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

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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.

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2   **the COVID-19 pandemic**

3   **Abstract**

4   Resilience in families of autistic children and children with intellectual disability is associated

5   with factors such as family functioning, social support, and financial strain. Little is known

6   about family resilience during the COVID-19 pandemic when many resources were limited.

7   This study examined the association of family resilience with child characteristics, family

8   resources and socio-ecological factors during the pandemic. Data collected during the COVID-

9   19 pandemic from 734 UK parents/caregivers of children who are autistic and/or have

10   intellectual disability were analyzed using path analysis. Greater family resilience was

11   significantly associated with fewer child behavior problems, absence of intellectual disability,

12   higher financial status, and greater family functioning, though not school support. These factors

13   might guide future research and practices to support vulnerable families at risk of low

14   resilience.

15   *Keywords.* resilience, COVID-19, autism spectrum disorder, intellectual disability, children,

16   family, behavioral problems

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1   **Resilience in families of autistic children and children with intellectual disability during**

2   **the COVID-19 pandemic**

3   Intellectual disability and autism spectrum disorder are among the most common

4   neurodevelopmental conditions in children, with an estimated global prevalence of 0.63% and

5   0.70–3% respectively (Francés et al., 2022). Intellectual disability and autism spectrum

6   disorder are also the most common neurodevelopmental conditions to occur comorbidly, with

7   a nationwide study of Scottish children estimating that 0.3% have both (Fleming et al., 2020).

8   The incidence of neurodevelopmental conditions in children, particularly autism spectrum

9   disorder, has increased in recent decades, and at a greater rate than other childhood problems

10 such as child psychiatric conditions (Cybulski et al., 2021). It remains unclear whether higher

11 incident rates are due to increased identification or a true increase in prevalence. Nevertheless,

12 this finding may be a concern, as autistic children and children with intellectual disability

13 present with a significantly higher rate of physical and mental health problems (Alabaf et al.,

14 2019; Danielsson et al., 2023), have poorer educational outcomes (Fleming et al., 2020), and

15 present with more behavioral and emotional problems (e.g. temper tantrums, restlessness,

16 fearfulness; Bailey et al., 2019, Hastings et al., 2022) than typically developing children.

17   Families of autistic children and children with intellectual disability experience a

18 number of challenges. A review by Karst and Hecke (2012) found that having an autistic child

19 was associated with increased parental stress, marital and sibling relationship conflict, financial

20 burden, and decreased quality of life. Parents of autistic children have been found to experience

21 greater stress not only compared to parents of typically developing children but also parents of

22 children with other neurodevelopmental conditions, such as Down syndrome (Pastor-Cerezuela

23 et al., 2021). Having a child with intellectual disability has also been found to correlate with

24 increased parental stress and decreased family quality of life (Staunton et al., 2023). Some of

25 these challenges are directly related to the child's symptoms and behaviors (Gardiner et al.,

1   2020), while others may result from decreased parent employment opportunities and

2   subsequently low family income (Wondemu et al., 2022), limited access to support services

3   (McManus et al., 2011), and social stigma (McLean & Halstead, 2021). Despite these

4   challenges, most families report positive perceptions of having an autistic child or a child with

5   intellectual disability (Blacher & Baker, 2007; Hastings & Taunt, 2002). This reflects an ability

6   to withstand and overcome disruptive life challenges, which is referred to as resilience (Walsh,

7   2021). Family resilience can be understood as a family's ability to function as a cohesive and

8   adaptive system, capable of withstanding and recovering from adversity (Walsh, 2021). A key

9   indicator of this ability is a family's maintenance of a sustainable daily routine (Gallimore et

10   al., 1999; Weisner et al., 2005) In the context of intellectual disability and autism spectrum

11   disorder, McConnell and Savage (2015) defined family resilience as a family's capacity to

12   maintain a sustainable daily routine that is consistent with the goals, interests and needs of all

13   family members, not only those of the child who is autistic or has an intellectual disability.

14   Family resilience is conceptually close to family functioning yet also meaningfully different.

15   Family functioning refers to the family's emotional environment, acceptance, and affective

16   communication in everyday life (Epstein et al., 1983). Family resilience refers more

17   specifically to the ability to overcome challenges and maintain sustainable daily routines in the

18   face of adversity.

19   While evidence of family resilience may be observed when there is positive family

20   adaptation in the face of challenges associated with raising an autistic child or a child with

21   intellectual disability (McConnell et al, 2014), it is unclear why some families are more

22   resilient than others. This is partly because there has been limited research on family resilience

23   in the context of autism spectrum disorder and intellectual disability. Much of the existing

24   research has explored the influence of within-family factors on resilience and found that certain

25   family characteristics such as optimism and positive affect are associated with positive family

1   adaptation (Trute et al., 2010). However, family resilience is not solely dependent on the

2   intrinsic resources and internal characteristics of family members, but also on the availability

3   of socio-ecological resources, such as schooling, employment, and support from services

4   (Ungar, 2011). Notably less research on resilience in families of autistic children and children

5   with intellectual disability has explored the importance of socio-ecological factors, despite

6   much evidence linking these factors to family outcomes. For instance, there is evidence that

7   low socioeconomic status is a putative risk factor for psychological distress and poor mental

8   health in mothers of autistic children (Nahar et al., 2022). Research has also found that social

9   support is a putative protective factor for maternal well-being (Ekas et al., 2010) and parenting

10   stress (Lu et al., 2018). It is, therefore, plausible that socio-ecological resources play a key role

11   in resilience among families of autistic children and children with intellectual disability,

12   justifying research which investigates these resources directly.

13   In the United Kingdom (UK), support from services (e.g. health, social care, and

14   education), which is a key socio-ecological resource, was significantly limited during the

15   COVID-19 pandemic. This was due to prolonged periods of national lockdowns. During this

16   period, schools continued to provide some support to families of autistic children and children

17   with intellectual disability. This was mostly in the form of practical support to facilitate home-

18   schooling (i.e., the education of children at home while schools were shut down). Some

19   children who had formal recognition of their special needs were also allowed to attend school

20   in person, while others who did not have this formal recognition were required to remain at

21   home. School closures had a significant impact on autistic children and children with

22   intellectual disability and their families. A recent study reported that as the COVID-19

23   pandemic progressed, parents of autistic children became increasingly worried about loss of

24   support from schools (Furar et al., 2022). Additionally, higher levels of school support were

25   associated with decreased parental stress and improved parental well-being for families of

1 autistic children during the pandemic (Alhuzimi, 2021). The disruption to normal routines

2 which occurred during the COVID-19 pandemic was thought to be associated with significant

3 increases in the frequency and intensity of behavioral problems among autistic children and

4 children with intellectual disability (Shorey et al., 2021). Interestingly, availability of school

5 support was found to significantly predict those changes in behavioral problems (Shorey et al.,

6 2021), again illustrating the importance of socio-ecological resources.

7 The COVID-19 pandemic also had a significant economic impact on many households,

8 demonstrating that lower-income families were disproportionally impacted by loss of income

9 (Andrade et al., 2023). During the COVID-19 pandemic, families of autistic children reported

10 increases in financial worries compared to before the pandemic (Isensee et al., 2022). In one

11 study of parents of children with neurodevelopmental conditions, nearly 40% of participants

12 reported experiencing financial problems as a result of the pandemic (Masi et al., 2021). This

13 is particularly concerning as low financial status has a well-established association with lower

14 family resilience, worse child behavioral outcomes, and worse family functioning (McConnell

15 et al., 2014). A study of families of autistic children found that during the pandemic those with

16 an average socioeconomic status reported more satisfaction with family functioning than those

17 with a low socioeconomic status (Gagat-Matula, 2021).

18 In light of the evidence of strong associations between family resilience and socio-

19 ecological factors, McConnell and colleagues (2014) aimed to test a unified socio-ecological

20 model of resilience among families of children with neurodevelopmental conditions, including

21 autism spectrum disorder and intellectual disability. They used the Family Life Congruence

22 scale (Llewellyn et al., 2010) as a measure of family resilience. Family life congruence refers

23 to the family's perception of having a meaningful and balanced routine according to the needs

24 and values of all family members. They collected data from 475 families of children with

25 neurodevelopmental conditions to model the association between family resilience, family

1　functioning, and child/family characteristics (e.g., behavioral problems, age, functional

2　impairment, financial hardship, and social support). While there was an association between

3　family resilience and child behavior problems, families showed more positive adaptation under

4　the conditions of higher social support and lower financial hardship. These results suggest that

5　multiple socio-ecological factors influence family resilience in families of children with

6　neurodevelopmental conditions and emphasize the importance of studying family resilience

7　from a socio-ecological perspective.

8　　　　The present study aimed to replicate the McConnell and colleagues (2014) socio-

9　ecological model of family resilience within the context of the COVID-19 pandemic. This

10　entailed testing the associations between child characteristics (e.g., age, presence of intellectual

11　disability, behavioral problems), family resources (e.g., finances, family functioning) and

12　socio-ecological factors (e.g., school support) and family resilience. Based on previous

13　research, the following hypotheses were made: (1) family resilience would be positively

14　associated with school support, family financial status, and family functioning, and (2) family

15　resilience would be negatively associated with child behavioral problems.

16　　　　　　　　　　　　　　　　**Method**

17　**Study Design**

18　　　　The current study drew on cross-sectional data collected from families of autistic

19　children and/or children with intellectual disability during the COVID-19 pandemic in the UK

20　collected as part of a study investigating the experiences of families of children with

21　neurodevelopmental conditions one year following the COVID-19 pandemic ([blinded for

22　review]). Data were collected via an online survey between June 1st and August 31st 2021.

23　Recruitment to the survey was facilitated by several UK-wide third-sector organizations (i.e.

24　charities) that advertised the survey via their social media accounts and/or closed mailing lists

1   of families. For a detailed description, see [blinded for review]. The study was approved by

2   [blinded for review] Research Ethics Committee (ref number: [blinded for review]).

3   To be eligible for inclusion, participants had to be the parent or primary caregiver of an

4   autistic child or a child with intellectual disability, who was aged 5 to 15, and resided in the

5   UK. The diagnosis of autism spectrum disorder or intellectual disability was reported by the

6   parent/caregiver. The accuracy and reliability of parent-reported diagnoses of

7   neurodevelopmental conditions have been previously reported to be very high. For example,

8   Warnell and colleagues (2015) found that the reliability of parent-reported autism spectrum

9   disorder was 96% when compared with clinician reports. The present study included additional

10 inclusion and exclusion criteria, with the final sample consisting of families of autistic children

11 and/or children with intellectual disability, who were registered with a school, and had

12 available data for the General Family Functioning and Family Life Congruence scales. This

13 resulted in a final sample of 734 families with autistic children and/or children with intellectual

14 disability.

15 **Participants**

16   Children were aged between 5 and 15, with a mean age of 10.5 (SD = 2.96). Among

17 them, 642 were autistic (87.5%), 303 had intellectual disability (41.3%), and 211 (28.8%) had

18 both conditions. Most children were male (N = 501, 68.3%) and the majority were of white

19 ethnic background (N = 660, 89.9%). Most had a special educational needs and disabilities

20 plan (N = 553, 75.3%) which is a formal recognition of a child's additional needs in the UK.

21 A full description of child demographic characteristics can be found in Table 1.

22 [INSERT TABLE 1 HERE]

23   The parent/primary caregiver who completed the survey was most often the child's

24 mother (n = 683, 93.1%). Parents/caregivers were aged between 24 and 73 years old, with the

1 mean age being 43.5 (SD = 7.13). Approximately a quarter of the sample were single

2 parents/caregivers (N = 172, 23.5%). Most parents/caregivers (N = 410, 55.9%) were employed

3 either full- or part-time. Among families that had a second adult in the household, 486 of those

4 adults (66.2%) were employed either full- or part-time. In most families, the child had at least

5 one sibling (N = 548, 75.1%). A full description of the parent/caregiver and family

6 demographic characteristics is presented in Table 2.

7 [INSERT TABLE 2 HERE]

8 **Measures**

9 *Strengths and Difficulties Questionnaire*

10 Parents/caregivers completed the parent-rated version of the Strengths and Difficulties

11 Questionnaire (SDQ) (Goodman, 1997). The SDQ is a 25-item questionnaire that measures

12 emotional and behavioral problems in children aged 2 to 17 years old. The SDQ measures

13 emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems,

14 and prosocial behavior. Parents/caregivers are asked to rate their child's behavior in the last six

15 months using a 3-point Likert-type scale, ranging from 0 (not true) to 2 (certainly true). A total

16 difficulties score is calculated as the sum of all subscale scores excluding the prosocial behavior

17 subscale. The parent-rated SDQ total difficulties score is a valid assessment of behavior

18 problems in this population (Murray et al., 2021). Internal consistency in the present study was

19 acceptable (Cronbach's α = 0.78, McDonald's ω = 0.75).

20 *General Family Functioning*

21 The General Family Functioning scale of the McMaster Family Assessment Device

22 (Epstein et al., 1983) is a 12-item scale with positively and negatively worded items that

23 measure general family functioning. In this study, a 6-item short, positively worded version of

24 the General Family Functioning scale (GF-6; Boterhoven de Haan et al., 2015) was used. The

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

1 alright" (2), "just about getting by" (3), "finding it quite difficult" (4), and "finding it very

2 difficult" (5). Higher scores indicated lower subjective financial status and more subjective

3 financial difficulties. Subjective measurements of financial difficulties have several benefits

4 over objective ones – they are more reflective of individuals' current needs and life

5 expectations (Wang et al., 2019) and more strongly associated with certain outcomes, such as

6 self-rated health (Cialani & Mortazavi, 2020). The single-item subjective measure used in this

7 study is also widely used in population studies to capture family perception of poverty status,

8 such as the UK's Millennium Cohort Study (University College London, UCL Institute of

9 Education, Centre for Longitudinal Studies, 2023).

10 ***School support***

11   A composite variable was created to capture support from school that the family

12 received for their child during the COVID-19 pandemic. It included measures of whether the

13 child had a special educational needs and disability plan (yes = 1, no = 0), whether the child

14 was allowed to attend school at least some days of the week during school closures (yes = 1,

15 no = 0), and the level of additional school support for home learning. The measure of additional

16 school support with home learning included seven binary (yes = 1, no = 0) items. These items

17 captured support that parents/caregivers or children may have received from school (e.g., "The

18 school offered us printouts of materials and homework", "The teacher called us on the phone

19 at least once while my child was learning from home"). A combined score for the support

20 received was calculated as the sum of all item scores. This score was then dichotomized, with

21 parents/caregivers who scored 0-1 being considered to have received no or low support (0) and

22 parents/caregivers who scored ≥2 being considered to have received higher support (1). The

23 overall composite school support variable was calculated as the sum of the three

24 aforementioned dichotomous variables. Scores ranged between 0 and 3, with 0 indicating no

25 school support and higher scores indicating more school support.

1   **Data Analysis Plan**

2   All data analyses were performed using Stata/MP 17.0. Descriptive statistics for each

3   measure were calculated including means, standard deviations, ranges, and Pearson

4   correlations. *P*-values were also calculated for Pearson correlations, which were considered

5   significant at alpha = 0.05. Path analysis was used to estimate regression coefficients between

6   variables. Path analysis was chosen as it allows for the testing of complex models with multiple

7   intermediary and outcome variables, making it more suitable for this study than univariate

8   methods (Streiner, 2005). Path analysis is a type of structural equation modelling that draws

9   on observed data only (i.e., no latent variables) and allows the exploration of multiple paths to

10   one or several outcomes. It is particularly suitable for the testing of complex theoretical models,

11   such as the McConnell and colleagues (2014) model tested here. The path analysis model

12   included three predictors (e.g., child age, SDQ total score, and presence of intellectual

13   disability), one outcome variable (e.g., FLC scores) and three intermediary variables (e.g., GF-

14   6 scores, school support scores, and SFS scores; see Figure 1). This model was estimated using

15   full information maximum likelihood estimation. All path coefficients were standardized, and

16   default standard errors were estimated for each path coefficient. Since this model was saturated,

17   model fit statistics were not calculable. Following the estimation of this model, non-significant

18   paths were removed in a stepwise manner. To test whether these paths were redundant, models

19   with paths removed were compared to the saturated model using likelihood ratio tests. The

20   alpha level for these tests was set at 0.05 and then Bonferroni corrected based on the number

21   of likelihood ratio tests being performed. After all of the likelihood ratio tests were performed,

22   a final model was produced, and path coefficients and fit statistics (RMSEA, CFI, TLI) were

23   estimated.

24   **Figure 1**

1   *Path analysis model*

2   [INSERT FIGURE 1 HERE]

3   *Note.* SDQ total difficulties = Total difficulties score from the Strengths & Difficulties

4   questionnaire; ID = Intellectual disability.

5   **Results**

6   **Descriptive statistics and correlations**

7   A statistically significant negative correlation was found between child behavior

8   problems (SDQ total score) and family resilience scores ($r = -0.36$, $p < .001$). Higher levels of

9   child behavioral problems were also found to correlate significantly with lower levels of

10 general family functioning ($r = -0.16$, $p < .001$), lower levels of school support ($r = -0.16$, $p =$

11 $.002$), and increased levels of subjective financial difficulties ($r = 0.25$, $p < .001$). Family

12 resilience correlated positively with general family functioning ($r = 0.33$, $p < .001$), indicating

13 that families with more positive functioning experienced greater family resilience. Family

14 resilience was also found to be significantly negatively correlated with subjective financial

15 status ($r = -0.24$, $p < .001$), indicating that families with higher levels of resilience reported

16 fewer financial difficulties. School support was not found to be significantly correlated with

17 family resilience ($r = 0.01$, $p = .744$), family functioning ($r = -0.05$, $p = .288$), or subjective

18 financial status ($r = -0.07$, $p = .098$). However, school support was found to be negatively

19 correlated with child's age, $r = -0.09$, $p = .028$, indicating that families of younger children

20 who were autistic or had intellectual disability received less school support. All study

21 correlations are presented in Table 3.

22 [INSERT TABLE 3 HERE]

1   *Note.* GF-6 = General Family Functioning scale, SDQ total difficulties = Total difficulties

2   score from the Strengths & Difficulties questionnaire, SFS = Subjective financial status.

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

4   **Path analysis**

5   The saturated path analysis model is presented in Figure 2. All of the estimated

6   standardized regression effects within the path analysis model are reported in Table 4. The

7   SDQ total score was found to have a significant negative effect on family resilience ($\beta = -0.28$,

8   95% CI [-0.35, -0.22], $p < .001$). This suggests that among families in which the child displayed

9   more behavioral problems, family resilience was significantly lower, even after controlling for

10   the other predictors in the model. Statistically significant associations were also found between

11   family resilience and subjective financial status (SFS) ($\beta = -0.15$, 95% CI [-0.22, -0.09], $p <$

12   .001), general family functioning (GF-6) ($\beta = 0.28$, 95% CI [0.22, 0.34], $p < .001$), and the

13   presence of intellectual disability ($\beta = -0.11$, 95% CI [-0.8, -0.05], $p = .001$). This suggests that

14   family resilience was higher under conditions of higher subjective financial status, better

15   general family functioning, and when the child did not have intellectual disability. However,

16   the associations of family resilience (FLC) with school support ($\beta = -0.02$, 95% CI [-0.10, 0.05,

17   $p = .564$) and child age ($\beta = -0.03$, 95% CI [-0.09, 0.04], $p = .369$) did not reach statistical

18   significance, suggesting that family resilience did not differ across families based on those

19   predictors, at least after controlling for the other predictors in the model. Overall, the model

20   accounted for 22.1% of the variance observed in family resilience scores, $R^2 = .22$, 95% CI

21   [.17, .27].

22   **Figure 2**

23   *Saturated path model with standardised effect estimates*

24   [INSERT FIGURE 2 HERE]

1   *Note*. Single-headed arrows represent regression coefficients. Double-headed arrows represent

2   correlation coefficients. SDQ total difficulties = Total difficulties score from the Strengths &

3   Difficulties questionnaire; ID = Intellectual disability.

4   [INSERT TABLE 4 HERE]

5   After the saturated model was estimated, nested models were estimated in which the

6   non-significant paths from the saturated model were dropped individually in a stepwise

7   manner. All models had non-significant likelihood ratio test statistics ($p > .006$), indicating that

8   these 9 paths could be dropped without a significant loss of model fit. A final path analysis

9   model was then estimated in which all 9 non-significant paths were dropped. This final model

10   is presented in Figure 3. Model fit statistics indicated excellent fit (RMSEA < .001, 90% CI

11   [<.001, .035], $\chi^2(1) = 7.05$, $p = .632$, CFI > 0.99, TLI = 1.01). The standardized regression

12   coefficients within this final model were comparable to the estimates from the saturated model

13   (see Table 5 for all estimates). The final model accounted for 21.7% of the variance in FLC

14   scores, which was only 0.4% less than the saturated model. In the final model, family resilience

15   was significantly predicted by SDQ total difficulties scores, presence of intellectual disability,

16   subjective financial status, and general family functioning, but not child age or school support.

17   **Figure 3**

18   *Final path model with standardised effect estimates*

19   [INSERT FIGURE 3 HERE]

20   *Note*. Single-headed arrows represent standardised regression coefficients. Double-headed

21   arrows represent correlations. SDQ total difficulties = Total difficulties score from the

22   Strengths & Difficulties questionnaire; ID = Intellectual disability.

23   [INSERT TABLE 5 HERE]

24   **Discussion**

1   The aim of this study was to investigate factors associated with resilience in families of

2   autistic children and children with intellectual disability during the COVID-19 pandemic.

3   Family resilience refers to the family's ability to overcome adversity whilst maintaining a

4   sustainable routine. The aim of the study was achieved by analyzing data from 734

5   parents/caregivers of autistic children and/or children with intellectual disability using path

6   analysis. Based on findings from previous research, it was hypothesized that school support,

7   family subjective financial status, and family functioning would be positively associated with

8   family resilience during the pandemic. This hypothesis was partly supported, with the finding

9   that subjective financial status and family functioning were positively associated with family

10   resilience. This means that families exhibited higher resilience under conditions of higher

11   financial status and better family functioning, both of which tap onto families' resources. It

12   was also hypothesized that child behavioral problems would be negatively associated with

13   family resilience. This hypothesis was supported by the data, suggesting that families were less

14   resilient when levels of child behavioral problems were higher. This finding aligns with

15   findings from the McConnell and colleagues' (2014) study of resilience in families of children

16   with neurodevelopmental conditions as well as findings from the wider neurodevelopmental

17   literature that child behavioral problems are associated with increased parental distress (Hill-

18   Chapman et al., 2013) and lower maternal psychological well-being (Firth & Dryer, 2013).

19   Families of children with intellectual disability (with or without autism spectrum

20   disorder) were found to receive less school support and have lower family resilience than

21   families of children without intellectual disability. This is similar to McConnell and colleagues'

22   (2014) finding that families of children with greater functional limitations have lower family

23   resilience, as children with intellectual disability are likely to experience more functional

24   limitations. Another finding by McConnell and colleagues (2014) that was also replicated by

25   this study was that higher financial status was positively associated with greater family

1 resilience. This is consistent with findings that financial difficulties are a risk factor for parental

2 resilience among families of autistic children (Ghanouni & Eves, 2023).

3   Positive family functioning was found to be significantly associated with greater family

4 resilience, consistent with the findings of McConnell and colleagues (2014). Family

5 functioning is a construct that refers to the family's emotional environment, acceptance and

6 affective communication (Epstein et al., 1983) and is an indicator of family resilience (Bekhet

7 et al., 2012). Family functioning is associated with other important outcomes in families of

8 autistic children, such as parental mental health (Johnson et al., 2011), parenting stress and

9 family quality of life (Pisula & Porębowicz-Dörsmann, 2017).

10   In our study, support from the school system did not appear to make a difference on

11 family resilience. McConnell and colleagues (2014) previously found that social support,

12 which encompassed informal support from family and the community, was the single most

13 significant predictor of resilience among families of children with neurodevelopmental

14 conditions. Here, school support was found not to significantly predict family resilience.

15 School support included support with home schooling and offer of in-person school attendance

16 during school closures. It is possible that the support provided by schools for autistic children

17 and children with intellectual disability during the COVID-19 pandemic was simply

18 insufficient and therefore did not make a positive impact on family outcomes. A previous study

19 from the Netherlands (Baten et al., 2021) found that parents of children with

20 neurodevelopmental conditions felt that home learning methods were less effective for their

21 children compared to typically developing children. According to an Australian study

22 (Simpson & Adams, 2023), even when autistic children attended school in-person some days

23 of the week, the majority of parents felt that they were not receiving sufficient support from

24 the school. Schooling systems differ across countries in numerous ways, such as curricula,

25 teaching methods, assessments, facilities, and resources. The fact that these findings have been

1 consistent across countries gives weight to the idea that school support for autistic children and

2 children with intellectual disability and their families was not sufficient or did not align with

3 families' perceived needs during the pandemic. This could be the reason why, in the present

4 study, school support was not associated with family resilience and family functioning.

5   It is also possible that social support is more intrinsically related to family resilience

6 and family outcomes than school support as it affects the whole family system. Social support

7 for families of children with neurodevelopmental conditions has been found to influence

8 maternal outcomes such as subjective well-being (Bi et al., 2022), sibling outcomes such as

9 psychosocial adjustment (Kirchhofer et al., 2022), and overall family outcomes such as family

10 health (Cavonius-Rintahaka et al., 2019). School support, on the other hand, is primarily in

11 place to support the child with their own needs. It is plausible that school support is simply too

12 specific to the needs of the child to be able to tap onto family-level outcomes. Another

13 possibility for the discrepant finding is that school support as assessed here tapped on more

14 instrumental aspects of support. There is some evidence that instrumental support is valued less

15 by families of children with neurodevelopmental conditions, especially when the availability

16 of formal supports declines (Schiltz et al., 2023). During the period of the present study when

17 COVID-19 restrictions had resulted in a dramatic decline of formal supports from all types of

18 services, school support was not perceived as helpful by the majority of parents (([blinded for

19 review], Avery et al., 2022).

20   Many studies have explored the effects of the COVID-19 pandemic on a wide range of

21 outcomes in families of autistic children and children with intellectual disability. The COVID-

22 19 pandemic has been reported to have had a negative impact on the well-being and behavioral

23 symptoms of many autistic children (Bhat, 2021; Masi et al, 2021). Negative effects have been

24 reported on the well-being and resilience of parents of children with neurodevelopmental

25 conditions (Camia et al., 2023; Masi et al., 2021), as well as on the well-being and behavior of

1   the siblings of autistic children (Camia et al., 2023). Loss of access to support and services had

2   a major impact on families during the pandemic (Haidar & Meadan, 2023). In an Australian

3   sample of parents of children with neurodevelopmental conditions, over two-thirds reported a

4   change in supports or services available to their child and over half were not satisfied with

5   services received (Masi et al., 2021). In a US-based study nearly 65% of families expressed

6   moderate to severe concern about stress because of service disruptions, with the highest

7   disruptions in service provision being reported for schools (Bhat, 2021). The findings of the

8   current study appear in line with the broader literature on the impacts of the COVID-19

9   pandemic on children with neurodevelopmental conditions and their families. They highlight

10   the important role that family resilience played during the COVID-19 pandemic, about which

11   this study has provided new insight.

12   The results of this study need to be considered within the context of its limitations.

13   Firstly, the study used cross-sectional data, the nature of which does not allow for causal

14   inference. For example, although this study found that child behavioral problems were

15   associated with family resilience, it is not possible to assess whether one causes the other based

16   on this association. Future research should aim to replicate this model using longitudinal data.

17   For example, researchers might use longitudinal data to assess the mediating effects of factors

18   such as family functioning in the relationship between child behavioral problems and family

19   resilience. Additionally, the measure of child emotional and behavioral difficulties through the

20   SDQ in this study does not capture some forms of challenging behaviors, such as aggressive

21   and self-injurious behaviors, that might be more relevant to participants in this study. Another

22   limitation of the data is that it does not include any measures from before the COVID-19

23   pandemic. Therefore, it could not be tested how resilience and its associations with socio-

24   ecological factors might have changed due to the pandemic. Finally, it is important to recognize

25   that the current study included only families of autistic children and/or children with

1   intellectual disability. The findings of this study might therefore not be generalizable to

2   families of children with other neurodevelopmental conditions, such as attention-

3   deficit/hyperactivity disorder, especially if these were associated with unique challenges during

4   the pandemic.

5   The findings of this study have important implications for policies aimed at improving

6   outcomes among families of autistic children and children with intellectual disability. Based

7   on the findings of this study, potential targets for intervention might include child behavioral

8   problems, the subjective financial status of families, or family functioning. Parent behavioral

9   interventions aimed at emotional and behavioral problems in autistic children and children with

10   intellectual disability have previously been found to improve both parent outcomes, such as

11   parenting stress, and child outcomes, such as disruptive behavior and hyperactivity (Tarver et

12   al., 2019). It is, therefore, possible that these interventions would lead to greater family

13   resilience and family functioning. The finding that subjective financial status is associated with

14   resilience among families of autistic children and children with intellectual disability indicates

15   that interventions to improve family resilience are most needed by families with lower financial

16   status. Similarly, the finding that the presence of intellectual disability was associated with

17   lower family resilience indicates that support and intervention may be most needed by families

18   of children with intellectual disability, whether they also have autism or not. However, it should

19   be reiterated that the findings of this study relate specifically to the COVID-19 pandemic and

20   so the extent of their generalizability is unclear.

21   To conclude, while the findings of this study did not support all its initial hypotheses,

22   this study was nonetheless successful in replicating some previous findings regarding resilience

23   among families of autistic children and children with intellectual disability and extending these

24   findings to the specific context of the COVID-19 pandemic. As with previous research by

25   McConnell and colleagues (2014), child behavioral problems, subjective financial status, and

1   family functioning were found to be significantly associated with family resilience. Each of

2   these factors has implications for how family resilience can be improved among families of

3   autistic children and children with intellectual disability. Future research should explore how

4   these factors can be translated to implementable interventions.

5

6

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1 **Table 1**

2 *Child demographic characteristics.*

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

1 *Note.* ID = intellectual disability; ASD = autism spectrum disorder. SEND plan = Special

2 Educational Needs and Disability plan.

3 **Table 2**

4 *Parent/caregiver and household demographic characteristics.*

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

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

1   *Note.* ID = intellectual disability; ASD = autism spectrum disorder. SEND plan = Special

2   Educational Needs and Disability plan.

3

1 **Table 3**

2 *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

3 *Note.* GF-6 = General Family Functioning scale, SDQ total difficulties = Total difficulties

4 score from the Strengths & Difficulties questionnaire, SFS = Subjective financial status.

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

1   **Table** 4

2   *Standardized regression effect estimates within the saturated path analysis model.*

Predictor	Criterion	β	SE	z	p	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]

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

4   Functioning.

5

1 **Table 5**

2 *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]

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

4 Functioning.

Figure 1

Figure 2

Figure 3