

RESILIENCE IN FAMILIES OF AUTISTIC CHILDREN AND CHILDREN WITH
INTELLECTUAL DISABILITY DURING THE COVID-19 PANDEMIC

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**Resilience in families of autistic children and children with intellectual disability during
the COVID-19 pandemic**

Abstract

Resilience in families of autistic children and children with intellectual disability is associated with factors such as family functioning, social support, and financial strain. Little is known about family resilience during the COVID-19 pandemic when many resources were limited. This study examined the association of family resilience with child characteristics, family resources and socio-ecological factors during the pandemic. Data collected during the COVID-19 pandemic from 734 UK parents/caregivers of children who are autistic and/or have intellectual disability were analyzed using path analysis. Greater family resilience was significantly associated with fewer child behavior problems, absence of intellectual disability, higher financial status, and greater family functioning, though not school support. These factors might guide future research and practices to support vulnerable families at risk of low resilience.

Keywords. resilience, COVID-19, autism spectrum disorder, intellectual disability, children, family, behavioral problems

Resilience in families of autistic children and children with intellectual disability during the COVID-19 pandemic

Intellectual disability and autism spectrum disorder are among the most common neurodevelopmental conditions in children, with an estimated global prevalence of 0.63% and 0.70–3% respectively (Francés et al., 2022). Intellectual disability and autism spectrum disorder are also the most common neurodevelopmental conditions to occur comorbidly, with a nationwide study of Scottish children estimating that 0.3% have both (Fleming et al., 2020). The incidence of neurodevelopmental conditions in children, particularly autism spectrum disorder, has increased in recent decades, and at a greater rate than other childhood problems such as child psychiatric conditions (Cybulski et al., 2021). It remains unclear whether higher incident rates are due to increased identification or a true increase in prevalence. Nevertheless, this finding may be a concern, as autistic children and children with intellectual disability present with a significantly higher rate of physical and mental health problems (Alabaf et al., 2019; Danielsson et al., 2023), have poorer educational outcomes (Fleming et al., 2020), and present with more behavioral and emotional problems (e.g. temper tantrums, restlessness, fearfulness; Bailey et al., 2019, Hastings et al., 2022) than typically developing children.

Families of autistic children and children with intellectual disability experience a number of challenges. A review by Karst and Hecke (2012) found that having an autistic child was associated with increased parental stress, marital and sibling relationship conflict, financial burden, and decreased quality of life. Parents of autistic children have been found to experience greater stress not only compared to parents of typically developing children but also parents of children with other neurodevelopmental conditions, such as Down syndrome (Pastor-Cerezuela et al., 2021). Having a child with intellectual disability has also been found to correlate with increased parental stress and decreased family quality of life (Staunton et al., 2023). Some of these challenges are directly related to the child's symptoms and behaviors (Gardiner et al.,

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2020), while others may result from decreased parent employment opportunities and subsequently low family income (Wondemu et al., 2022), limited access to support services (McManus et al., 2011), and social stigma (McLean & Halstead, 2021). Despite these challenges, most families report positive perceptions of having an autistic child or a child with intellectual disability (Blacher & Baker, 2007; Hastings & Taunt, 2002). This reflects an ability to withstand and overcome disruptive life challenges, which is referred to as resilience (Walsh, 2021). Family resilience can be understood as a family's ability to function as a cohesive and adaptive system, capable of withstanding and recovering from adversity (Walsh, 2021). A key indicator of this ability is a family's maintenance of a sustainable daily routine (Gallimore et al., 1999; Weisner et al., 2005). In the context of intellectual disability and autism spectrum disorder, McConnell and Savage (2015) defined family resilience as a family's capacity to maintain a sustainable daily routine that is consistent with the goals, interests and needs of all family members, not only those of the child who is autistic or has an intellectual disability. Family resilience is conceptually close to family functioning yet also meaningfully different. Family functioning refers to the family's emotional environment, acceptance, and affective communication in everyday life (Epstein et al., 1983). Family resilience refers more specifically to the ability to overcome challenges and maintain sustainable daily routines in the face of adversity.

While evidence of family resilience may be observed when there is positive family adaptation in the face of challenges associated with raising an autistic child or a child with intellectual disability (McConnell et al., 2014), it is unclear why some families are more resilient than others. This is partly because there has been limited research on family resilience in the context of autism spectrum disorder and intellectual disability. Much of the existing research has explored the influence of within-family factors on resilience and found that certain family characteristics such as optimism and positive affect are associated with positive family

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adaptation (Trute et al., 2010). However, family resilience is not solely dependent on the intrinsic resources and internal characteristics of family members, but also on the availability of socio-ecological resources, such as schooling, employment, and support from services (Ungar, 2011). Notably less research on resilience in families of autistic children and children with intellectual disability has explored the importance of socio-ecological factors, despite much evidence linking these factors to family outcomes. For instance, there is evidence that low socioeconomic status is a putative risk factor for psychological distress and poor mental health in mothers of autistic children (Nahar et al., 2022). Research has also found that social support is a putative protective factor for maternal well-being (Ekas et al., 2010) and parenting stress (Lu et al., 2018). It is, therefore, plausible that socio-ecological resources play a key role in resilience among families of autistic children and children with intellectual disability, justifying research which investigates these resources directly.

In the United Kingdom (UK), support from services (e.g. health, social care, and education), which is a key socio-ecological resource, was significantly limited during the COVID-19 pandemic. This was due to prolonged periods of national lockdowns. During this period, schools continued to provide some support to families of autistic children and children with intellectual disability. This was mostly in the form of practical support to facilitate home-schooling (i.e., the education of children at home while schools were shut down). Some children who had formal recognition of their special needs were also allowed to attend school in person, while others who did not have this formal recognition were required to remain at home. School closures had a significant impact on autistic children and children with intellectual disability and their families. A recent study reported that as the COVID-19 pandemic progressed, parents of autistic children became increasingly worried about loss of support from schools (Furar et al., 2022). Additionally, higher levels of school support were associated with decreased parental stress and improved parental well-being for families of

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autistic children during the pandemic (Alhuzimi, 2021). The disruption to normal routines which occurred during the COVID-19 pandemic was thought to be associated with significant increases in the frequency and intensity of behavioral problems among autistic children and children with intellectual disability (Shorey et al., 2021). Interestingly, availability of school support was found to significantly predict those changes in behavioral problems (Shorey et al., 2021), again illustrating the importance of socio-ecological resources.

The COVID-19 pandemic also had a significant economic impact on many households, demonstrating that lower-income families were disproportionately impacted by loss of income (Andrade et al., 2023). During the COVID-19 pandemic, families of autistic children reported increases in financial worries compared to before the pandemic (Isensee et al., 2022). In one study of parents of children with neurodevelopmental conditions, nearly 40% of participants reported experiencing financial problems as a result of the pandemic (Masi et al., 2021). This is particularly concerning as low financial status has a well-established association with lower family resilience, worse child behavioral outcomes, and worse family functioning (McConnell et al., 2014). A study of families of autistic children found that during the pandemic those with an average socioeconomic status reported more satisfaction with family functioning than those with a low socioeconomic status (Gagat-Matula, 2021).

In light of the evidence of strong associations between family resilience and socio-ecological factors, McConnell and colleagues (2014) aimed to test a unified socio-ecological model of resilience among families of children with neurodevelopmental conditions, including autism spectrum disorder and intellectual disability. They used the Family Life Congruence scale (Llewellyn et al., 2010) as a measure of family resilience. Family life congruence refers to the family's perception of having a meaningful and balanced routine according to the needs and values of all family members. They collected data from 475 families of children with neurodevelopmental conditions to model the association between family resilience, family

functioning, and child/family characteristics (e.g., behavioral problems, age, functional impairment, financial hardship, and social support). While there was an association between family resilience and child behavior problems, families showed more positive adaptation under the conditions of higher social support and lower financial hardship. These results suggest that multiple socio-ecological factors influence family resilience in families of children with neurodevelopmental conditions and emphasize the importance of studying family resilience from a socio-ecological perspective.

The present study aimed to replicate the McConnell and colleagues (2014) socio-ecological model of family resilience within the context of the COVID-19 pandemic. This entailed testing the associations between child characteristics (e.g., age, presence of intellectual disability, behavioral problems), family resources (e.g., finances, family functioning) and socio-ecological factors (e.g., school support) and family resilience. Based on previous research, the following hypotheses were made: (1) family resilience would be positively associated with school support, family financial status, and family functioning, and (2) family resilience would be negatively associated with child behavioral problems.

Method

Study Design

The current study drew on cross-sectional data collected from families of autistic children and/or children with intellectual disability during the COVID-19 pandemic in the UK collected as part of a study investigating the experiences of families of children with neurodevelopmental conditions one year following the COVID-19 pandemic ([blinded for review]). Data were collected via an online survey between June 1st and August 31st 2021. Recruitment to the survey was facilitated by several UK-wide third-sector organizations (i.e. charities) that advertised the survey via their social media accounts and/or closed mailing lists

of families. For a detailed description, see [blinded for review]. The study was approved by [blinded for review] Research Ethics Committee (ref number: [blinded for review]).

To be eligible for inclusion, participants had to be the parent or primary caregiver of an autistic child or a child with intellectual disability, who was aged 5 to 15, and resided in the UK. The diagnosis of autism spectrum disorder or intellectual disability was reported by the parent/caregiver. The accuracy and reliability of parent-reported diagnoses of neurodevelopmental conditions have been previously reported to be very high. For example, Warnell and colleagues (2015) found that the reliability of parent-reported autism spectrum disorder was 96% when compared with clinician reports. The present study included additional inclusion and exclusion criteria, with the final sample consisting of families of autistic children and/or children with intellectual disability, who were registered with a school, and had available data for the General Family Functioning and Family Life Congruence scales. This resulted in a final sample of 734 families with autistic children and/or children with intellectual disability.

Participants

Children were aged between 5 and 15, with a mean age of 10.5 (SD = 2.96). Among them, 642 were autistic (87.5%), 303 had intellectual disability (41.3%), and 211 (28.8%) had both conditions. Most children were male (N = 501, 68.3%) and the majority were of white ethnic background (N = 660, 89.9%). Most had a special educational needs and disabilities plan (N = 553, 75.3%) which is a formal recognition of a child's additional needs in the UK. A full description of child demographic characteristics can be found in Table 1.

[INSERT TABLE 1 HERE]

The parent/primary caregiver who completed the survey was most often the child's mother (n = 683, 93.1%). Parents/caregivers were aged between 24 and 73 years old, with the

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mean age being 43.5 (SD = 7.13). Approximately a quarter of the sample were single parents/caregivers (N = 172, 23.5%). Most parents/caregivers (N = 410, 55.9%) were employed either full- or part-time. Among families that had a second adult in the household, 486 of those adults (66.2%) were employed either full- or part-time. In most families, the child had at least one sibling (N = 548, 75.1%). A full description of the parent/caregiver and family demographic characteristics is presented in Table 2.

[INSERT TABLE 2 HERE]

Measures

Strengths and Difficulties Questionnaire

Parents/caregivers completed the parent-rated version of the Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997). The SDQ is a 25-item questionnaire that measures emotional and behavioral problems in children aged 2 to 17 years old. The SDQ measures emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems, and prosocial behavior. Parents/caregivers are asked to rate their child's behavior in the last six months using a 3-point Likert-type scale, ranging from 0 (not true) to 2 (certainly true). A total difficulties score is calculated as the sum of all subscale scores excluding the prosocial behavior subscale. The parent-rated SDQ total difficulties score is a valid assessment of behavior problems in this population (Murray et al., 2021). Internal consistency in the present study was acceptable (Cronbach's $\alpha = 0.78$, McDonald's $\omega = 0.75$).

General Family Functioning

The General Family Functioning scale of the McMaster Family Assessment Device (Epstein et al., 1983) is a 12-item scale with positively and negatively worded items that measure general family functioning. In this study, a 6-item short, positively worded version of the General Family Functioning scale (GF-6; Boterhoven de Haan et al., 2015) was used. The

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GF-6 reflects positive family functioning (e.g., “In times of crisis we can turn to each other for support”). Each item is scored on a 4-point Likert-type scale, ranging from 1 (strongly agree) to 4 (strongly disagree). A total score is calculated as the mean of all item scores. Total scores range from 1 to 4, and this was reversed such that higher scores indicate more positive family functioning. The reliability and validity of this 6-item version have previously been assessed (Boterhoven de Haan et al., 2015) and found to be highly correlated with the original 12-item scale ($r = 0.91$). In this study, its internal consistency was excellent (Cronbach’s $\alpha = 0.92$, McDonald’s $\omega = 0.92$).

Family life congruence

The family life congruence (FLC) scale is a 9-item measure of the perceived fit between a family’s daily routine and the family’s values, goals, needs, interests, and competences (McConnell et al, 2016). The FLC is a measure of family resilience for families of children with a neurodevelopmental condition (McConnell & Savage, 2015). The FLC was developed based on the Family Life Interview (Llewellyn et al., 2010). The FLC contains 9 positively and negatively worded items (e.g., “I am creating the life that I want for my children”, “We are trapped by our daily routine”). Each item is scored on a 4-point Likert-type scale, ranging from 1 (strongly agree) to 4 (strongly disagree). Negative items were reverse scored. A total score is calculated as the mean of all item scores. Total scores range from 1 to 4, with higher scores indicating higher levels of family resilience. In this study, its internal consistency was very good (Cronbach’s $\alpha = 0.87$, McDonald’s $\omega = 0.87$).

Subjective financial status

Family subjective financial status (SFS) was measured by a single item, measuring the subjective experience of financial pressure: “How well would you say your family is managing financially?”. This item was rated on a 5-point scale, including “living comfortably” (1), “doing

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alright” (2), “just about getting by” (3), “finding it quite difficult” (4), and “finding it very difficult” (5). Higher scores indicated lower subjective financial status and more subjective financial difficulties. Subjective measurements of financial difficulties have several benefits over objective ones – they are more reflective of individuals’ current needs and life expectations (Wang et al., 2019) and more strongly associated with certain outcomes, such as self-rated health (Cialani & Mortazavi, 2020). The single-item subjective measure used in this study is also widely used in population studies to capture family perception of poverty status, such as the UK’s Millennium Cohort Study (University College London, UCL Institute of Education, Centre for Longitudinal Studies, 2023).

School support

A composite variable was created to capture support from school that the family received for their child during the COVID-19 pandemic. It included measures of whether the child had a special educational needs and disability plan (yes = 1, no = 0), whether the child was allowed to attend school at least some days of the week during school closures (yes = 1, no = 0), and the level of additional school support for home learning. The measure of additional school support with home learning included seven binary (yes = 1, no = 0) items. These items captured support that parents/caregivers or children may have received from school (e.g., “The school offered us printouts of materials and homework”, “The teacher called us on the phone at least once while my child was learning from home”). A combined score for the support received was calculated as the sum of all item scores. This score was then dichotomized, with parents/caregivers who scored 0-1 being considered to have received no or low support (0) and parents/caregivers who scored ≥ 2 being considered to have received higher support (1). The overall composite school support variable was calculated as the sum of the three aforementioned dichotomous variables. Scores ranged between 0 and 3, with 0 indicating no school support and higher scores indicating more school support.

Data Analysis Plan

All data analyses were performed using Stata/MP 17.0. Descriptive statistics for each measure were calculated including means, standard deviations, ranges, and Pearson correlations. *P*-values were also calculated for Pearson correlations, which were considered significant at $\alpha = 0.05$. Path analysis was used to estimate regression coefficients between variables. Path analysis was chosen as it allows for the testing of complex models with multiple intermediary and outcome variables, making it more suitable for this study than univariate methods (Streiner, 2005). Path analysis is a type of structural equation modelling that draws on observed data only (i.e., no latent variables) and allows the exploration of multiple paths to one or several outcomes. It is particularly suitable for the testing of complex theoretical models, such as the McConnell and colleagues (2014) model tested here. The path analysis model included three predictors (e.g., child age, SDQ total score, and presence of intellectual disability), one outcome variable (e.g., FLC scores) and three intermediary variables (e.g., GF-6 scores, school support scores, and SFS scores; see Figure 1). This model was estimated using full information maximum likelihood estimation. All path coefficients were standardized, and default standard errors were estimated for each path coefficient. Since this model was saturated, model fit statistics were not calculable. Following the estimation of this model, non-significant paths were removed in a stepwise manner. To test whether these paths were redundant, models with paths removed were compared to the saturated model using likelihood ratio tests. The alpha level for these tests was set at 0.05 and then Bonferroni corrected based on the number of likelihood ratio tests being performed. After all of the likelihood ratio tests were performed, a final model was produced, and path coefficients and fit statistics (RMSEA, CFI, TLI) were estimated.

[INSERT FIGURE 1 HERE]

Results

Descriptive statistics and correlations

A statistically significant negative correlation was found between child behavior problems (SDQ total score) and family resilience scores ($r = -0.36, p < .001$). Higher levels of child behavioral problems were also found to correlate significantly with lower levels of general family functioning ($r = -0.16, p < .001$), lower levels of school support ($r = -0.16, p = .002$), and increased levels of subjective financial difficulties ($r = 0.25, p < .001$). Family resilience correlated positively with general family functioning ($r = 0.33, p < .001$), indicating that families with more positive functioning experienced greater family resilience. Family resilience was also found to be significantly negatively correlated with subjective financial status ($r = -0.24, p < .001$), indicating that families with higher levels of resilience reported fewer financial difficulties. School support was not found to be significantly correlated with family resilience ($r = 0.01, p = .744$), family functioning ($r = -0.05, p = .288$), or subjective financial status ($r = -0.07, p = .098$). However, school support was found to be negatively correlated with child's age, $r = -0.09, p = .028$, indicating that families of younger children who were autistic or had intellectual disability received less school support. All study correlations are presented in Table 3.

[INSERT TABLE 3 HERE]

Note. GF-6 = General Family Functioning scale, SDQ total difficulties = Total difficulties score from the Strengths & Difficulties questionnaire, SFS = Subjective financial status.

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

Path analysis

The saturated path analysis model is presented in Figure 2. All of the estimated standardized regression effects within the path analysis model are reported in Table 4. The SDQ total score was found to have a significant negative effect on family resilience ($\beta = -0.28$,

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95% CI [-0.35, -0.22], $p < .001$). This suggests that among families in which the child displayed more behavioral problems, family resilience was significantly lower, even after controlling for the other predictors in the model. Statistically significant associations were also found between family resilience and subjective financial status (SFS) ($\beta = -0.15$, 95% CI [-0.22, -0.09], $p < .001$), general family functioning (GF-6) ($\beta = 0.28$, 95% CI [0.22, 0.34], $p < .001$), and the presence of intellectual disability ($\beta = -0.11$, 95% CI [-0.8, -0.05], $p = .001$). This suggests that family resilience was higher under conditions of higher subjective financial status, better general family functioning, and when the child did not have intellectual disability. However, the associations of family resilience (FLC) with school support ($\beta = -0.02$, 95% CI [-0.10, 0.05], $p = .564$) and child age ($\beta = -0.03$, 95% CI [-0.09, 0.04], $p = .369$) did not reach statistical significance, suggesting that family resilience did not differ across families based on those predictors, at least after controlling for the other predictors in the model. Overall, the model accounted for 22.1% of the variance observed in family resilience scores, $R^2 = .22$, 95% CI [.17, .27].

[INSERT FIGURE 2 HERE]

[INSERT TABLE 4 HERE]

After the saturated model was estimated, nested models were estimated in which the non-significant paths from the saturated model were dropped individually in a stepwise manner. All models had non-significant likelihood ratio test statistics ($p > .006$), indicating that these 9 paths could be dropped without a significant loss of model fit. A final path analysis model was then estimated in which all 9 non-significant paths were dropped. This final model is presented in Figure 3. Model fit statistics indicated excellent fit (RMSEA $< .001$, 90% CI [$< .001$, .035], $\chi^2(1) = 7.05$, $p = .632$, CFI > 0.99 , TLI = 1.01). The standardized regression coefficients within this final model were comparable to the estimates from the saturated model (see Table 5 for all estimates). The final model accounted for 21.7% of the variance in FLC

scores, which was only 0.4% less than the saturated model. In the final model, family resilience was significantly predicted by SDQ total difficulties scores, presence of intellectual disability, subjective financial status, and general family functioning, but not child age or school support.

[INSERT FIGURE 3 HERE]

[INSERT TABLE 5 HERE]

Discussion

The aim of this study was to investigate factors associated with resilience in families of autistic children and children with intellectual disability during the COVID-19 pandemic. Family resilience refers to the family's ability to overcome adversity whilst maintaining a sustainable routine. The aim of the study was achieved by analyzing data from 734 parents/caregivers of autistic children and/or children with intellectual disability using path analysis. Based on findings from previous research, it was hypothesized that school support, family subjective financial status, and family functioning would be positively associated with family resilience during the pandemic. This hypothesis was partly supported, with the finding that subjective financial status and family functioning were positively associated with family resilience. This means that families exhibited higher resilience under conditions of higher financial status and better family functioning, both of which tap onto families' resources. It was also hypothesized that child behavioral problems would be negatively associated with family resilience. This hypothesis was supported by the data, suggesting that families were less resilient when levels of child behavioral problems were higher. This finding aligns with findings from the McConnell and colleagues' (2014) study of resilience in families of children with neurodevelopmental conditions as well as findings from the wider neurodevelopmental literature that child behavioral problems are associated with increased parental distress (Hill-Chapman et al., 2013) and lower maternal psychological well-being (Firth & Dryer, 2013).

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Families of children with intellectual disability (with or without autism spectrum disorder) were found to receive less school support and have lower family resilience than families of children without intellectual disability. This is similar to McConnell and colleagues' (2014) finding that families of children with greater functional limitations have lower family resilience, as children with intellectual disability are likely to experience more functional limitations. Another finding by McConnell and colleagues (2014) that was also replicated by this study was that higher financial status was positively associated with greater family resilience. This is consistent with findings that financial difficulties are a risk factor for parental resilience among families of autistic children (Ghanouni & Eves, 2023).

Positive family functioning was found to be significantly associated with greater family resilience, consistent with the findings of McConnell and colleagues (2014). Family functioning is a construct that refers to the family's emotional environment, acceptance and affective communication (Epstein et al., 1983) and is an indicator of family resilience (Bekhet et al., 2012). Family functioning is associated with other important outcomes in families of autistic children, such as parental mental health (Johnson et al., 2011), parenting stress and family quality of life (Pisula & Porębowicz-Dörsmann, 2017).

In our study, support from the school system did not appear to make a difference on family resilience. McConnell and colleagues (2014) previously found that social support, which encompassed informal support from family and the community, was the single most significant predictor of resilience among families of children with neurodevelopmental conditions. Here, school support was found not to significantly predict family resilience. School support included support with home schooling and offer of in-person school attendance during school closures. It is possible that the support provided by schools for autistic children and children with intellectual disability during the COVID-19 pandemic was simply insufficient and therefore did not make a positive impact on family outcomes. A previous study

from the Netherlands (Baten et al., 2021) found that parents of children with neurodevelopmental conditions felt that home learning methods were less effective for their children compared to typically developing children. According to an Australian study (Simpson & Adams, 2023), even when autistic children attended school in-person some days of the week, the majority of parents felt that they were not receiving sufficient support from the school. Schooling systems differ across countries in numerous ways, such as curricula, teaching methods, assessments, facilities, and resources. The fact that these findings have been consistent across countries gives weight to the idea that school support for autistic children and children with intellectual disability and their families was not sufficient or did not align with families' perceived needs during the pandemic. This could be the reason why, in the present study, school support was not associated with family resilience and family functioning.

It is also possible that social support is more intrinsically related to family resilience and family outcomes than school support as it affects the whole family system. Social support for families of children with neurodevelopmental conditions has been found to influence maternal outcomes such as subjective well-being (Bi et al., 2022), sibling outcomes such as psychosocial adjustment (Kirchhofer et al., 2022), and overall family outcomes such as family health (Cavonius-Rintahaka et al., 2019). School support, on the other hand, is primarily in place to support the child with their own needs. It is plausible that school support is simply too specific to the needs of the child to be able to tap onto family-level outcomes. Another possibility for the discrepant finding is that school support as assessed here tapped on more instrumental aspects of support. There is some evidence that instrumental support is valued less by families of children with neurodevelopmental conditions, especially when the availability of formal supports declines (Schiltz et al., 2023). During the period of the present study when COVID-19 restrictions had resulted in a dramatic decline of formal supports from all types of

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services, school support was not perceived as helpful by the majority of parents ([blinded for review], Avery et al., 2022).

Many studies have explored the effects of the COVID-19 pandemic on a wide range of outcomes in families of autistic children and children with intellectual disability. The COVID-19 pandemic has been reported to have had a negative impact on the well-being and behavioral symptoms of many autistic children (Bhat, 2021; Masi et al., 2021). Negative effects have been reported on the well-being and resilience of parents of children with neurodevelopmental conditions (Camia et al., 2023; Masi et al., 2021), as well as on the well-being and behavior of the siblings of autistic children (Camia et al., 2023). Loss of access to support and services had a major impact on families during the pandemic (Haidar & Meadan, 2023). In an Australian sample of parents of children with neurodevelopmental conditions, over two-thirds reported a change in supports or services available to their child and over half were not satisfied with services received (Masi et al., 2021). In a US-based study nearly 65% of families expressed moderate to severe concern about stress because of service disruptions, with the highest disruptions in service provision being reported for schools (Bhat, 2021). The findings of the current study appear in line with the broader literature on the impacts of the COVID-19 pandemic on children with neurodevelopmental conditions and their families. They highlight the important role that family resilience played during the COVID-19 pandemic, about which this study has provided new insight.

The results of this study need to be considered within the context of its limitations. Firstly, the study used cross-sectional data, the nature of which does not allow for causal inference. For example, although this study found that child behavioral problems were associated with family resilience, it is not possible to assess whether one causes the other based on this association. Future research should aim to replicate this model using longitudinal data. For example, researchers might use longitudinal data to assess the mediating effects of factors

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such as family functioning in the relationship between child behavioral problems and family resilience. Additionally, the measure of child emotional and behavioral difficulties through the SDQ in this study does not capture some forms of challenging behaviors, such as aggressive and self-injurious behaviors, that might be more relevant to participants in this study. Another limitation of the data is that it does not include any measures from before the COVID-19 pandemic. Therefore, it could not be tested how resilience and its associations with socio-ecological factors might have changed due to the pandemic. Finally, it is important to recognize that the current study included only families of autistic children and/or children with intellectual disability. The findings of this study might therefore not be generalizable to families of children with other neurodevelopmental conditions, such as attention-deficit/hyperactivity disorder, especially if these were associated with unique challenges during the pandemic.

The findings of this study have important implications for policies aimed at improving outcomes among families of autistic children and children with intellectual disability. Based on the findings of this study, potential targets for intervention might include child behavioral problems, the subjective financial status of families, or family functioning. Parent behavioral interventions aimed at emotional and behavioral problems in autistic children and children with intellectual disability have previously been found to improve both parent outcomes, such as parenting stress, and child outcomes, such as disruptive behavior and hyperactivity (Tarver et al., 2019). It is, therefore, possible that these interventions would lead to greater family resilience and family functioning. The finding that subjective financial status is associated with resilience among families of autistic children and children with intellectual disability indicates that interventions to improve family resilience are most needed by families with lower financial status. Similarly, the finding that the presence of intellectual disability was associated with lower family resilience indicates that support and intervention may be most needed by families

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of children with intellectual disability, whether they also have autism or not. However, it should be reiterated that the findings of this study relate specifically to the COVID-19 pandemic and so the extent of their generalizability is unclear.

To conclude, while the findings of this study did not support all its initial hypotheses, this study was nonetheless successful in replicating some previous findings regarding resilience among families of autistic children and children with intellectual disability and extending these findings to the specific context of the COVID-19 pandemic. As with previous research by McConnell and colleagues (2014), child behavioral problems, subjective financial status, and family functioning were found to be significantly associated with family resilience. Each of these factors has implications for how family resilience can be improved among families of autistic children and children with intellectual disability. Future research should explore how these factors can be translated to implementable interventions.

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FAMILY RESILIENCE DURING COVID-19

Table 1

Child demographic characteristics.

Variable	N	Values
Child Age – Mean (SD)	731	10.55 (2.96)
Child Gender – Freq (%)	734	
<i>Male</i>		501 (68.26%)
<i>Female</i>		223 (30.38%)
<i>Other</i>		7 (0.95%)
<i>Prefer not to say</i>		3 (0.41%)
Child Ethnicity – Freq (%)	734	
<i>White</i>		660 (89.92%)
<i>Non-white</i>		74 (10.08%)
Child ID – Freq (%)	734	
<i>Yes</i>		431 (58.72%)
<i>No</i>		303 (41.28%)
Child ASD – Freq (%)	734	
<i>Yes</i>		642 (87.47%)
<i>No</i>		92 (12.53%)
Child ID <i>and</i> ASD – Freq (%)	734	
<i>Yes</i>		211 (28.75%)
<i>No</i>		523 (71.25%)
Child SEND Plan – Freq (%)	734	
<i>Yes</i>		553 (75.34%)
<i>No</i>		181 (24.66%)

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Note. ID = intellectual disability; ASD = autism spectrum disorder. SEND plan = Special Educational Needs and Disability plan.

Table 2

Parent/caregiver and household demographic characteristics.

Variable	N	Values
Parent/caregiver Age – Mean (SD)	716	43.52 (7.13)
Parent/caregiver Gender – Freq (%)	731	
<i>Male</i>		30 (4.10%)
<i>Female</i>		695 (95.08%)
<i>Other</i>		1 (0.14%)
<i>Prefer not to say</i>		5 (0.68%)
Parent/caregiver Relationship – Freq (%)	734	
<i>Mother</i>		683 (93.05%)
<i>Father</i>		30 (4.09%)
<i>Carer/Guardian</i>		21 (2.86%)
Single Parent/caregiver – Freq (%)	732	
<i>Yes</i>		172 (23.50%)
<i>No</i>		560 (76.50%)
Siblings in household – Freq (%)	730	
<i>Yes</i>		548 (75.07%)
<i>No</i>		183 (24.93%)
Parent/caregiver Employment – Freq (%)	727	
<i>Employed full-time</i>		154 (21.18%)
<i>Employed part-time</i>		242 (33.29%)

FAMILY RESILIENCE DURING COVID-19

<i>Employed other</i>	14 (1.93%)
<i>Unemployed</i>	317 (43.6%)
<hr/>	
Other Adult in Household – Freq (%)	711
<i>Yes (employed)</i>	486 (66.21%)
<i>Yes (unemployed)</i>	94 (12.81%)
<i>Not applicable</i>	131 (20.98%)
<hr/>	
Subjective Financial Status – Freq (%)	730
<i>Living Comfortably (1)</i>	146 (20.00%)
<i>Doing alright (2)</i>	279 (38.22%)
<i>Just about getting by (3)</i>	230 (31.51%)
<i>Finding it quite difficult (4)</i>	54 (7.40%)
<i>Finding it very difficult (5)</i>	21 (2.88%)
<hr/>	

Note. ID = intellectual disability; ASD = autism spectrum disorder. SEND plan = Special Educational Needs and Disability plan.

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Table 3

Pairwise correlations of study variables

	GF-6	Family resilience	SDQ total difficulties	School Support	SFS	Child age
GF-6	1					
Family resilience	0.33**	1				
SDQ total difficulties	-0.17**	-0.36**	1			
School support	-0.05	0.01	-0.16**	1		
SFS	-0.06	-0.24**	0.25**	-0.07	1	
Child age	< 0.01	-0.02	0.02	-0.09*	-0.04	1

Note. GF-6 = General Family Functioning scale, SDQ total difficulties = Total difficulties score from the Strengths & Difficulties questionnaire, SFS = Subjective financial status.

*p<.05, **p<.001.

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Table 4

Standardized regression effect estimates within the saturated path analysis model.

Predictor	Criterion	β	SE	<i>z</i>	<i>p</i>	95% CI
SFS	School support	-0.04	0.04	-1.01	.312	[-0.13, 0.04]
SDQ total	School support	-0.13	0.04	-3.09	.002	[-0.22, -0.05]
Child age	School support	-0.09	0.04	-2.01	.044	[-0.17, -0.00]
Presence of ID	School support	0.15	0.04	3.70	<.001	[0.07, 0.23]
SDQ total	SFS	0.25	0.04	7.31	<.001	[0.19, 0.32]
Child age	SFS	-0.05	0.04	-1.29	.198	[-0.12, 0.02]
Presence of ID	SFS	0.02	0.04	0.56	.574	[-0.05, 0.09]
School support	GF-6	-0.07	0.04	-1.61	.106	[-0.16, 0.016]
SFS	GF-6	-0.03	0.04	-0.69	.491	[-0.10, 0.05]
SDQ total	GF-6	-0.16	0.04	-4.28	<.001	[-0.24, -0.09]
Child age	GF-6	-0.00	0.04	-0.06	.955	[-0.07, 0.07]
Presence of ID	GF-6	0.01	0.04	0.30	.761	[-0.06, 0.08]
School support	Family resilience	-0.02	0.04	-0.58	.564	[-0.10, 0.05]
SFS	Family resilience	-0.15	0.03	-4.52	<.001	[-0.22, -0.09]
GF-6	Family resilience	0.28	0.03	8.74	<.001	[0.22, 0.34]
SDQ total	Family resilience	-0.28	0.03	-8.58	<.001	[-0.35, -0.22]
Child age	Family resilience	-0.03	0.03	-0.90	.369	[-0.09, 0.04]
Presence of ID	Family resilience	-0.11	0.03	-3.42	.001	[-0.18, -0.05]

Note. SFS = Subjective financial status; ID = Intellectual disability; GF-6 = General Family Functioning.

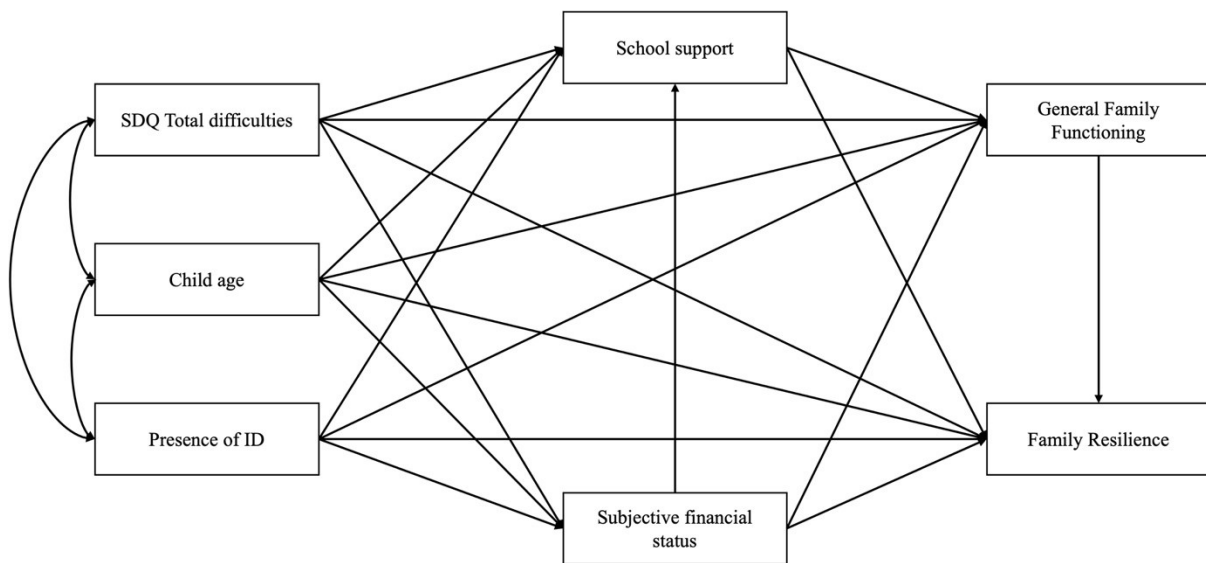
Table 5*Standardized regression effects within final path analysis model.*

Predictor	Criterion	β	SE	z	p	95% CI
SDQ total	School support	-0.14	0.04	-3.50	<.001	[-0.22, -0.06]
Child age	School support	-0.08	0.04	-1.96	.049	[-0.17, 0.00]
Presence of ID	School support	0.15	0.04	3.67	<.001	[0.07, 0.23]
SDQ total	SFS	0.25	0.04	7.26	<.001	[0.18, 0.32]
SDQ total	GF-6	-0.16	0.04	-4.38	<.001	[-0.23, -0.09]
SFS	Family resilience	-0.15	0.03	-4.44	<.001	[-0.21, -0.08]
GF-6	Family resilience	0.28	0.03	8.81	<.001	[0.22, 0.34]
SDQ total	Family resilience	-0.28	0.03	-8.63	<.001	[-0.35, -0.22]
Presence of ID	Family resilience	-0.11	0.03	-3.53	<.001	[-0.18, -0.05]

Note. SFS = Subjective financial status; ID = Intellectual disability; GF-6 = General Family Functioning.

Figure 1

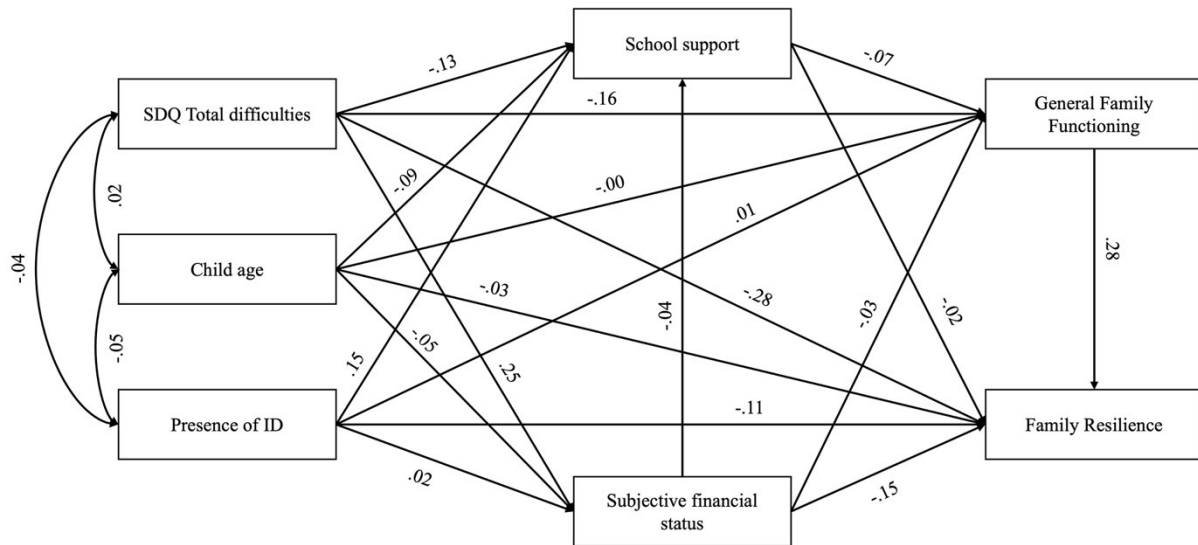
Path analysis model



Note. SDQ total difficulties = Total difficulties score from the Strengths & Difficulties questionnaire; ID = Intellectual disability.

Figure 2

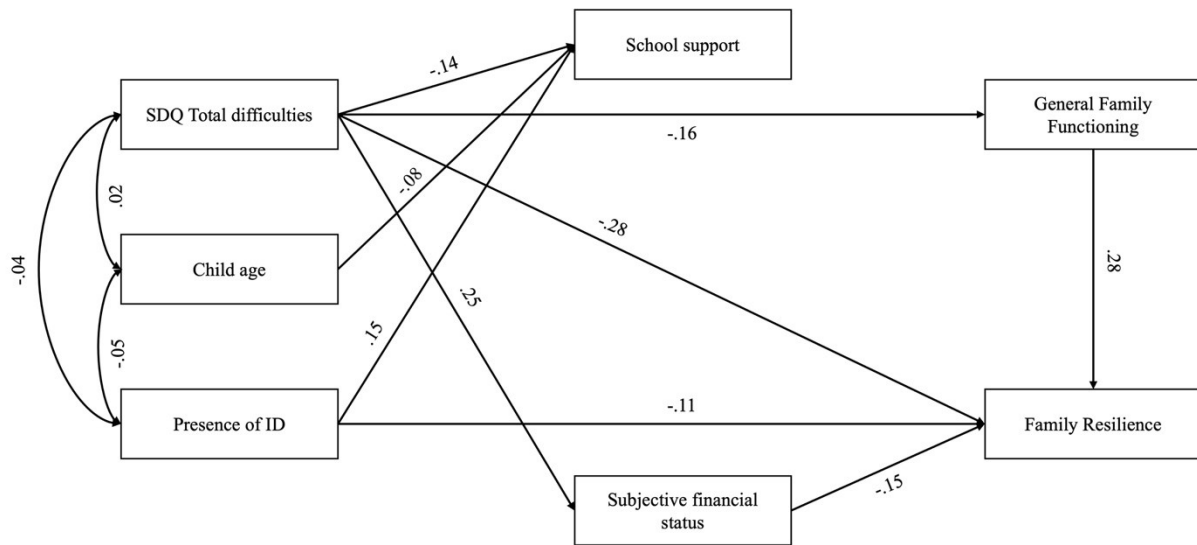
Saturated path model with standardised effect estimates



Note. Single-headed arrows represent regression coefficients. Double-headed arrows represent correlation coefficients. SDQ total difficulties = Total difficulties score from the Strengths & Difficulties questionnaire; ID = Intellectual disability.

Figure 3

Final path model with standardised effect estimates



Note. Single-headed arrows represent standardised regression coefficients. Double-headed arrows represent correlations. SDQ total difficulties = Total difficulties score from the Strengths & Difficulties questionnaire; ID = Intellectual disability.