

Brief Report**COVID-19 impact on psychological outcomes of parents, siblings and children with intellectual disability: longitudinal before and during lockdown design****T. Bailey,¹  R. P. Hastings^{1,2}  & V. Totsika^{1,2,3} **¹ CEDAR, University of Warwick, Coventry, UK² Centre for Developmental Psychiatry and Psychology, Department of Psychiatry, School of Clinical Sciences at Monash Health, Monash University, Melbourne, Vic, Australia³ Department of Psychiatry, University College London, London, UK**Abstract**

Background Parents of children with intellectual disability (ID) report comparatively lower levels of well-being than parents of children without ID. Similarly, children with ID, and to a lesser extent their siblings, are reported to show comparatively higher levels of behaviour and emotional problems. Psychological problems may be accentuated by restrictions associated with the COVID-19 pandemic, due to increased social, caring and economic stressors and reduced social support. However, existing studies have not been able to examine the impact of COVID-19 restrictions accounting for pre-COVID levels of well-being in these families. In a naturalistic design, we examined outcomes for parents, siblings and children with ID in a two-wave longitudinal study where Wave 2 data were gathered for some families before and some during COVID-19 restrictions.

Methods Parents of children with ID who took part in a Wave 2 survey pre-lockdown ($n = 294$) and

during/post-lockdown ($n = 103$) completed a number of measures about their well-being and the behaviour and emotional problems of both their child with ID and their nearest-in-age sibling. These same measures had also been completed for all families 2–3 years previously in Wave 1 of the study.

Results After accounting for covariates including family socio-economic circumstances, pre-lockdown and post-lockdown groups did not differ on Waves 1 to 2 change for measures of parental psychological distress, life satisfaction, the impact of caregiving on their lives or perceived positive gains; nor child or sibling internalising or externalising behaviour problems.

Conclusions Findings of the current study indicate that during and shortly after the COVID-19 lockdown in the United Kingdom, well-being in families of children with an ID (as reported by parents) was at similar levels compared with prior to the lockdown period.

Keywords coronavirus, COVID-19, externalising behaviour, intellectual disability, internalising behaviour, parental well-being, siblings

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Introduction

The 2020 COVID-19 pandemic and associated social and other restrictions have raised questions about the putative impact on children with intellectual disability (ID) and their families. Findings from existing research suggest several mechanisms by which the pandemic situation may lead to negative impact on families. First, the pandemic may lead to increased financial stress for families related to job losses or reduced income where governments have implemented policies to support employment especially through several months of social restrictions (i.e. 'lockdown'). Family socio-economic position is a key explanatory variable in driving some of the observed group differences in mental health outcomes between families of children with and without ID; for children with ID themselves (Emerson and Hatton 2007), and for their mothers (Emerson 2003), fathers (Langley *et al.* 2020) and siblings (Hayden *et al.* 2019). Second, there may be negative life events associated with the pandemic (e.g. seriously ill relatives and increased exposure to family bereavement). Such life events are associated with increased mental health problems generally, and there is direct evidence that children with ID are already differentially exposed to more negative life events that increases their risk for mental health problems (Emerson and Hatton 2007).

A third potential pandemic-related mechanism of effect relates to the systemic nature of families and family members' impact on each other. For example, parents experiencing increased financial stress are more likely to also experience reduced well-being; this may exacerbate negative parenting practices, which in turn lead to increased behaviour and emotional problems for children with ID (Totsika *et al.* 2020). Increased parent stress (Hastings *et al.* 2006; Hastings 2016) and/or sibling distress (Hastings 2007) have also been shown in longitudinal research to be directly related to increased behaviour and emotional problems in children with ID. In turn, the behaviour problems of children with ID lead to increased psychological distress for parents and siblings (Hastings 2016). A fourth significant mechanism of effect of the pandemic relates to formal and informal support, which is generally positively associated with well-being in families of children with ID (Hastings 2016). Pandemic-associated restrictions

have led to reduced availability of services and support from professionals and also significantly reduced social support from family and friends (due to lockdown and ongoing social distancing public health policies). Reduced formal and informal support may have had direct effects on families but may also have exacerbated other difficulties (e.g. changes in routine for children leading to increases in behaviour problems, lack of professional expertise to treat emerging mental health or behaviour difficulties in children with ID).

Existing COVID-19 research generally supports the expectation of negative effects of pandemic-related restrictions in general on children, and on children with ID and their family members. In a nationally representative panel study in the United States, 27% of parents of children generally reported worsening mental health for themselves, and 14% of parents reported worsening mental health for their children (Patrick *et al.* 2020). The Patrick *et al.* study did not present analyses for disabled children compared with other children, and a systematic review of COVID-19 research on the psychosocial consequences on children and young people found no studies focused on children with ID (Stavridou *et al.* 2020). Italian (Fontanesi *et al.* 2020) and UK (Willner *et al.* 2020) researchers have reported that family members of children with ID were more likely during lockdown periods to report more stress and mental health problems than other families, alongside also less social support. Families have also reported challenges including being stuck at home unable to go out (Neece *et al.* 2020), their own and their child's anxiety (Asbury *et al.* 2020), increases in the behaviour problems of their children with intellectual and developmental disabilities (Asbury *et al.* 2020; Neece *et al.* 2020) and significant reductions of up to 75% in ratings of availability and suitability of services and therapeutic interventions and activities for their children (Jeste *et al.* 2020; Neece *et al.* 2020; Toseeb *et al.* 2020).

A significant challenge for researchers in understanding the effects of the COVID-19 situation on families of children with ID is that the pandemic was not anticipated. Thus, research studies were not generally in place that could examine changes in outcomes before and after lockdown restrictions. In the research published to date, expected differences in well-being are found between parents of individuals

with and without ID (Willner *et al.* 2020) during the pandemic period but such findings cannot be attributed to the ‘impact’ of the pandemic. Similarly, asking parents about the effects of the COVID-19 situation on themselves and their children, including asking them to reflect on what has changed since the start of the pandemic, is likely to bias responses obtained. This is because their current experiences may be interpreted primarily in relation to COVID-19. Also asking explicitly about positive effects (e.g. Neece *et al.* 2020) is unlikely to mitigate such biases even though the resulting responses may be interesting. Longitudinal data are needed to begin to examine the impact of the COVID-19 pandemic.

In the current study, we examined the impact on families of children with ID of the pandemic lockdown and ongoing social restrictions by taking advantage of a naturalistic exposure design. On the basis of the rationale above, we expected families completing measures in a survey during and soon after the beginning of UK lockdown to report greater negative changes in well-being since a preceding data collection wave than families completing the survey before the UK lockdown.

Method

Design and procedure

We used data from an ongoing UK study of families of children with ID (refer to the detailed description of the study methods, sample and measures in a cohort profile, known as the 1000 Families Study (Hastings *et al.* 2020). Data for Wave 2 of this study of over 1000 families of children with ID were being gathered via an online and paper survey when COVID-19 restrictions began in the United Kingdom in March 2020. Wave 1 for this study was 2.5 years prior to data collection for Wave 2. Some families had already completed the Wave 2 survey before the UK Covid-19 lockdown. After a brief pause, Wave 2 data collection then continued during the UK lockdown period (9 April 2020 to 2 July 2020), creating a rare opportunity to examine ‘impact’ on children with ID, a primary parental caregiver, and closest-in-age siblings. The UK lockdown included instruction to work from home unless this was not possible, to cease meeting other people outside of one’s household, the closure of schools (except for key workers’ children),

instruction to stay at home (except for exercise, food shopping or emergencies). Most restrictions were lifted in the United Kingdom by 15 June 2020.

The ongoing cohort study enabled a naturalistic design that allowed us to examine whether ‘change’ in well-being in family members from Waves 1 to 2 of the study was different if Wave 2 data were collected pre-UK lockdown vs. during/immediately post-UK lockdown. The COVID-19 pandemic was an unanticipated event, and so there was no reason to expect that families due to take part in the Wave 2 survey (each family was invited 2.5 years after their initial survey completion, and so at different times through 2019 and into 2020) pre-COVID-19 vs. post-COVID-19 were any different to each other. If the COVID-19 situation had a negative impact on children with ID or their family members, Waves 1–2 change on outcomes would be ‘more negative’ for families completing the Wave 2 survey post-lockdown than for families completing the survey pre-lockdown. The pandemic may also have changed which families were likely to respond to the Wave 2 survey. To account for this possibility, we used Wave 1 data on key variables to reduce this potential bias – examining change between data collection waves while accounting for Wave 1 levels of outcomes and other factors that have been found in previous research to be key covariates (adaptive skills of the child with ID, and socio-economic position).

Participants

Data were available from 397 primary parental caregivers (94.2% were mothers) of children with ID aged between 5 and 16 years ($M = 11.53$, $SD = 2.56$) at Wave 2 of the study. Demographics for the sample, broken down by group (those who completed the Wave 2 survey pre-post UK lockdown), are shown in Table 1.

Measures

Data were available on both positive and negative aspects of parents’ general well-being, and well-being related to the care of their child with ID; and the rationale for and full description of these measures can be found in the study cohort profile, known as the 1000 Families Study (Hastings *et al.* 2020). It is important to note that the measures were not chosen for a study of the impact of the COVID-19 pandemic,

Table 1 Participant demographics for groups completing Wave 2 surveys pre-lockdown vs. post-lockdown

Demographics	Pre-lockdown (n = 294)	Post-lockdown (n = 103)
Relationship to child		
Biological mother	259 (88.1%)	82 (79.6%)
Adoptive mother	16 (5.4%)	9 (8.7%)
Foster mother	2 (0.7%)	–
Grandmother	4 (1.4%)	2 (1.9%)
Biological father	11 (3.7%)	4 (3.9%)
Grandfather	1 (0.3%)	1 (1%)
Parent degree		
Yes	161 (54.8%)	45 (43.7%)
No	131 (44.6%)	51 (49.5%)
Parent with job		
Yes	146 (49.7%)	57 (55.3%)
No	147 (50%)	40 (38.8%)
Median weekly household income	Between £601 and £700	Between £501 and £600
Bottom neighbourhood deprivation decile	24 (7.7%)	5 (5.8%)
Not managing financially	46 (15.6%)	11 (10.7%)
Struggle to raise £2000 in an emergency	144 (49.0%)	40 (38.8%)
Mean socio-economic risk composite (SD)	1.42 (SD = 1.06)	1.25 (SD = 0.98)
Mean parent age in years (range; SD)	44.06 (26–67; SD = 6.94)	45.03 (14–70; SD = 8.00)
Mean age of child with ID in years (range; SD)	11.36 (6–16; SD = 2.51)	12.10 (7–17; SD = 2.64)
Sex of child with ID		
Male	196 (66.7%)	74 (71.8%)
Female	96 (32.7%)	24 (23.3%)
Mean sibling age in years (range; SD)	12.17 (4–18; SD = 3.43)	12.98 (4–18; SD = 3.46)
Sibling sex		
Male	98 (33.3%)	19 (18.4%)
Female	99 (33.7%)	18 (17.5%)

but they do offer a broad perspective on different family members' psychological functioning.

The Kessler 6 (K6; Kessler *et al.* 2002) is a six-item self-report measure developed to screen for the presence of psychological distress in non-clinical community samples and was used as a general mental health measure for parents. A single-item measure asked participants to rate their general life satisfaction on a scale of 1 (*completely dissatisfied*) to 10 (*completely satisfied*). This scale has been used within major UK social surveys with large-normative samples ($n = 1000+$), including the Millennium Cohort Study (Plewis 2007). Child-related positive perceptions were measured using the 7-item Positive

Gains Scale (Jess *et al.* 2020; Pit-ten Cate 2003). A 7-item 'Impact of caregiving on carer' scale from the Survey of Informal Carers in Households 2009/10 (NHS Information Centre 2010) was used. A higher summed number of options chosen on this scale indicates more (negative) impact of caregiving on participant's life.

Behavioural and emotional problems of the child with ID and their nearest-in-age sibling (if there was a sibling in the family in the age range 4–16 years of age) were measured using the Strength and Difficulties Questionnaire parent report version (Goodman 1999). An externalising behaviour problems score is derived from 10 items assessing hyperactivity and conduct problems, and an internalising problems score from 10 items assessing emotional problems and peer problems (Goodman *et al.* 2010).

Two other key measures were used from the Wave 2 survey to assess covariates for analysis. The adaptive skills of the child with ID were measured using the 8-item GO4KIDDS Brief Adaptive scale (Perry *et al.* 2014), with an additional item on augmentative communication because many children with ID may have good communication but through alternative means (therefore totalling 9 items). Family level socio-economic risk was measured using a composite variable created by incorporating four single-item Wave 2 indicators of poverty: whether the family is living in poverty (equalised income more than 60% the UK median), subjective poverty, family hardship, and whether the family live in the 10% poorest neighbourhoods in their UK country. Other socio-economic indicators were measured at the level of the survey respondent (respondent education and employment).

Analysis

All analyses were conducted in SPSS v. 26. Eight multiple regression analyses were utilised to examine the association between whether Wave 2 measures were completed pre-lockdown or during/immediately post-lockdown and outcome change (from Waves 1 to 2) in relation to parental well-being (psychological distress, life satisfaction, caregiving impact and positive gains), and externalising and internalising problems for the child with ID and a sibling. Waves 1–2 change scores for the outcome were the criterion

variables, and a two-step hierarchical entry approach was utilised. Covariates were added in Step 1, including the Wave 1 score for the outcome (to control for initial levels of the outcome, and reduce bias in the design). In Step 2, a binary indicator of lockdown status at the time of Wave 2 survey completion (coded 0 = *pre-lockdown*, 1 = *during/immediately post-lockdown*; based on whether the participant completed the Wave 2 survey before or after the UK lockdown date of 23 March 2020) was added to the model. Standardised mean differences (SMDs) were calculated as effect sizes for the 'lockdown' beta coefficients by dividing each coefficient by the standard deviation of the respective outcome. Regression model assumptions were checked and met for all eight models.

Results

The addition of the lockdown variable to the analysis models suggested that the parental caregivers who completed their Wave 2 surveys pre-lockdown vs. during/immediately post-lockdown did not differ in their change from Waves 1 to 2 in psychological distress ($B = 0.56, p = 0.32, SMD = 0.128$), life satisfaction ($B = 0.34, p = 0.63, SMD = 0.055$), caregiving impact ($B = 0.17, p = 0.49, SMD = 0.086$), or positive gains ($B = 0.04, p = 0.95, SMD = 0.045$) (Table 2).

Further, groups who completed their Wave 2 surveys pre-lockdown vs. during/immediately

post-lockdown did not differ with respect to change from Waves 1 to 2 in externalising ($B = -0.32, p = 0.27, SMD = 0.172$), or internalising ($B = -0.06, p = 0.87, SMD = 0.125$) behaviour of the child with ID; nor for sibling externalising ($B = -0.23, p = 0.66, SMD = 0.054$), and sibling internalising ($B = -0.12, p = 0.86, SMD = 0.126$) problems (Table 3).

Discussion

After accounting for a number of relevant covariates and Wave 1 levels of the outcome, the present study did not find any difference in the amount of change in parental well-being and child/sibling behaviour and emotional problems for cohort study participants who completed their Wave 2 surveys pre-COVID-19 lockdown and during/immediately post-COVID-19 lockdown. As far as we are aware, these are the first longitudinal data on the impact of the COVID-19 associated restrictions on the well-being of family carers of children with ID, the children themselves and siblings. Our findings suggest that the hypothesised almost universal negative impact may not be as straightforward as anticipated at this group level.

Our research design has allowed a longitudinal investigation of the question of COVID-19 impact. The design is probably the strongest available to examine the broader impact of COVID-19 on children with ID and their families because the pandemic could not have been anticipated and

Table 2 Regression models predicting Waves 1–2 change in parental well-being

Variable	Psychological distress		Caregiving impact		Positive gains		Life satisfaction	
	B	SE	B	SE	B	SE	B	SE
Family socio-economic risk	0.450	0.237	-0.021	0.098	-0.211	0.237	-1.288*	0.285
Parent without degree	-0.166	0.464	-0.329	0.201	-0.641	0.475	0.428	0.573
Parent without job	0.225	0.478	-0.014	0.207	0.088	0.486	-1.064	0.589
Parent age	-0.043	0.037	-0.039*	0.015	-0.044	0.035	0.187*	0.044
Child with ID age	-0.042	0.100	0.016	0.043	0.058	0.099	-0.057	0.123
Child with ID gender	-0.428	0.490	-0.210	0.212	-0.616	0.486	0.714	0.607
Child with ID adaptive skills	-0.082*	0.031	-0.019	0.014	-0.035	0.032	0.031	0.039
Wave 1 score on outcome	-0.410*	0.048	-0.560*	0.055	-0.408*	0.059	1.417*	0.141
Lockdown status	0.562	0.559	0.165	0.240	0.035	0.547	-0.341	0.710
R^2	0.210		0.280		0.175		0.422	
ΔR^2	0.003		0.001		0.000		0.000	
F (dfs)	9.167 (9, 311)*		12.439 (9, 288)*		5.971 (9, 254)*		25.194 (9, 310)*	

* $p < 0.05$.

Child/sibling gender (0 = female, 1 = male); lockdown status (0 = pre-lockdown, 1 = post-lockdown).

Table 3 Regression models predicting Waves 1 to 2 change in child and sibling behaviour problems

Variable	Child externalising		Child internalising		Sibling externalising		Sibling internalising	
	B	SE	B	SE	B	SE	B	SE
Family socio-economic risk	-0.079	0.117	0.022	0.151	0.217	0.186	0.272	0.246
Parent without degree	0.127	0.239	0.314	0.308	-0.628	0.392	0.097	0.524
Parent without job	-0.272	0.245	0.131	0.315	0.117	0.406	0.497	0.529
Parent age	-0.033	0.019	-0.082*	0.024	-0.072*	0.032	-0.021	0.041
Child with ID age	-0.061	0.052	-0.027	0.068	-	-	-	-
Child with ID gender	-0.674*	0.253	0.210	0.323	-	-	-	-
Sibling age	-	-	-	-	-0.080	0.068	-0.117	0.089
Sibling gender	-	-	-	-	-0.027	0.363	0.955*	0.473
Child with ID adaptive skills	0.051*	0.016	0.134*	0.021	0.002	0.024	-0.045	0.032
Wave 1 score on outcome	-0.599*	0.037	-0.515*	0.037	-0.782*	0.038	-0.633*	0.052
Lockdown status	-0.322	0.290	-0.063	0.372	0.230	0.515	-0.116	0.678
R ²	0.488		0.428		0.725		0.524	
ΔR ²	0.002		0.000		0.000		0.000	
F (dfs)	32.747 (9, 309)*		25.629 (9, 308)*		48.812 (9, 154)*		18.862 (9, 154)*	

*p < 0.05.

Child/sibling gender (0 = female, 1 = male); lockdown status (0 = pre-lockdown, 1 = post-lockdown).

families could not be assigned at random to experience the event. However, there are a number of limitations with the current study that should be considered. First, we compared groups who had completed their Wave 2 survey pre-lockdown and during/immediately post-lockdown with an assumption that the two groups would not otherwise be systematically different (i.e. the pandemic was a random event). To partly address the possibility of an unidentified retention bias, we focused on change in outcomes from Waves 1 to 2 of data collection and also controlled for a number of factors known to affect outcomes in families of children with ID including initial levels of the outcome. Second, it may be that the experiences of loss of services, worries about COVID-19 and restrictions in social contact will have taken longer to affect families and may be more clearly seen in future research. Third, given the UK policy approach (in particular, the national jobs retention scheme in place during the whole of the study period), the financial impact of the COVID-19 situation may hit families later. Our data may be most relevant to understanding the short term impact of the COVID-19 lockdown and associated restrictions.

It is also important to point out that the lack of a group differences in the current study may be masking considerable individual variability. One possibility is that at the group level, there are also some positive

effects of the lockdown experience on children with IDs and their families. Other research (Neece *et al.* 2020) suggests that families have been valuing more time together. This may have contributed to enhanced positive parent-child relationships, which may contribute to both improved parental well-being, and to reduced behaviour problems in children with ID (Totsika *et al.* 2014). Although the availability of services has reduced during lockdown periods, dealing with services and professionals can be very stressful for parents (Griffith and Hastings 2014), and it is possible that this had a positive impact on parental well-being. More significantly, it is likely that individual families did experience and are experiencing particularly stressful circumstances and future research should move towards working out who these families might be and how best to support them.

Additional longitudinal research is also needed to understand the medium and longer term effects (positive and negative) of the COVID-19 pandemic on children with ID, their parental caregivers and their siblings. Research from different perspectives – in particular, children with ID and their siblings themselves – is also needed. Findings of the current study indicate that during the COVID-19 lockdown in the United Kingdom, well-being in families of children with an ID (as reported by parents) was at similar levels compared with prior to the lockdown period.

Acknowledgements

The authors would like to express their thanks to the research team who contributed to data collection for this study, as well as to all of the families who took part in this research.

Sources of Funding

The research charity Cerebra (UK) provided grant funding for the 1000 Families Study.

Conflict of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data from this study are not able to be shared, due to ethics approval restrictions.

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Accepted 12 January 2021