the sample characteristics.

Nearly all the interviewees were women, making the cohort compatible with overall gender differences in the social work

Table 1
Sample characteristics.

Characteristic	N(%) or Mean ± SD (range)
Gender	
Men	1 (4.8%)
Women	20 (95.2%)
Age	46 ± 9.72 (33-66)
Years of experience in the social work profession	17 ± 9.30 (5-44)
Position in the department	
ID/SN social workers	11 (52.4%)
Family social workers	3 (14.3%)
Youth social workers	1 (4.7%)
ID/SN *and* social workers to the Welfare law	4 (19%)
Family *and* social workers to the Youth law	1 (4.7%)
ID/SN *and* Family social workers	1 (4.7%)

profession in Israel (Knesset Information & Research Center, 2015). The social workers ranged in age from 33 to 66, with a mean age of 46. Experience in the profession ranged from 5 to 44 years, with a mean score of 17 years of social service practice.

Social workers were contacted directly by the authors by phone and invited to take part in this study. Potential interviewees were identified by a list available online which included their contact information. Participants were recruited from each of Israel's six districts: North district, Haifa district, Tel-Aviv district, center, Jerusalem district and south district. In order to recruit social worker specializing in ID, priority was given to larger social service departments. No incentives were offered.

Responsiveness rate was approximately 1 out of 12. The participants were recruited from the three social worker categories to provide different insights. Family social workers were recruited so that participants from smaller social services departments, which did not have specialized sub-departments relating to persons with ID, could be included.

2.4. Instrumentation

Semi-structured interview guides were developed based on current issues raised by the literature. A preliminary list of key issues to be explored during interviews was produced and examined by three experts in the intellectual disability field. The following four issues were identified and incorporated into the data-collection protocol:

(1) Case descriptions of families in which a parent has ID.
(2) Social worker perceptions of the treatment and services for families where a parent has ID.
(3) Social worker perceptions on the parental capacity of persons with ID.
(4) Social worker perceptions on the rights of persons with ID to create and maintain families.

The data-collection protocol included open-ended questions, for example: "Tell me about your experience in working with clients who are parents with ID", "what kind of support does you clients have?", and "what kind of support does you clients need?",

The gender, age, professional experience, and current positions of the participants were collected.

2.5. Procedure

The study, including interview protocol and guide and ethical considerations (i.e., methodology, informed consent, anonymity, and privacy) was approved by the Research Division of the Ministry of Labor, Social Affairs and Social Services, State of Israel, the governmental entity responsible for reviewing and authorizing such studies.

The interviews were held at the participants' social services departments in a quiet place chosen by the respective participants. Most interviews took place at the participant's own office. The first author who conducted the interviews is a social worker. Her research interests are social policy and disability, and issues related to the social inclusion and human rights of persons with disabilities. Her experience in the disability field began while working as a social worker in one of the largest institutional care facilities for individuals with ID in Israel. She has no prior experience working with parents with disabilities. The researcher had neither professional or personal relationships with the participants.

Over the period October 2016-January 2017, 21 interviews were conducted. Each interview took approximately an hour to complete.

2.6. Data coding and analysis

A thematic analysis identified major themes and sub-themes that arose in response to open-ended questions. Thematic analysis was chosen due to its flexibility. Because the thematic analysis was not bounded by a specific theoretical framework, it provided rich, detailed, and complex data. Data analysis began with transcribing the verbal data, a standard part of data familiarizing processes. Next, initial codes were generated and sorted into potential themes. At the second phase of the analysis, the themes were reviewed to

Table 2

Themes and sub-themes on grandparent involvement with parents with ID.

Theme	Sub-themes
Parents of adults with ID express interest in their children's intimate relationships and parenting (Raised by 16 participants)	• Attitudes ranged from active resistance to active encouragement • Positive attitudes are associated with extensive support
Grandparent involvement (Raised by 19 participants)	• The critical role of grandparent support • Complex relationships between grandparents and their children, the parents with ID
The role of social workers working with grandparents (Raised by 15 participants)	• To encourage grandparent involvement • To ensure grandparent involvement is beneficial

understand how they fit together, and what comprehensive story appeared throughout the data (Braun & Clarke, 2006; Denzin & Lincoln, 2011; Holloway & Todres, 2003). Appropriate quotes were incorporated into the results section to highlight the themes under discussion.

3. Findings

Families with one or more parent with ID are rare in Israeli Jewish society. Jewish families that do have parents with ID are characterized as multi-problem families. In many such couples, the spouse of the person with ID is likewise a person with ID or borderline intellectual functioning, or a mental disability. Among the additional problems that were described by social workers are frequent marital conflicts, domestic violence, poverty, and children at risk.

Our findings indicate that, according to social workers who serve parents with ID, grandparents expressed interest in the intimate relationships and parenting of their children, the parents with ID. The attitudes of these grandparents ranged dramatically from active resistance to their adult children with ID procreating to actively encouraging procreation. All the families described by the social workers involved grandparents who went to great lengths to support their grandchildren—at times too extensively and to the detriment of the parents with ID. Families certainly exist wherein parents with ID do not receive family support, but those families were not described by the interviewees and are beyond the scope of this study. Instead, we focused on the complexity of family involvement in the lives of parents with ID from their social workers' perspectives. Two sub-themes of social workers' perception on family involvement were identified: the critical role of grandparent support and the complex relationships between grandparents and their adult children, the parents with ID. Two further interrelated subthemes emerged on the role of social workers in their engagement with grandparents: encouraging grandparent involvement, and ensuring that such grandparent involvement is beneficial. Table 2 summarizes the themes and sub-themes that emerged from the data.

3.1. Grandparents express interest in their children's intimate relationships and parenting

Our findings indicate that, according to social workers who work with parents with ID, grandparents express interest in the intimate relationships and parenting of their adult children with ID. As one participant stated: *"They are very involved and worried about their children's ability to be partners and parents. There are some families where it's more challenging for them to understand their children's need for partnership and family"* (ID/SN *and* social workers to the Welfare law).

Notably, the attitudes of grandparents vary as to the prospects for their adult children with ID effectively creating and maintaining a family. Some expressed absolute resistance, while others enthusiastically supported the idea. One social worker described a male client with ID living in a "successful out-of-home placement" and married to a woman with ID, whose parents *"accepted his relationship, but at the same time stated that he will not become a parent."* (ID/SN *and* social worker to the Welfare Law).

Conversely, some grandparents actively encouraged their children with ID to start a family, either with or without a spouse. One interviewee related her experiences with multiple clients: *"I was surprised that I met parents who really encouraged their children with ID to continue the family. They really push their children—and then they end up raising their grandchildren. I have at least four clients who are mothers with ID. And their mothers, the grandmothers, are very involved in raising the children and are very happy to take on this role. They feel they've had a success—that their child with disabilities was able to bring them a grandchild"* (ID/SN social worker). Another participant shared her experiences of grandparents who not only encourage their children to procreate but who subsequently provide extensive support: *"I have a client with ID who has significant language, communication, and mobility impairments, who has endured several crises over the years. However, she comes from a very supportive household. She is forty years old and still lives with her family, and she became pregnant through a sperm donor at her parents' encouragement. Today her son is in kindergarten. The mother and her son live with the grandparents, and the grandmother is a very important figure in the child's life"* (ID/SN social worker).

3.2. Grandparent involvement

Two sub-themes of grandparent involvement were identified from social workers' view: the critical role of grandparent support, and the often-complex relationships between grandparents and their children, the parents with ID.

According to social workers, in most cases grandparents are highly involved, comprising the most significant part of these

families' support systems. One participant described her client's parents as wanting their daughter with ID to become a mother and offering to support her through the parenting process. In her view, this rapport was appropriate because *"Grandparents have an important role in any family, not just those where their children have ID, but even more so when the disability is present. It is very important for the social workers to hear the grandparents' perspective, as they know their children better than anyone else"* (ID/SN social worker).

Furthermore, most families were described as having the parents with ID living in proximity to their parents, the grandparents, who in turn assisted significantly in raising their grandchildren. Indeed, many families featured the three generations living together in the same house, such that the grandparents were intimately involved in raising the children. In addition, some grandparents were financially supporting their children, the parents with ID; other grandparents acted as supported decision makers, thereby enabling their children, the parents with ID, to have greater agency in their daily lives.

However, in some families, social workers described excessive involvement. Those families usually exhibited complex relationships between the grandparents and the parents with ID, and mainly implicated the grandmothers. The complications usually arose from the very close bond between the grandparents and their grandchildren, causing the parents with ID to feel excluded: One participant described the experiences of her client, a mother with ID, who *"has a difficult/challenging relationship with her mother. The daughter is jealous of her mother–her son has a very close relationship with his grandmother, and the daughter envies this connection. There is tension between them... the daughter instructed me not to speak with her mother"* (ID/SN social worker). Added examples of excessive involvement include grandparents attending parent-teacher meetings or taking grandchildren to a doctor or to meetings with child development services without parental consent or knowledge.

Another participant described the difficulties of a relationship at length: *"The grandparents provide a lot of support. They've ended up becoming the primary caregivers, usurping her role as mother. She felt useless, and no one respected her role as the parent or listened to her opinions. Instead of spending time taking care of their daughter, the grandparents turned all of their attention to their grandson, showering him with love. Where is the daughter in this situation? What about taking her to therapies and classes? She was rejected, physically and mentally. It is hard for the grandparents to teach their children how to be better parents, so they take on these roles themselves, rather than empowering their children."* (ID/SN social worker).

3.3. The role of social workers engaging with grandparents

Two subthemes emerged from the data on the role of social worker engagement with grandparents. Further to the previous theme of grandparent involvement and its subthemes, the social workers viewed their role as encouraging grandparent involvement with the family while also striving to warrant that such interaction was not excessive. The interviewees viewed this balance as somewhat tricky because the desired ultimate result was to empower the parents with ID to perform their parental roles better while also safeguarding against the grandparents detrimentally interfering with their children's parenting.

Overall, the interviewees viewed the grandparents as playing a necessary and significant role in supporting the parents with ID. This role was frequently described in terms of partnership: *"The grandparents are partners in the care. They're often the legal guardians of their adult children, and are thus very involved in their decision-making"* (ID/SN social worker). Notably, although the social workers encouraged grandparent involvement, they acknowledged that any contributions had first to be approved by their clients: *"I will ask the mother for permission to reach out to them, but it is up to her. I want to reach out to them in hopes that they will be a support system for her, but it has to be her call. If she says no, I cannot reach out"* (ID/SN social worker).

Participants likewise acknowledged that partnerships between grandparents (as part of the local community) and parents with ID (as their clients), raises important questions for social work practice, since grandparent involvement may sometimes be excessive: *"There are certainly cases* over over-*involvement where the parents with ID are left with no autonomy, even in areas where they can and should be able to make their own decisions. On the other hand, sometimes the grandmother holds the family together. We try to juggle these two realities, noting that the parent needs to be involved, but that the family would fall apart without the grandparents' involvement"* (ID/SN and social worker to the Youth Law).

Working with the grandparents to precipitate beneficial family involvement was described by social workers as an essential element in supporting their clients, the parents with ID. One interviewee shared that: *"Usually the grandparents' involvement is total, they often make decisions in their children's place. I'm not judgmental of this, but I have noticed that I often have to go through a process of interventions with the grandparents; this often makes up the bulk of my work"* (ID/SN social worker). Another participant describes her frequently repeated quandaries: *"These are dilemmas that I face every day. I work with adults who are over 18, and it can be very complicated. On the one hand they are legally adults, but on the other hand they sometimes lack the capacity to be parents. On the one hand, the mother needs to be given the opportunity to make decisions; on the other hand, if there is a legal guardian involved, it is important to also listen to the guardian's opinion. These are not simple situations"* (ID/SN social worker).

4. Discussion

Contemporary studies of parents with ID increasingly focus on the social environment supporting the exercise of their rights to marriage, creating families, and parenting (Llewellyn et al., 2008). This shift in emphasis reflects the theoretical underpinnings of the ICF model which understands functioning and disablement as an interconnected dynamic involving health conditions, and the fundamental impact of contextual factors. Among such considerations are family relationships and state-sponsored support. The ICF thus acknowledges that environment factors can be either facilitators or barriers (World Health Organization, 2002, 2011). However, family support as enabling parents with ID, has received relatively little attention in the literature (Lightfoot & LaLiberte, 2011). The present investigation adds to this scarce knowledge by illuminating grandparent involvement in the lives of parents with ID from

their social workers' perspective.

Social workers' experiences indicate that grandparents—the parents of adults with ID in our study—express interest in their children's intimate relationships and parenting; their attitudes ranged from strong resistance to vigorous encouragement. Two sub-themes of family involvement were identified from social workers' perspective: the critical role of grandparent support and the complex relationships between grandparents and their children, the parents with ID. Two further interrelated subthemes emerged on the role of social workers working with grandparents: encouraging grandparent involvement, while concurrently ensuring that such involvement is beneficial to the family, and especially the parents with ID.

The first theme that emerged from the data was that according to social workers, grandparents expressed interest in their adult children's intimate relationships and parenting. Their attitudes ranged from opposing procreation by their adult children with ID to enthusiastically encouraging their parenting. All the families related to us by the social workers involved grandparents who provided support, sometimes too extensively. Previous studies showed that grandparent attitudes toward parenting by their own adult children with ID remain negative, and that many grandparents still support sterilization as a form of contraception (Aunos & Feldman, 2002). Cuskelly and Bryde (2004), who assessed attitudes toward the sexuality, personal relationships, marriage, and parenthood of adults with ID among those individuals' parents (i.e., grandparents), found that grandparents hold conservative attitudes and were less positive about parenthood than about other aspects of sexuality. Yet, despite any negative attitudes, family members are still viewed as the main source of support for parents with ID (Llewellyn & McConnell, 2002; Llewellyn, 1995).

Our findings emphasize that albeit the general negative attitudes toward persons with ID's sexuality and parenthood, some family member do express positive view and positive action to encourage persons with ID to fulfil their desire to become parents. Furthermore, our findings confirm the complexity of grandparents' position and possible conflicted one. It seems that even if they initially resist the idea of parenthood for their son or daughter with ID, they don't deny their role as their main source of support.

The second theme, focused on grandparent involvement from social workers' view, included two sub-themes: The critical role of grandparent support and the complex relationships between grandparents and their adult children, the parents with ID. As in previous studies (Llewellyn & McConnell, 2002; Llewellyn, 1995), our data indicated that in most cases the grandparents are highly involved, comprising the most significant part of these families support systems.

In some families, however, the grandparent involvement was described as excessive and overbearing, implicating complex relationships between the grandparents and their children, the parents with ID. The thorniness seemed to originate from the very close bond between the grandparents and the grandchildren, a bonding that made the parent with ID—the biological mother, and socially assigned primary caregiver—feel excluded. This finding confirms that the mere presence of social contacts does not inexorably guarantee beneficial support (Booth & Booth, 1998; Kroese et al., 2002; Llewellyn, 1995; Tucker & Johnson, 1989). It also reinforces the distinction made by Tucker and Johnson (1989) between competence-promoting support and competence-inhibiting support.

We believe that the excessive involvement that characterizes many family relations among parents with ID reflects competence-inhibiting support that assumes parental incompetence (Tucker & Johnson, 1989). Conversely, Tucker and Johnson found that competence-promoting support was associated with more effective parenting by mothers with ID (Tucker & Johnson, 1989). We agree with Tucker and Johnson, and therefore conclude that a positive perception regarding the parental capacity of parents with ID, and specifically the expressed belief that their parenting skills can be developed and strengthened, forms the cornerstone of beneficial support and should be encouraged by social service professionals.

As a counter-example, Mayes et al. (2008) described the phenomenon of active negotiation by mothers with ID in creating their social support networks for themselves and for their children. These women sought practical assistance from those they chose to live with, while also actively distancing themselves from individuals—including family—they believed would try to usurp care of their children (Mayes et al., 2008). Further, the mothers with ID purposely negotiated a support network that included people who recognized their central importance in their children's' lives. The authors interpreted this activity as challenging the stereotype of women with disabilities being passive or dependent on the support of others (Mayes et al., 2008). The present study, in sync with these findings, adds to rare evidence found in the literature of the existing and potential agency of parents with ID.

Further, Traustadóttir and Sigurjónsdóttir (2008) emphasized the advocacy role performed by family members as part of their support. Our findings suggest that social workers should promote family involvement that empowers parents with ID by supporting their parental needs, while also scrupulously guarding against these individuals being excluded from performing their parenting roles. Professionals should therefore be made more sensitive to the fact that grandparent involvement may either support or undermine parents with ID.

Social services that support parents with ID and their families should adopt the notion of 'distributed competence' made by Booth and Booth (1998) as a framework for working with parents with ID and the grandparents. 'Distributed competence' means that parenting is a shared activity consisting of interdependent relationships that comprise the actual parenting tasks and provide support to parents with ID in performing their parental roles (Booth & Booth, 1998).

Finally, we acknowledge some unavoidable limitations of this study. First, this study examined social workers serving primarily Jewish population areas. Due to the multicultural nature of Israeli society, an additional analysis will be drawn that focuses on grandparent involvement in the families of parents with ID within Israel's Muslim society. Second, as with any qualitative study, the reported findings arise from our sample and cannot responsibly be generalized to the entire population of Israeli Jewish families wherein a parent has ID. Third, and again as with any qualitative study, the authors' interpretations of data are affected by personal characteristics and experience. Hence, we recognize that different conclusions could be derived by others from the same data.

Future research should explore the experiences and perceptions of parents with ID with respect to their own parents, the grandparents, and their involvement in family life. Similarly, the experiences and perceptions of grandparents who support their adult children with ID, the parents with ID, and their grandchildren, should be explored.

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