

# Intellectual and Developmental Disabilities

## Family Resilience in Families of Children with Autism Spectrum Disorders: Ecological Systems Theory Perspective

--Manuscript Draft--

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FAMILY RESILIENCE OF FAMILIES OF CHILDREN WITH ASD

**FAMILY RESILIENCE IN FAMILIES OF CHILDREN WITH AUTISM  
SPECTRUM DISORDERS: ECOLOGICAL SYSTEMS THEORY  
PERSPECTIVE**

## FAMILY RESILIENCE OF FAMILIES OF CHILDREN WITH ASD

### **Family Resilience in Families of Children with Autism Spectrum**

#### **Disorders: Ecological Systems Theory Perspective**

#### **Abstract**

Drawing on Bronfenbrenner's ecological systems theory (1992), we asked how certain resources contribute to family resilience in families of children with ASD: family quality of life (FQOL) (family resources), sense of community and loneliness (informal resources), and family-centered support provided by the state (formal resources). 121 **Israeli** parents of children with ASD completed an online survey. Path analysis using AMOS was conducted. FQOL contributed to increased family resilience. Path analysis showed loneliness, sense of community and services use contributed to family resilience through FQOL. Overall, the research model explained 68% of the variance in family resilience. Implications for research and practice are discussed.

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### **Introduction**

The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) defines autism spectrum disorders (ASDs) as neurodevelopmental disorders that include impairments in both communication abilities and stereotypical behaviors (American Psychiatric Association, 2013). The World Health Organization (WHO) estimates one in 100 children has an ASD (WHO, 2021). The occurrence of ASD diagnoses worldwide is on the rise (Zeidan et al., 2022), making the need to examine various aspects of the lives of persons with ASD and their natural support system – their families – increasingly important.

The family-centered approach to ASD argues family members play a key role in the lives of children with ASD (Meadan et al., 2010). All members of the family are affected by the child's situation; thus, the provision of care and services needs to consider the family as a whole (Bamm & Rosenbaum, 2008; Frost et al., 2010). Families of children with ASD have a unique experience that includes both positive aspects and challenges (Batool & Khurshid, 2015; Hayes & Watson, 2013). Resilience is a key coping mechanism more generally, but difficult life circumstances can be risk factors reducing resilience (Masten & Monn, 2015), including coping with ASD (Gayatri & Irawaty, 2022; Suzuki et al., 2018; Uddin et al., 2020).

Thus, in our study, we examined variables that can contribute to better family resilience in families of children with ASD. Drawing on Bronfenbrenner's ecological systems theory (1992) whereby the various systems in which children live affect one another and the children's outcomes, we asked how certain resources contribute to family resilience in this population: family quality of life (FQOL) (family resources), sense of community and loneliness (informal resources), and family-centered support

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provided by the state (formal resources). More specifically, we examined FQOL as a mediator between informal and formal resources and family resilience.

### **Literature Review**

#### ***Family Resilience***

Family resilience builds on the concept of individual resilience and refers to the way a family deals with hardship as a unit (Patterson, 2002; Walsh, 1996, 2016), including its ability to face challenges and crises and adapt, survive, and recover as a family (Harini & Kaloeti, 2021; Masten & Monn, 2015).

High family resilience is connected to positive outcomes for the individuals in the family; for example, it can weaken the effect of adverse childhood experiences on children's mental health (Uddin et al., 2020), ease post-traumatic stress disorders of individuals with severe health issues (Chen et al., 2021; Chew et al., 2018), and reduce mental health problems, such as anxiety, stress, and depression (Gayatri & Irawaty, 2022).

In the context of families of children with disabilities, family resilience eases distress of mothers (Suzuki et al., 2018) and is negatively correlated with parental depression (Keum et al., 2016). Many families of children with ASD report low family resilience (Al-Jadiri et al., 2021), but if families are resilient, parents will experience less stress (Plumb, 2011). They can manage adversity associated with caring for a child with ASD better than parents with lower resilience (Bekhet et al., 2012).

#### ***Ecological Systems Model***

Family resilience is connected to both environmental and individual aspects (Grant et al., 2007). Therefore, to better understand aspects that affect the family resilience of families of children with ASD, it is important to understand the systems

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in which these families operate. Bronfenbrenner's (1992) ecological approach focuses on the social systems surrounding the individual. To understand individuals and assist them, it is necessary to go beyond focusing on the individuals and account for their interaction with their surroundings. According to this model, people are affected by their surroundings, and they, in turn, affect their surroundings, ultimately reaching a balance.

Bronfenbrenner described these systems as circles, with each circle including others closer to the individual; when trying to assist the individual, it is vital to consider these systems and the interactions between them. Changes in one circle can affect the other circles. Bronfenbrenner's model includes six circles: the individual; the microsystem, including things with a direct impact on the individual, such as family members and teachers; the mesosystem, including the interactions between the settings in the microsystem, such as interactions between teachers and parents; the exosystem, including systems that do not involve the individual directly but can affect the individual; the macrosystem, where interactions take place between the previously mentioned systems (microsystem, mesosystem, and exosystem); the chronosystem, including the role or setting of the individual. Each circle affects the other circles and is affected in turn. Bar-on (2012) explained that intervention programs to create change can be effective in any one of these circles.

We adopted Bronfenbrenner's model and examined how different components from different circles, including the microsystem and the mesosystem, may increase family resilience in families of children with ASD. In this study, FQOL components represent the microsystem, and the interaction of the family with its surroundings in the mesosystem is represented by SOC and loneliness (informal resources), and family-centered services (formal resources).

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### *Family Quality of Life (FQOL)*

FQOL refers to the degree to which individuals in the family assess their own quality of life in the familial context; it also refers to the family as a whole and the way the family pursues and achieves its goals (Brown & Brown, 2014). FQOL is conceptualized as comprising five domains: family interactions, parenting, emotional well-being, physical and material well-being, and disability-related support (Beach Center, 2006). Parents and siblings of children with ASD tend to report lower FQOL than parents and siblings of typically developing children (Garrido et al., 2020; McKechnie et al., 2017).

### *Sense of Community (SOC)*

McMillan and Chavis defined SOC as the ‘feeling that the members matter to one another in the group’ (1986, p. 9). According to their definition, SOC includes four elements: membership, influence, fulfillment of needs, and emotional connection. SOC is a predictor of hope (Jason et al., 2016) and is correlated with higher satisfaction with life (Hombrados-Mendieta et al., 2013). Weaker SOC is associated with more mental health problems (Michalski et al., 2020).

In the context of families of children with ASD, some mothers express a need to be connected and understood (Reinke & Solheim, 2015). Interventions focused on SOC can enhance parents’ SOC (Pearson & Meadan, 2021). However, research on the SOC of families of children with ASD is scarce.

Although to the best of our knowledge the correlation between SOC and family resilience has not been studied, it is worth noting that a positive correlation has been found between family resilience and social support and community engagement (Harms, 2021; Kavaliotis, 2017)

### *Loneliness*

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Peplau and Caldwell (1978) defined loneliness as a state wherein a gap exists between the actual and desired amount of one's social interactions. Loneliness has negative impact on cognitive, behavioral, and physiological aspects (Hawkley & Cacioppo, 2010). It is correlated with depression (Domènech-Abella et al., 2017; Erzen & Çikrikci, 2018) and mortality and health problems (Rico-Urbe et al., 2016, 2018). Parents and siblings of children with ASD tend to experience more loneliness than parents and siblings of typically developing children (Koukouriki et al., 2021; Sipowicz et al., 2022), and reducing loneliness can improve their life satisfaction (Lu et al., 2021).

To the best of our knowledge, no study has addressed the association between the loneliness of parents of children with ASD and family resilience. We aimed to fill this gap.

### *Family-Centered Services*

In what follows, we refer to family-centered services as the support the state provides families of children with ASD. These services collectively revolve around fostering a supportive ecosystem for families with children with ASD. Such services encompass emotional support, information dissemination, and interactive platforms such as parent and sibling support groups. In addition, educational lectures offer valuable insights while creative kits and family-oriented activities contribute to sensory engagement and shared experiences. This wide-ranging array of services reflects a commitment to address not only the child's needs but also those of the entire family unit. Although families of people with ASD report difficulties accessing services (Stahmer et al., 2019; Vohra et al., 2014; Zuna et al., 2016), family-centered services can be highly beneficial for family members of children with ASD. Family-centered support has demonstrated positive correlations with the well-being of family

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members (Banach et al., 2010; Hodgetts et al., 2015). Services like support groups for parents and siblings have shown significant benefits for family members of children with ASD (Calio & Higgins-D'Alessandro, 2021; Clifford & Minnes, 2013).

We examined both the extent of support offered and the level of satisfaction with the support provided. While research on the benefits of family-centered support is limited (Bailey et al., 2012), in the current study, its contribution to family resilience was examined.

### Method

#### Participants

A convenience sample of 121 Israeli parents (88.4% of whom were mothers) of children with ASD participated in the study. A majority of the participants were married (80%), and more than half (61.8%) had either a higher education degree or a professional certification. More than two-thirds (70.1%) reported having an average household income of 21 thousand Shekels or higher (as defined by the guidelines of the Israeli Central Bureau of Statistics, 2018). Approximately two-thirds had either a part-time or a full-time job, and the rest were stay-at-home parents (16.7%) or unemployed (16.7%). Almost half identified as either ultra-orthodox or religious (46%). The ages of the children with ASD ranged from one to 24 years, with a mean age of 12.18 years (SD=6.08).

#### Measures

##### *Outcome Variable: Family Resilience*

Family resilience was measured using the family resilience assessment scale (FRAS) developed by Sixbey (2005). The Hebrew version was translated and validated by Pagorek-Eshel and Finklestein (2019). The original questionnaire includes 54 items; each item is ranked on a 4-point Likert-type scale, where

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1=disagree and 4=agree. A high total score implies high family resilience. In this study, we used a 12-item version. Eight items measured communication and problem-solving (e.g., ‘We work to make sure family members are not emotionally or physically hurt’), two items measured resources (e.g., ‘We ask neighbors for help and assistance’), and two items measured maintaining a positive outlook (e.g., ‘We trust things will work out, even in difficult times’). A pilot study was conducted to examine the internal reliability of the 12-item version of the FRAS. This study comprised 43 participants recruited from the general population through a convenience sampling method, with data collected via an online survey. The pilot study demonstrated adequate internal reliability with  $\alpha=.70$ . In this study, the FRAS yielded excellent internal consistency of  $\alpha=.86$ .

### *Mediating Variable: Family Quality of Life*

We assessed FQOL with an abbreviated version of the Beach Center Family Quality of Life Scale (Beach Center, 2006). The purpose of this questionnaire is to measure families' satisfaction with the quality of their family life in five domains: family interactions (e.g., ‘My family enjoys spending time together’), parenting (e.g., ‘Adults in my family have time to take care of the individual needs of every child’), emotional well-being (e.g., ‘My family members have some time to pursue their own interests’), physical and material well-being (e.g., ‘My family has a way to take care of our expenses’), and disability-related support (e.g., ‘My family member with a disability has support to accomplish goals at home’). Participants rated the 20 items on a 5-point Likert-type scale, where 1=very dissatisfied, 3=neither satisfied nor dissatisfied, and 5=very satisfied. Psychometric analysis supports the validity of the scale (Hoffman, 2006). We then calculated a composite quality of life score for the family by averaging the responses. In this study, the scale showed an internal

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consistency of  $\alpha=.91$  for the total score,  $\alpha=.80$  for family interactions,  $\alpha=.64$  for parenting,  $\alpha=.80$  for emotional well-being,  $\alpha=.69$  for physical and material well-being, and  $\alpha=.60$  for disability-related support.

### ***Independent Variables: Informal and Formal Resources***

**Loneliness (Informal Resource).** To measure sense of loneliness, we used Russell et al.'s (1980) UCLA Loneliness Scale. This questionnaire includes 20 items measuring a person's subjective feeling of loneliness and social isolation. Participants rate each item on a Likert-type scale between 1=never and 5=often. A mean total score is calculated, and items 1, 5, 6, 9, 10, 15, 16, 19, and 20 are all reverse coded. The Hebrew version of this questionnaire previously showed excellent internal consistency of  $\alpha=.89$  (Khalaila & Vitman-Schorr, 2021). In this study,  $\alpha=.58$ .

**Sense of Community (Informal Resource).** To measure SOC, we used McMillan and Chavis's (1986) Sense of Community Index, the most widely used validated measure of the SOC (Long & Perkins, 2003). It understands sense of community as a perception with an affective component. For this study, we modified two items to assess the local SOC. Participants provided their responses to the items using a 5-point Likert-type scale, where 1 represented "Completely disagree" and 5 denoted "Completely agree." We then calculated their overall score as the average of the responses. The SOC showed high reliability;  $\alpha=.77$ .

**Family-Centered Services (Formal Resource).** To assess the formal support provided to families by the state, we developed a service usage index measuring their use of family-centered services provided by the local social services department and their satisfaction with those services. The index included seven services: receiving emotional support, receiving information, a support group for parents, a support group for siblings, lectures, creative kits for children, and activities for families. Participants

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were requested to specify the services they had utilized and express their level of satisfaction with each using a 5-point Likert-type scale, where 1 indicated minimal satisfaction and 5 denoted a high level of satisfaction. We calculated two scores: the sum of services participants used and a mean score of their satisfaction. The satisfaction with services scale showed good internal reliability;  $\alpha = .93$ .

### **Procedure**

Measures were completed through an online survey using Qualtrics software. The study was approved by the institutional review board of the School of Social Work at Bar-Ilan University. It was also approved by the Research Division of the Ministry Welfare and Social Affairs, State of Israel. Participants were all service users of an Israeli family-centered program. They were recruited by the managers of Israeli family-centered programs chosen by the steering committee of the study to participate. We gave the managers a link to the online questionnaire, which they then forwarded to all users of the programs. Information on the response rate is not available.

### **Statistical Analysis**

We used Pearson's correlations to assess the associations between the research variables, and we employed path analysis using AMOS (analysis of moment structures) software to examine the mediation model. Data normality was scrutinized using skewness and kurtosis in SPSS. All factors displayed validated values for skewness and kurtosis ( $<+2$ ), confirming the absence of data abnormality. The fit indices were the normed fit index (NFI), incremental fit index (IFI), comparative fit index (CFI), and the root mean square error of approximation (RMSEA).

## **Results**

### ***Association between Formal and Informal Support, FQOL, and Family Resilience***

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The associations between the research variables (formal and informal support, FQOL, and family resilience) are shown in Table 1.

[Table 1 about here]

As shown in the table, there was a strong positive association between FQOL and family resilience. No association was found between family resilience and formal support services (both number of services and satisfaction with services). There was a significant association between informal support and family resilience, with lower sense of loneliness and higher SOC associated with increased family resilience.

Similarly, although no significant correlation was found between formal support services and FQOL, we found a strong correlation between informal support services and FQOL. Low levels of loneliness and high levels of SOC were also associated with increased FQOL.

We found a moderate correlation between satisfaction with services and loneliness: higher satisfaction with services was associated with decreased loneliness. In addition, there was an association between SOC and loneliness, whereby higher SOC was associated with decreased loneliness.

### **Path Analysis to Explain Family Resilience based on FQOL, Formal Support, and Informal Support**

Path analysis relies on the significant correlations found between the research variables (Table 1). The independent variables included in this model were: loneliness, SOC, number of services provided, and satisfaction with services. The mediating variables were subscales of FQOL, including family interactions, parenting, emotional well-being, physical and material well-being, and disability-related support. The dependent variable was family resilience.

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The fit indices indicated that the model fit the data very well:  $\chi^2_{(df=16)} = 22.55$ ,  $p = .126$ , IFI=0.984; NFI=0.948; CFI=0.983; RMSEA=.058. Figure 1 presents the research model.

[Figure 1 about here]

Path analysis showed that the three components of FQOL, i.e., family interactions ( $\beta = 0.35$ ,  $p < .001$ ), parenting ( $\beta = 0.29$ ,  $p = .004$ ), and familial emotional well-being ( $\beta = 0.31$ ,  $p < .001$ ), directly contributed to increased family resilience. Better family interactions, parenting and family well-being were associated with improved family resilience. Disability-related support and physical and material well-being did not make a significant contribution.

Informal resources (loneliness and SOC) contributed to three components of FQOL: family interactions, parenting, and familial emotional well-being. Loneliness ( $\beta = -0.31$ ,  $p < .001$ ) and SOC ( $\beta = 0.26$ ,  $p = .017$ ) were associated with family interactions: decreased loneliness and increased SOC contributed to better family interactions. Likewise, loneliness ( $\beta = -0.32$ ,  $p < .001$ ) and SOC ( $\beta = 0.26$ ,  $p = .020$ ) were associated with parenting: decreased loneliness and increased SOC contributed to better parenting. In addition, loneliness ( $\beta = -0.33$ ,  $p = .001$ ), SOC ( $\beta = 0.37$ ,  $p < .001$ ), and number of services provided to the family ( $\beta = 0.21$ ,  $p = .012$ ) contributed to emotional well-being. Decreased loneliness, increased SOC, and higher number of services provided to the family contributed to increased emotional well-being.

No direct associations were found between formal support (number of services provided and satisfaction with these services) and informal support (loneliness and SOC) and family resilience. This suggests formal and informal support contributed to family resilience through FQOL. Overall, in the context of families of children with ASD, the model explained 68% of the variance in family resilience.

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### Discussion

This study examined the factors that contribute to family resilience, based on Bronfenbrenner's ecological theory (1992). More specifically, we examined how FQOL (family resources), SOC and loneliness (informal resources), and family-centered support (formal resources) can contribute to family resilience.

The path analysis to explain family resilience demonstrated communal factors, i.e., SOC and loneliness, were not directly associated with family resilience. These factors were only correlated to family resilience through FQOL, specifically by contributing to better family interactions, parenting, and emotional well-being. These findings are in line with previous research showing FQOL is positively connected to family resilience in families of children with ASD (Chiu et al., 2020; Gardiner et al., 2019). They also accord with previous findings that communal engagement and social support are positively associated with family resilience (Harms, 2021; Kavaliotis, 2017).

Our findings suggest that, in line with existing research (Fong et al., 2021) there is potential for a positive correlation between informal services and family resilience. It is worth exploring in further detail whether services that prioritize inner family components, including family interactions, parenting, and emotional well-being, would significantly contribute to enhancing family resilience.

The findings are also consistent with Bronfenbrenner's (1992) ecological systems theory: the different circles surrounding the individual are connected, and the communal aspects, such as SOC and loneliness, affect familial aspects, such as family resilience. To enhance family resilience, then, we need to look beyond the family circle and into the community and the policy climate as reflected in social services.

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An additional interesting finding in this study was that a family's physical and material well-being was not connected to family resilience. Previous studies on families of children with ASD have found that family income does not contribute to family resilience (La Madrid Carpena, 2016). The lack of association between physical and material well-being and family resilience can be explained by the fact that low-income families can also be very resilient (Orthner et al., 2004).

### **Limitations**

The study had several limitations that should be acknowledged. First, we used convenience sampling; this sampling method may fail to represent the general population (Clark, 2017). Secondly, a notable proportion of participants were female, resulting in an underrepresentation of fathers in this study. This pattern aligns with the common tendency for fathers to participate in research less frequently than mothers, as highlighted by Doyle et al. (2016). Third, the study lacked a comparison group of families without children with ASD. Fourth, the study's design was cross-sectional; all variables were measured simultaneously, so there was no way to determine causation. An additional limitation pertains to the SOC measurement, which was not validated after modification to two items. Nonetheless, it demonstrated good reliability.

### **Implications for Theory and Research**

The study strengthens Bronfenbrenner's ecological systems theory (1992) by showing different circles can play a role in family resilience. Future studies should include a control group of families of children without ASD to examine whether our results are unique to families of children with ASD. In addition, future studies should focus not only on parents' reports of family resilience but include siblings, as their experience of family resilience may differ from their parents' experience.

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We found parenting practices, such as parents helping their children get along with other children, were positively correlated with family resilience. There is a need for more studies examining how parenting practices can contribute to family resilience and which parental functioning plays a role in enhancing family resilience.

Finally, in our study, SOC was associated with family resilience. Future studies should examine how the SOC of families of children with ASD can be enhanced to strengthen family resilience.

### **Implications to Practice and Policy**

Our findings suggest families of children with ASD do not feel high SOC. This may be because these families feel stigmatized by other families with no experience of ASD (Selman et al., 2018; Salleh et al., 2020). One barrier to family resilience and SOC is the lack of inclusiveness in the everyday lives of individuals with ASD. In Israel, for example, many children with ASD learn in special education schools separate from the general population of children (Barlev et al., 2021). Thus, children with and without ASD do not meet each other; their families do not have an opportunity to meet, break stigmas, and create an inclusive community. Expanding the inclusiveness of children with ASD in schools and communities may improve the SOC families of children with ASD.

In the context of social services, as our findings show that SOC and loneliness are correlated with family resilience, families at risk of low SOC and high loneliness need to be identified so they can be given the assistance they need to increase their SOC, improve family resilience, and reduce loneliness. Social services and practitioners should take advantage of technology to enhance SOC. Social media platforms, such as WhatsApp, Facebook, and Twitter, can be used to create effective communities (Owoseni et al., 2017; Papadopoulos, 2021). We suggest using these

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tools to create online communities of families of children with ASD. In addition, social services should work to create inclusive communities of parents whose children have ASD and parents whose children do not have disabilities. This can be done by arranging joint parental learning communities with joint goals relevant to all parents.

Since parental practices are associated with family resilience, social services should emphasize elements that contribute to better parental practices. For example, this could involve strategies on how to address problematic behaviors and how parents can support their children in managing sensory issues (Pashazadeh Azari et al., 2019; Whittingham et al., 2009). In addition, building social communities of families of people with ASD could create opportunities for parents to consult and learn from each other's successes on ways to improve their own parental practices.

In terms of policy implications, it is noteworthy that the Ministry of Social Security and Social Affairs has demonstrated a commitment to family-centered disability policies through the establishment of over 70 family centers for families of children with disabilities across the state. These centers function as supplementary facilities to the social departments operating within local authorities. However, it is evident that the services provided by family social workers at the local authority level and those offered by the family centers currently lack a specific focus on intrafamilial dynamics. This gap exists because these particular services fall under the purview of the Ministry of Health and its associated agencies within the communities. Consequently, there is a need for the integration of comprehensive, multi-ministerial policies within the operational framework of family centers. This integration should encompass a range of multidisciplinary psychosocial and educational interventions designed to support families with children experiencing disabilities. Such an approach

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would contribute to a more holistic and synergistic support system for families grappling with the challenges posed by disabilities.

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### **Declaration of Conflict of Interest**

The authors report no conflicts of interest.

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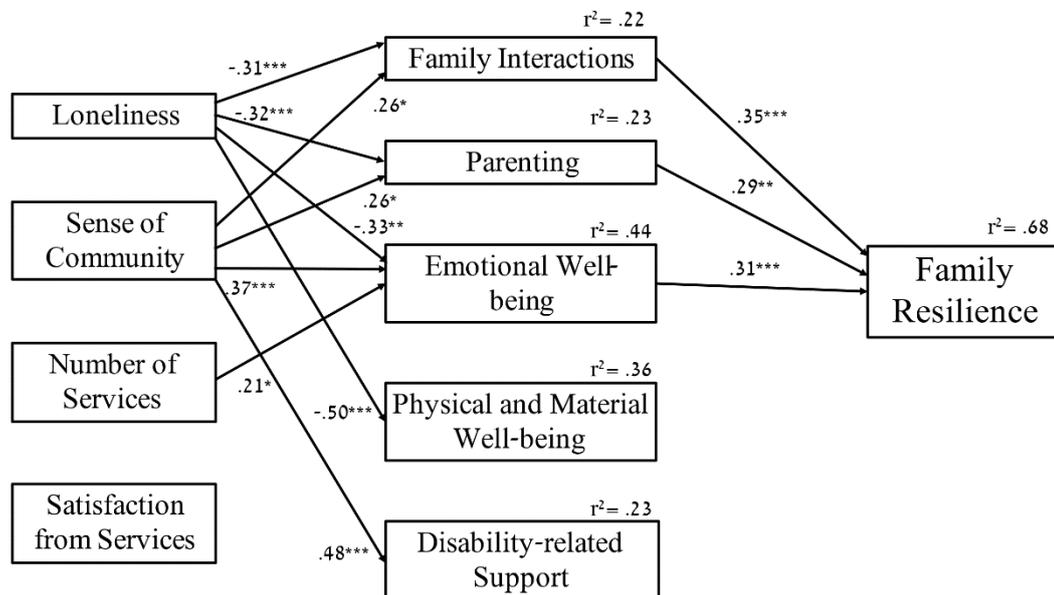
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**Figure 1***Path Analysis to Explain Family Resilience in Families of Children with ASD*

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

Note. The correlations between the FQOL subscales were all significant ( $r$  ranged from .41 to .70,  $p < .01$ , .001). The correlations between formal and informal resources are given in Table 3.

**Table 1***Descriptive Statistics: Formal and Informal Support, FQOL, and Family Resilience*

	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>
<b>1</b> Family resilience – total score	1	.61***	-.01	.08	-.36**	.40**
<b>2</b> Family quality of life – total score		1	-.09	.20	-.47**	.47***
<b>3</b> Number of services			1	.17	.23	.20
<b>4</b> Satisfaction with services				1	-.30*	.24
<b>5</b> Loneliness					1	-.37**
<b>6</b> Sense of community						1

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