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Formal and Informal Support for Parents of Children With Severe Intellectual Disability

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ABSTRACT

Parents of children with severe and profound intellectual disabilities (SPID) experience an enormous burden of care, which affects family function and well-being. Formal and informal support can contribute to the family's functioning. This study explores perceived support among these parents. Sixty Israeli parents of children with SPID completed questionnaires on (1) Family quality of life (FQoL); (2) Shame and guilt; and (3) Parental stress. They were also asked to respond to open-ended questions regarding their experiences with formal and informal support. Parents' statements underwent inductive content analysis. Parents rated the importance of formal support as very high, yet the attainment of the domains was rated below average. The importance of informal support was rated high, and its attainment was above average. The child's medical challenges increased parental personal responsibility, which mediated higher levels of parental shame, guilt, and stress. Informal, but not formal support, mitigated this effect, reducing the association between medical problems and parental stress and guilt. Parents expressed the need for reliable and accessible support systems to ensure stability for the child and family. Disability-related services need to be strengthened to better meet the expectations and needs of parents of children with SPID. Professionals should assess and encourage the utilization of extended family and community resources.

1 | Introduction

The importance of support for caregivers of children with disabilities is well documented (Cheng and Lai 2023; Migerode et al. 2012). While research has focused on support as a broad concept, less is known about the role of different types of social support, or about parents' experiences when caring for children with severe and profound intellectual disability (SPID). Children with SPID have intellectual and adaptive functioning approximately four standard deviations below the mean, and consequently need support in all environments (Patel et al. 2020). SPID is also associated with other impairments, including limited acquisition and use of motor, adaptive, or social skills (Nakken and Vlaskamp 2007; Van Timmeren et al. 2017).

In recent years, health policy advocates have promoted a family-centered approach to the care of children with SPID (Coyne et al. 2016; Smith et al. 2015; McCarthy and Guerin 2022). Thus, their parents are encouraged to collaborate closely with professionals and become more involved in the daily management care (De Geeter et al. 2002; Doyle 2022), whether at home, in an educational setting (Miller et al. 2019; Vanderkerken et al. 2021), or in residential placement (Jansen et al. 2017).

This study is part of a larger project exploring the quality of life of families with children with SPID.

Family members of children with SPID often experience significant psychological and social burdens (Luijkx et al. 2019). Parents of children with intellectual or developmental disabilities (IDDs) report high stress levels (Staunton et al. 2023), affecting their health quality of life (Baykal et al. 2019; Masefield et al. 2020). This is particularly evident among families of children with SPID, which affects approximately 4% and 2% of the intellectually disabled population, respectively (Maulik et al. 2011).

Guilt or shame may also be experienced by parents of children with SPID. Their unique needs require parents to invest significant energy that may prevent them from investing in their other children and family members (Broomhead 2013; Findler et al. 2016), further exacerbating their sense of burden (Dieleman et al. 2019).

Support is a key resource necessary for the functioning of both children with disabilities and their parents (Staunton et al. 2023; Geuze and Goossensen 2021; Peer and Hillman 2014a). Social support has been described as a multidimensional construct comprising formal (medical, therapeutic) and informal support (family, friends) (Mantri-Langeveldt et al. 2019). High levels of social support were found to decrease parental stress (Staunton et al. 2023; Patton et al. 2018; Peer and Hillman 2014b), while low levels were linked to physical and mental health symptoms (Cantwell et al. 2014; Gallagher and Whiteley 2012).

Studies have found that the relationship between "child-centric" factors such as symptom severity and parental mental health difficulties was mediated by socioeconomic support for parents to children with autism (Falk et al. 2014), suggesting that these variables do not necessarily demonstrate a linear predictive relationship. Halstead et al. (2018) explored whether perceived social support, positive perceptions, and coping style could serve as protective factors for children with IDDs and other comorbidities and found that only perceived social support did—affecting the relationship between child behavioral and emotional problems and maternal depression, life satisfaction, and positive affect.

Importantly, it is not clear whether both formal and informal support serve as protective factors for parents of children with SPID (Boehm and Carter 2016a). Moreover, it is unclear whether previous findings on social support refer to the importance of social networks or to their perceived or received support (Uchino 2009). Formal support for families of children with SPID is considered especially important (Kilburn and Shapiro 2020; Wakimizu and Fujioka 2024). It has been found to positively affect both family and child functioning (Bailey et al. 2007; Cassidy et al. 2008); family quality of life (Davis and Gavidia-Payne 2009); stress (Kilburn and Shapiro 2020); and resilience (Peer and Hillman 2014a). However, few studies have addressed the difference between formal and informal support among caregivers of children with severe IDDs, and their results are mixed. White and Hastings (Geuze and Goossensen 2021) reported that informal sources of support were most reliably associated with parental well-being, while access to services and professional support was not. Others also found negative experiences and tensions with care professionals. Still, other studies reported a positive impact of formal support on parents' tasks and satisfaction (Tadema and Vlaskamp 2010). An in-depth study described relationships with friends as limited in their availability, while parents reported positive experiences with professionals, citing expertise, patience, and respect (Sedláčková et al. 2023). Finally, a series of studies on the relationship between four parents and their formal support resources (Jansen et al. 2017, 2013, 2014) found that maternal perceived burden of care could be more effectively reduced with formal support.

Given the complexity that children with SPID present and the need to further enhance the support for this group, the purpose of this study was to examine the role of social support in the relationship between child-specific characteristics (such as illness complexity) and the parents' emotional burden, including the alleviation of self-conscious emotions and stress. Therefore, we address the following questions: (1) What significance do parents of children with SPID attribute to formal and informal support, and to what extent are these types of support provided in practice? (2) What role do formal and informal social support play in alleviating these parents' emotional burden? (3) What are parents' experiences accessing these forms of support?

2 | Methods

This study is part of a larger project exploring the FQoL of children with SPID (Karni-Visel et al. 2023). This study employed a sequential explanatory mixed-methods design, which involves the collection and integration of quantitative and qualitative data to generate comprehensive and theoretically grounded insights (Creswell and Clark 2017; Creswell and Plano Clark 2023). The quantitative phase served as the primary component of the study, followed by a qualitative phase aimed at expanding and contextualizing the quantitative findings.

2.1 | Participants and Procedure

The criteria for inclusion were parents or grandparents of a child with SPID who manage their daily care. The child was required to meet the following conditions: (1) Age: 2–18 years; (2) SPID (DQ/IQ < 35), based on medical records and/or the Israel Ministry of Welfare's diagnostic committee evaluation. The children attended specialized settings such as rehabilitative daycare centers, special education kindergartens, and special care schools. A subset of these children lived in residential care, yet received partial care from their parents on a daily or weekly basis.

Parents of children with SPID were invited to participate in the study. Due to the sensitive nature of the study, the research team collaborated with social workers experienced in disabilities. They received the caregivers' contact information from the health maintenance organization (HMO) or residential care staff and made initial contact to obtain approval and scheduled a meeting at the participants' preferred location or a phone call. Written informed consent was obtained. Medical data regarding the child's DQ/IQ were obtained from the HMO or residential care facility, while data related to other medical/behavioral issues were collected using the FQoL (Brown et al. 2000).

The cohort included 60 caregivers (46 mothers, 13 fathers, and one grandfather) aged 24–62 (*M* = 38.17, *SD* = 9.06). Twelve participants were couples who completed the questionnaires separately. The sample was ethnically diverse, with a high proportion of Arab parents (60%). Note that Arabs represent 20.1% of Israel's population (Central Bureau of Statistics 2024). This over-representation is consistent with national data showing that the rate of intellectual disparity has been attributed to several factors, including high rates of consanguineous marriage, hereditary conditions, low socioeconomic status, and limited awareness of certain genetic disorders (Sandler-Loeff and Shahak 2006; Sharkia et al. 2010; Myers JDC 2025).

The participants represented 92% of those approached. See Table 1 for participant data. Most children were male (36 of 54; 66.7%) and lived at home (70.6%). As mentioned, their ages ranged from 2–18 (*M* = 8.8, *SD* = 4.6). On average, they had 5.5 additional medical or behavioral problems (range = 0–13; *SD* = 2.5), Comorbidities included psychiatric (88.9%), digestive (88.9%), sensory (79.6%), speech/language (72.2%), behavioral (68.5%), mood (62.9%), seizures (55.6%), hearing loss (55.6%), visual impairment (43.3%), motor/coordination (42.3%), respiratory (29.6%), cardiac (24.1%), and other disorders (74.1%).

TABLE 1 | Parent and family characteristics.

	***n* = 60 (%)**
Gender of respondent	
Male	14 (23.3)
Female	46 (76.7)
Age of respondent (SD)	38.17 (9.06)
Child's type of residence (home)	42 (70)
Family structure	
Two parents	50 (83.3)
Other	6 (10.0)
Unknown	4 (6.7)
Ethnicity	
Jewish	24 (40.0)
Arab	36 (60.0)
Parental level of education	
Up to 12 years	32 (53.3)
More than 12 years (vocational)	7 (11.7)
More than 12 years (academic)	19 (31.7)
Unknown	2 (3.3)
Socioeconomic status	
Lower-than-average income	18 (40.0)
Average income and above	42 (70.0)
Disability	
Severe	24 (40.0)
Profound	36 (60.0)

2.2 | Instruments

2.2.1 | Quantitative Instruments

The family quality of life survey (FQoL) (Brown et al. 2000) includes 54 items that examine nine core quality-of-life domains (health, finances, family relationships, support from others, support from disability-related services, values, careers, leisure, and community), and six dimensions (importance, opportunities, initiative, attainment, stability, and satisfaction), as well as questions regarding medical/behavioral conditions additional to the SPID (e.g., convulsions, severe visual impairment, severe hearing loss). The survey's internal reliability in this study was high (Cronbach's $\alpha = 0.90$). We tested the attainment of two dimensions: support from others (informal support) and support from services related to the child's disability (formal support). Furthermore, the respondents rated their level of responsibility for the child with SPID on a five-point scale, from "much more responsibility than I would like" to "the amount of responsibility I like."

The parental stress index-short form (Abidin 1997) comprises 36 items rated on a five-point scale and includes three subscales: *Parental Distress*—the extent to which parents feel competent, restricted, conflicted, supported, and/or depressed in their caregiving role; *Parent–Child Interaction*—the extent to which parents feel satisfied with their child and their interactions with them; and *Difficult Child*—how a parent perceives their child to be, whether the child is easy or difficult to take care of. The scale's internal reliability in this study was acceptable–high (Cronbach's $\alpha = 0.86$, 0.64, 0.80, and 0.84 for subscales I, II, and III, and overall scale, respectively).

The state shame and guilt scale (Tangney and Dearing 2003) consists of 15 items on a 5-point scale. Participants are asked to rate how they currently feel, from 1 = not at all to 5 = very strongly. For example, shame ("I feel humiliated, disgraced"); guilt ("I feel remorse, regret"). The internal reliability in this study was acceptable (Cronbach's $\alpha = 0.71$).

2.2.2 | Qualitative Instrument

Following the quantitative section, respondents were asked to answer three open-ended questions regarding the following themes: (1) Perception of attaining formal support (including information, explanations and examples); (2) Perception of attaining informal support (including information, explanations and examples); and (3) Perception of the involvement of a social worker in caring for their child. The qualitative questions were presented to all participants; however, responding to them was not mandatory.

2.3 | Data Analysis

2.3.1 | Quantitative Analysis

Data analyses were conducted on SPSS version 28. A preliminary power analysis for testing differences between two independent means indicated that a sample size of 58 would be sufficient to detect a significant primary measure effect with a power of 0.80 and an alpha of 0.05.

A covariate controlling for whether one or both caregivers participated was added to all analyses. We performed a moderated mediation analysis using structural equation modeling (SEM) to examine the indirect relationship between the sum of the child's medical problems and parental outcomes of shame/guilt and stress through parental personal responsibility toward the child, while assessing the moderating role of formal and informal support. SEM is preferable to a series of regressions as it can simultaneously test multiple hypotheses regarding multiple dependent variables in a single model and thus avoid alpha inflation. Another advantage is its ability to treat missing data using the full information maximum likelihood.

The child's age and residence were added to the model as covariates because children living at home were significantly younger ($M = 7.05$, $SD = 3.73$; $t(58) = 4.33$, $p < 0.001$) than children in residential care ($M = 11.72$, $SD = 4.52$), and parental personal responsibility towards them was significantly higher ($M = 4.31$, $SD = 0.82$; $t(56) = 2.69$, $p = 0.009$) than towards children living in residential care ($M = 3.55$, $SD = 1.34$).

2.3.2 | Qualitative Analysis

Forty-nine (82%) of the parents responded to the first two open-ended questions regarding perceptions of attaining formal and informal support. In addition, 31 parents (52%) answered the third question, which focused on the perceived involvement of a social worker in their child's care.

The findings were subjected to inductive content analysis (Elo and Kyngäs 2008), to enhance and deepen the quantitative results (Tangney and Dearing 2003). Each response was examined, and individual content units were assigned code names. In the second stage, we identified commonalities and variations among responses, and grouped codes into initial themes based on their content and context. Axial coding further elucidated similar and distinct patterns. To ensure interrater reliability, two researchers analyzed the answers and then engaged in discussions to examine any disparities in their analyses and collaborated to achieve consistency (Hemmler et al. 2022).

2.4 | Ethics

The study was approved by the Ministry of Labor, Social Affairs, and Social Services and by the HMO Helsinki Committee (02-31-12-18).

3 | Results

3.1 | Quantitative Findings

Analysis of the FQoL data revealed that parents rated the importance of formal support as very high (4.40 ± 0.94), yet its attainment as below average (2.47 ± 1.22). The importance of informal support was high (3.65 ± 0.34), and its attainment was above average (2.97 ± 0.45). Table 2 presents all analytic stages. Given the model's complexity, the findings are illustrated in Figure 1. As shown in Figure 1, the sum of the child's medical problems was positively related to parental personal responsibility towards the child, which in turn was positively related to parental shame and guilt and to parental stress.

The significance of the indirect effects of the sum of medical problems on parental shame and guilt and parental stress via parental personal responsibility was estimated using 95% confidence intervals, calculated based on a bootstrapping of 10 000 samples. Tests of indirect effects revealed that parental personal responsibility mediated the associations between the sum of medical problems and parental shame and guilt (indirect relationship 95% CI = 0.01, 0.05), and between the sum of medical problems and parental stress (indirect relationship 95% CI = 0.01, 0.10). As seen in Figure 1, in the presence of the

TABLE 2 | Descriptive statistics and correlations.

		1	2	3	4	5	6	7	8
1.	Sum of medical problems	1.00							
2.	Responsibility for the child	0.19	1.00						
3.	Shame and guilt	0.15	0.40**	1.00					
4.	Parental stress	0.23	0.34*	−0.20	1.00				
5.	Support from others	−0.06	−0.20	−0.02	−0.15	1.00			
6.	Support from services	−0.08	−0.29*	0.05	−0.21	0.12	1.00		
7.	Child's age	−0.11	−0.11	0.10	−0.24	−0.11	−0.02	1.00	
8.	Child's type of residence	−0.11	0.34**	0.04	0.15	−0.09	−0.20	−0.49**	1.00
	M	5.46	4.02	2.47	2.88	2.97	2.50	8.77	0.63
	SD	2.49	1.10	0.42	1.02	1.12	1.23	4.60	0.49

Note: $N = 60$.
*$p < 0.05$.
**$p < 0.01$.

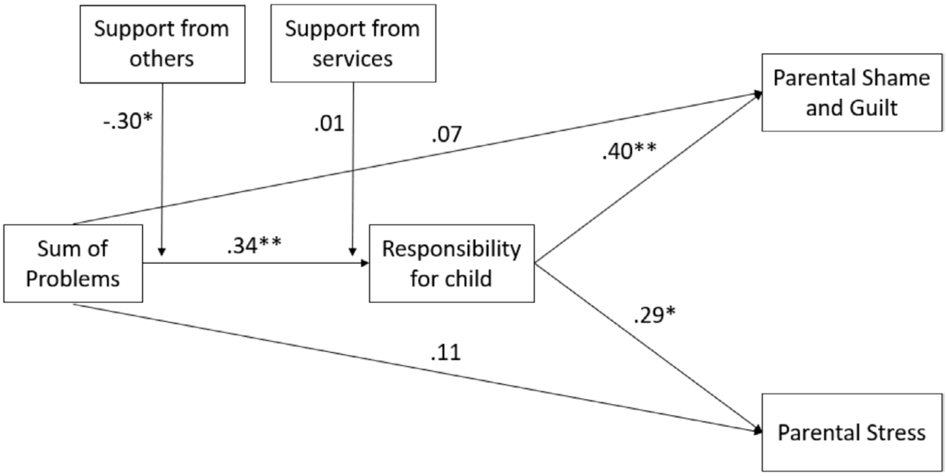

FIGURE 1 | Conditional effects of the sum of the child's medical problems on parental stress, shame, and guilt via parental personal responsibility towards the child as a function of attaining support from others and from services. For reasons of visual clarity, the control variables child's age and child's type of residence are not presented, despite being included in the model. *$p < 0.05$, **$p < 0.01$.

mediator, parental personal responsibility, the direct effects of the sum of medical problems on parental shame and guilt and parental stress were not significant (see Table 3).

Next, we tested whether the indirect effect of a child's medical problems on parental shame/guilt and stress via parental responsibility was moderated by formal or informal support. The moderating effects of formal support were not significant, suggesting that the association between a child's medical problems and parents feeling greater responsibility was not affected by the availability of formal support. However, the attainment of informal support significantly moderated the positive association between the sum of the child's medical problems and parental personal responsibility.

We probed the significant moderation effect of informal support by assessing the indirect effects at different levels of attainment. When attainment of informal support was low, parental personal responsibility significantly mediated the relationship between the sum of medical problems on the one hand, and parental shame and guilt (indirect relationship 95% CI = 0.01, 0.09) and parental stress (indirect relationship 95% CI = 0.01, 0.19), on the other. Namely, when attainment of informal support was low, parents whose children had more medical problems felt greater personal responsibility, leading to increased shame and guilt, as well as stress. Conversely, when attainment of informal support was high, parental personal responsibility did not significantly mediate the relationship between the sum of medical problems on the one hand, and parental shame and guilt (indirect relationship 95% CI = −0.02, 0.03) and parental stress (indirect relationship 95% CI = −0.04, 0.05), on the other. This indicates that high informal support mitigates the effect of medical problems on parents' responsibility. Parents who received more informal support did not feel greater personal responsibility based on the number of medical problems. Hence, they did not experience increased shame and guilt or stress.

Regarding control variables, the child's type of residence was significantly related to parental personal responsibility. Parental responsibility towards children who resided at home was significantly higher than towards children in residential care.

3.2 | Qualitative Findings

The findings revealed two key themes: consistency of support and personalized and available support.

3.2.1 | Consistency of Support

The participants highlighted the importance of the consistency of support and addressed such issues as sudden cessation of communication and its impact on their emotional states. Overall, the parents' experience of *formal* support was mixed. Some felt they were receiving consistent and effective professional care. One mother shared: "The family is constantly supported by two social workers who call and help when needed; they are constantly in touch". Others, however, were frustrated with the sporadic nature of the support. One mother noted: "We communicate only when *he* [the social worker] needs technical details."

About one-third of the parents pointed to the uncertainty of their support. One mother described the sudden cessation of communication with a social worker following her child's move to a residential facility: "She would call and check.... helped a lot in making the decision, but then she disappeared." Similarly, one father pointed to inconsistency in professional relationships and to his limited influence: "It depends on the individual, and you have no control over that... they go on vacation, maternity leave, change [their working] days. I no longer know who I'd meet."

Regarding *informal* support, parents valued social networks. However, they seemed to have different expectations from friends and family and were more forgiving of limited or inconsistent support. One mother described the reliability of her family and friends: "The main, continuous emotional assistance

TABLE 3 | Indirect effects of the sum of medical problems on parental stress, shame, and guilt via responsibility for the child, moderated by attainment of support from others and services.

	Beta	B	SE	CR	*p*
Predicting parental personal responsibility					
Sum of the child's medical problems	0.34	0.15	0.06	2.62	0.009
Sum of the child's medical problems × support from others	−0.30	−0.13	0.06	−2.34	0.019
Sum of the child's medical problems × support from services	0.01	0.00	0.05	0.10	0.923
Child's age	0.15	0.04	0.03	1.08	0.279
Child's type of residence	0.38	0.87	0.31	2.81	0.005
Predicting parental shame and guilt					
Sum of the child's medical problems	0.07	0.01	0.02	0.53	0.597
Parental responsibility for the child	0.40	0.15	0.05	3.04	0.002
Child's age	0.18	0.02	0.01	1.27	0.204
Child's type of residence	0.02	0.02	0.13	0.13	0.897
Predicting parental stress					
Sum of the child's medical problems	0.11	0.05	0.06	0.80	0.425
Parental responsibility for the child	0.29	0.27	0.13	2.13	0.034
Child's age	−0.21	−0.05	0.03	1.43	0.152
Child's residence	−0.03	−0.06	0.33	−0.17	0.865

is from our [extended] family and close friends.... I have no expectations from others, perhaps modest expectations, but when they are met, it is touching and meaningful."

Changes in social contacts were also mentioned, yet those were described as a natural filtering process that strengthened emotional support over time. One mother reflected:

> There used to be more people in our lives, [yet] the situation creates a sense of remoteness. It's [because of] us and it's also [because of] others – they don't know what to say or do: should they invite [the girl with SPID] to come with us? So they give up... Eventually, those who can [cope] are the ones who are left, and we also feel comfortable with them and it's a big help.

3.2.2 | Personalized and Available Support

Parents appreciated a personalized approach. As one mother described, "The social worker cares. She always checks not only how the girl is doing but also about us, the family. I share my problems with her, and she tries to help. Sometimes, just talking to her is a relief". Others experienced lack of interest from professionals. One mother said her social worker "is not involved in our lives at all... He never asked about the family or took an interest in the girl's situation."

The participants also stressed the need for accessible and timely professional support. One mother expressed frustration with the difficulty of accessing welfare services and the administrative burden involved:

> It's difficult to reach [the social workers] at the welfare service; you submit documents and wait for an answer. There is a single phone line [it's either] busy or disconnected. You can't even leave a message, and it's frustrating and annoying that I have to waste my time on this.

Another subtheme was availability of support, especially in unpredictable situations. One mother highlighted the disparity in accessibility by comparing informal to formal support:

> I can pop over to our good friends who live next to us in the middle of the night... and check if they can come and watch the kids so we can take the child [with SPID] to the emergency room. I feel that [our friends] are there for me. If I need anything during the holidays or on the caregiver's free days, there's nothing I can do. The situation can change in an instant for you... Sometimes you need help here and now."

A few parents mentioned the need to consult professionals. One mother expressed the difficulties in finding a specialist outside regular hours:

> [When] the girl is sick on the weekend, I can't just take her to just any doctor, only to a doctor who understands such complex conditions... The doctors at the hotline won't take responsibility. That's why, somehow, we always end up in the emergency room every time she has a fever.

Taken together, the findings reveal that parents' experiences of support are shaped by two key dimensions: the consistency with which support is provided and the degree to which it is personalized and available in demanding situations. Together, these themes illuminate the ways in which the presence or absence of such consistent and personalized support within formal and informal systems shapes families' daily coping.

4 | Discussion

This study explored the role of support in alleviating the burden of caring for children with SPID by bridging the knowledge gap regarding parents' expectations and needs, as well as their perceptions of the barriers to both formal and informal support. The study also examined how support mitigated care demands and affected parents' emotional well-being.

Consistent with the literature (Bailey et al. 2007; Cassidy et al. 2008; Davis and Gavidia-Payne 2009), parents valued formal support highly but reported it to be insufficient, while informal support was both valued and available. Previous studies have also suggested that social support—regardless of its source—serves as a protective factor influencing the relationship between child behavioral and emotional problems and maternal outcomes such as depression, life satisfaction, and positive affect (Falk et al. 2014; Halstead et al. 2018; Park and Lee 2022; White and Hastings 2004). The current findings emphasize that informal rather than formal support mitigates the effect of the burden of care associated with the medical complexity of children with SPID on parental stress, shame, and guilt.

Examination of the reasons for these gaps illustrated caregivers' expectations and the barriers they experience with both types of support. First, parents stressed the importance of consistency of informal support over time, which was often lacking. They valued professionals' consistent caring, while frequent changes of personnel caused instability and added to their stress. Such instability is consistent with previous findings on parents raising children with IDD (Boehm and Carter 2016b), and more specifically, SPID (Tadema and Vlaskamp 2010). Although parents reasonably expected stable and responsive support from professionals, these expectations were not always met. Moreover, when dissatisfaction arose, they had little to no choice in selecting alternative personnel.

While parents expected consistency and commitment from professionals in welfare and healthcare services, informal support was not perceived as guaranteed. Moreover, instability and reduction in social contacts due to the child's condition were perceived as natural processes. It is possible that social and self-stigma (Mak and Cheung 2008) resulted in higher expectations from professionals, whereas others could “choose.”

Access to personalized support was also mentioned as an essential criterion in quality care, yet daily health and bureaucratic obstacles were evident. Difficulties handling daily administrative requirements were also evident in the blogs of Dutch parents of children with profound intellectual and multiple disabilities (Jansen et al. 2017, 2013, 2014; Geuze and Goossensen 2021).

Another challenge was the lack of accessible health and practical support during emergencies or out-of-office hours, forcing parents to seek alternative care in emergency rooms, for example, adding to their stress while not always providing the specialized care required (Iacono and Davis 2003). The lack of adequate “backup” from formal services, involving both limited alternative formal options and the low suitability of mainstream services for children with complex needs, resulted in parents having no effective professional support to turn to in emergencies. Consequently, they relied primarily on informal sources, which shaped both their sense of security and their satisfaction with the overall quality of care.

This discrepancy between informal and formal support highlights that parents of children with SPID continually struggle to find solutions that meet their child's needs in routine and emergencies. The medical fragility of children with SPID (Van Timmeren et al. 2017) further underscores caregivers' need for stability and autonomy in accessing the services required for them to care for their child (Kilburn and Shapiro 2020; Wakimizu and Fujioka 2024). This can also be understood as a parallel process: just as children rely on their caregivers for sustained and responsive care, caregivers require consistent and expert professional support, as well as a comprehensive care framework, to navigate the complexities of securing appropriate care for their child.

4.1 | Strengths and Limitations

The current study is the first to examine the differential effect of types of social support among caregivers of children with SPID. Despite its strengths, it has several limitations. First, it is cross-sectional, necessitating cautious interpretation of the results. However, the qualitative part offers an in-depth and multidimensional understanding of the impact of support. Second, while the sample is relatively small and not representative, it focuses on caregivers raising children with SPID, a small minority within the IDD population (Maulik et al. 2011). Moreover, it reflects a broader social context, contributing to a more nuanced understanding of caregivers' experiences across communities, including those from a minority population often underrepresented in research: Arab society in Israel.

4.2 | Implications for Policy and Practice

Our findings underscore the need for policymakers to establish streamlined and accessible services tailored to the needs of individuals with SPID. These services must be delivered by professionals who are both sensitive to the challenges faced by this population and proficient in navigating complex medical and social systems in routine and emergencies.

While parents need stable and accessible services, changes within services are probably inevitable. Services and policymakers should address their emotional impact and implement policies ensuring continuity of care, especially during critical educational transitions. They should also enable parents to select their professionals. Accessible emergency support through hotlines or digital platforms staffed by specialists is also warranted. Finally, ongoing monitoring should include assessment of informal support systems and encourage informal support networks.

5 | Conclusion

The findings highlight the differential aspects of support, whether formal and informal, and demonstrate how inadequate formal support systems fail to alleviate the stress parents face when raising children with SPID, underscoring the importance of informal social support. Whereas it cannot be relied upon to meet all needs, there is a clear need to improve formal service provision to ensure families receive timely and appropriate support tailored to their familial needs, preferences, and circumstances.

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Ethics Statement

The study was approved by the Ministry Social Services and the HMO's ethics committee.

Consent

All participants provided informed consent prior to their participation in the study.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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