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# Effect of the COVID-19 pandemic on the mental health of carers of people with intellectual disabilities

Paul Willner<sup>1</sup> | John Rose<sup>2</sup> | Biza Stenfert Kroese<sup>2</sup> | Glynis H Murphy<sup>3</sup> | Peter E Langdon<sup>4,5</sup> | Claire Clifford<sup>6</sup> | Hayley Hutchings<sup>7</sup> | Alan Watkins<sup>7</sup> | Steve Hiles<sup>7</sup> | Vivien Cooper<sup>8</sup>

<sup>1</sup>Department of Psychology, Swansea University, Swansea, UK

<sup>2</sup>School of Psychology, University of Birmingham, Birmingham, UK

<sup>3</sup>Tizard Centre, University of Kent, Canterbury, UK

<sup>4</sup>Centre for Educational Development, Appraisal and Research, University of Warwick, Coventry, UK

<sup>5</sup>Coventry and Warwick Partnership NHS Trust, Coventry, UK

<sup>6</sup>Independent Researcher, Solihull, UK

<sup>7</sup>Swansea University Medical School, Swansea, UK

<sup>8</sup>The Challenging Behaviour Foundation, Chatham, UK

## Correspondence

Paul Willner, Department of Psychology, Swansea University, Swansea SA2 8PP, UK. Email: p.willner@swansea.ac.uk

## Abstract

**Introduction:** The measures implemented to manage the COVID-19 pandemic have been shown to impair mental health. This problem is likely to be exacerbated for carers.

**Method:** Informal carers (mainly parents) of children and adults with intellectual disabilities, and a comparison group of parents of children without disabilities, completed an online questionnaire. Almost all the data were collected while strict lockdown conditions were in place.

**Results:** Relative to carers of children without intellectual disability, carers of both children and adults with intellectual disability had significantly greater levels of a wish fulfilment coping style, defeat/entrapment, anxiety, and depression. Differences were 2–3 times greater than reported in earlier pre-pandemic studies. Positive correlations were found between objective stress scores and all mental health outcomes. Despite their greater mental health needs, carers of those with intellectual disability received less social support from a variety of sources.

**Conclusions:** The greater mental health needs of carers in the context of lesser social support raises serious concerns. We consider the policy implications of these findings.

## KEYWORDS

carers, COVID-19, depression, intellectual disability, mental health, social support, stress

## 1 | INTRODUCTION

People with intellectual disabilities are a group at specific risk during the COVID-19 coronavirus pandemic because of marked mental and physical health multimorbidity (Cuypers et al., 2020; Turk, Landes, Formica, & Goss, 2020). The social distancing and isolation measures implemented to manage the pandemic are known to impair mental

health (Brooks et al., 2020; Torales, O'Higgins, Castaldelli-Maia, & Ventriglio, 2020), and this burden is also likely to be greater for people with intellectual disabilities, because they have generally poorer coping abilities (Courtenay & Perera, 2020). Caring for people with intellectual disability is stressful, leading, even under normal conditions, to high levels of perceived stress and burnout (Panicker & Ramesh, 2019; Patton, Ware, McPherson, Emerson, & Lennox, 2018;

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Rose, 2011; Willner & Goldstein, 2002). The burden of greater care demands causes a further exacerbation of the anxieties and practical difficulties created by the pandemic and places carers under increasing strain (Alexander et al., 2020), albeit that anecdotal reports suggest that the predictability of life under lockdown may lead to a reduction in challenging behaviour for some carers (Rose et al., 2020).

It is well known that stress is buffered by social support (Cohen & Wills, 1985; Dean & Lin, 1977) and the dilution of social support during lockdown may be particularly severe for carers of people with intellectual disability because their access to professional support and services such as respite is much reduced (Mind, 2020). While the difficulties experienced by paid care staff during the coronavirus crisis have attracted extensive publicity, little attention has been paid to the situation of family and other unpaid and informal carers. However, a few News stories published in the early weeks of the lockdown highlighted the severe difficulties experienced by family carers of disabled children and adults during lockdown, who reported feeling forgotten and ignored, at breaking point, and “on the brink of collapse” (Coughlan, 2020; Harris, 2020; Hill, 2020; Youssef, 2020).

A report published in April 2020 identified an immediate priority of “collecting high-quality data on the mental health effects of the COVID-19 pandemic across the whole population and vulnerable groups” (Holmes et al., 2020). The data for the current study were collected in May 2020, when the UK was under a strict lockdown. We aimed to document the mental health of informal carers of children and adults with intellectual disability during the coronavirus pandemic, and to relate carers’ mental health status to the extent of social support available to them and their stress-coping strategies.

Mental health was assessed using standard screening instruments for depression (PHQ-9) and anxiety (GAD-7) and a measure of defeat and entrapment (Griffiths et al., 2015). The concept of defeat and entrapment is closely related to hopelessness, and, like hopelessness, is strongly predictive of suicide (Lester, 2012; Panagioti, Gooding, & Tarrier, 2012; Tarsafi, Kalantarkousheh, & Lester, 2015).

Social support was assessed using a customized version of the Family Support Scale (Dunst, Jenkins, & Trivette, 1984). Social support is known to provide a buffer against stress that protects against mental ill health (Cohen & Wills, 1985; Dean & Lin, 1977). There is an extensive pre-pandemic literature describing carers’ concerns about their unmet support needs and access to professional intellectual disability support services (James, 2013; McGill, Papachristoforou, & Cooper, 2006; Wodehouse & McGill, 2009). Carlson and Miller (2017) found that there are differences between actual and perceived social support; however, due to the difficulties in collecting objective data during the pandemic, we focussed on perceived social support in this research.

The shortened Ways of Coping Questionnaire (Hatton & Emerson, 1995) was used to provide measures of adaptive and maladaptive coping. A range of coping strategies have been found to be related to stress in care givers including wishful thinking, one of the scales on this measure (Rose, David, & Jones, 2003). High levels

of wishful thinking have been previously reported to be associated with low levels of life satisfaction, burnout and a poor response to mental health interventions in carers (Gilhooly et al., 2016; Hastings & Brown, 2002; Hatton & Emerson, 1995), and to predict the onset of PTSD after major trauma (Tsay, Halstead, & McCrone, 2001).

We also estimated whether the extent of mental health problems was greater than would have been seen under pre-pandemic conditions, by comparing the present data to earlier published literature.

## 2 | METHODS

### 2.1 | Participants

Potential participants, who were carers of children or adults with intellectual disability, were contacted by email via the mailing lists of three intellectual disability charities (the Challenging Behaviour Foundation, Mencap and the British Institute of Learning Disabilities). We also recruited a sample of carers of children without disabilities. (There is no obvious comparison group for carers of adults with intellectual disability, and the absence of this group is recognized in the data analysis.) Participants in the intellectual disability group were asked to pass on the invitation to participate to a friend who was the carer of a child without intellectual disability. This strategy was initially unsuccessful, but a second approach to carers in the intellectual disability groups who had responded to the survey did provide some volunteers for the comparison group, which was supplemented by approaches to personal contacts by member of the research team.

For inclusion in the study, participants were required to be: aged 18 or over; living in the UK; with access to the internet and comfortable with answering a survey online; and the primary provider of care for a child with intellectual disability (below age 18), an adult with intellectual disability (above age 18), or, for the comparison group, a child without intellectual disability (below age 18). The study received a favourable ethical opinion from the Swansea University Dept. of Psychology ethics committee [ref. 3874].

### 2.2 | Procedure

The study was designed as a brief (median completion time = 10 min) anonymous online survey presented via the RedCap online platform, hosted by Swansea Clinical Trials Unit. To reduce the administrative burden on the respondent, a single opportunity link was provided, omitting “save & return” functionality, so reducing the need for user verification of credentials, user generated passwords or keys to return to their survey. On accessing the site via the link, participants found information about the study and a consent form. They then completed the following assessments:

1. A short questionnaire reporting on demographics, household composition and contact with COVID-19 victims. Input from

representatives of family carers was taken into account when deciding what items to include.

2. Coping strategies (shortened Ways of Coping Questionnaire: Hatton & Emerson, 1995). The scale includes 7 adaptive (Problem-Solving) and 7 maladaptive (Wishful Thinking) strategies, rated on a 4-point scale of 0 (not used) to 3 (used a great deal). In the analysis, these sub-scales were treated as separate variables.
3. Social support (a customized version of the Family Support Scale: Dunst et al., 1984). The customization involved a reduction to 12 items in the number of categories of support (including a very infrequently used "other" category), and a change in some items to make them more relevant to people with intellectual disability (see Table 2 for details). Sources of support were rated on a 5-point scale from 0 (not available or not at all helpful) to 4 (extremely helpful), along with a question about how each source of support was provided.
4. Measures of anxiety (GAD-7: Kroenke, Spitzer, & Williams, 2001) and depression (PHQ-9: Spitzer, Kroenke, Williams, & Lowe, 2006). These 7- and 9-item screening instruments are widely used, inter alia within the NHS, and sometimes combined as a 16-item Patient Health Questionnaire Anxiety and Depression Scale (PHQ-ADS: Kroenke et al., 2016). Items are rated on a 4-point scale of 0 (not at all) to 3 (nearly every day).
5. Defeat/entrapment (Short Defeat and Entrapment Scale: Griffiths et al., 2015). This scale has 8 items, rated on a 4-point scale of 0 (not at all like me) to 3 (extremely like me).

At the end of the survey, participants were invited to express an interest in participating in repeat surveys and/or participating in an interview. Interviews were conducted with a sample of participants in each of the intellectual disability groups: these data will be reported separately.

## 2.3 | Stress scale

In addition to the formal scales, a 20-point objective stress scale was constructed from items of demographic data. The scale comprised three sub-scales: carer stress (10 points), reflecting severity of intellectual disability, autism and challenging behaviour (0–3 points each: none/mild/moderate/severe), with an additional point for being a lone carer; financial stress (6 points), reflecting household income (4 points: >£2,500/m = 0 down to <£500/m = 4) and household size (0–2 points, for 0, 1 or >1 other children at home); lockdown stress (up to 4 points: working from home, no garden, no room to escape to, practicing social isolation or shielding). The overall concept of the scale and the items to include were decided during the course of the study to make best use of the available data—a reflection of the crisis conditions under which the study was designed. Because the carer stress scale only applies to those with intellectual disability, the total stress score is also only meaningful for the intellectual disability groups.

## 2.4 | Analysis

Scale scores were pro-rated if they contained no more than 25% of missing data (maximum 1 or 2 items per scale); scales with more than 25% missing values were excluded from the analysis. Pro-rating was required as follows: PS:  $n = 0$ ; WF:  $n = 1$ ; GAD-7:  $n = 1$ ; PHQ-9:  $n = 11$ ; SDES:  $n = 16$ . The greater frequency of pro-rating for the PHQ-9 and SDES may reflect the painful nature of some items.

Categorical data were analysed using chi-squared tests. Quantitative data were analysed by analysis of variance (ANOVA) of data from the three groups, followed by two post hoc comparisons using Scheffe contrasts, one comparing carers of children with and without intellectual disability, the other comparing carers of children versus adults with intellectual disability. Effect sizes are reported as Cohen's  $d$  using the pooled standard deviation. Further anovas were conducted to examine the effects of severity of intellectual disability, autism and challenging behaviour on carers' perceptions of social support, and the effects of severity of challenging behaviour on individual sources of support.

Relationships between variables, analysed in the intellectual disability groups only, were explored using Pearson partial correlations, controlling for group. As initial analyses showed very similar results for the GAD-7 and PHQ-9 (see Results), subsequent correlational analyses used the combined PHQ-ADS scale.

Where results are reported below as "not significant",  $p > .05$ .

## 3 | RESULTS

### 3.1 | The sample

A total of 100 records were excluded from the analysis for the following reasons: false starts or no consent ( $n = 71$ ); partial completion ( $n = 23$ ); no age recorded for career ( $n = 6$ ).

We received a total of 244 usable questionnaires from carers, relating to adults with intellectual disability ( $n = 107$ , of which 85 were living at home, 7 were living independently and 15 were living in care), children with intellectual disability ( $n = 100$ ) and children without intellectual disability ( $n = 37$ ).

The three adult intellectual disability groups did not differ significantly on any of the variables examined (with a single exception: marginally greater coping scores, largely reflecting greater wish fulfilment, in carers of adults living in care vs. those living at home). Because the numbers were small, the two groups of adults living other than at home were not included in any of the subsequent analyses.

A UK-wide lockdown was imposed on 23 March 2020. Data for this study were collected between 28 April and 5 June 2020, the final 5 days being after a slight easing of lockdown conditions. As a result of a lack of response to the initial invitation to participate, the data for the comparison group without intellectual disability were collected in the final two weeks. However, none of the variables examined varied systematically in any group as a function of when the

data were collected. (With a single exception: as time went on, the carers of children with intellectual disability reported a decreasing overall severity of intellectual disability, autism and challenging behaviour [ $r(100) = -0.39, p < .01$ ].)

### 3.2 | Demographics

Children without intellectual disability were younger than children with intellectual disability (7.4 years vs. 11.2 years;  $p < .001$ : mean age of adults = 28.6 years) and more likely to be female (56% vs. 29%;  $p < .01$ : adults = 40%). Table 1 shows the breakdown of the cared-for samples as a function of degree of intellectual disability, autism and challenging behaviour. A small proportion (2% of adults and 11% of children) displayed autism and/or challenging behaviour but not intellectual disability. We were unable to identify instances where the inclusion of this group distorted the results presented below.

Most respondents (91%) were female and carers of children were significantly younger than carers of adults (42.1 years vs. 56.5 years;  $p < .001$ ). Thirty-four percent were lone carers. Ninety-three percent of carers (including all in the comparison group) were parents. A total of 11 households (5%; one current) had experienced COVID-19. This was a relatively affluent sample: 46% had a monthly household income during lockdown of more than £2.5K (the national median income pre-lockdown); most homes had at least 3 bedrooms (91%) and a garden (95%); reported occupations were predominantly professional or white collar.

The comparison group were more likely than carers of children or adults with intellectual disability to be working, both before the pandemic (86% vs. 55%;  $X^2 = 13.8, p < .001$ ) and during the pandemic (68% vs. 41%;  $X^2 = 8.9, p < .005$ ). Family size was similar for children with and without intellectual disability, but smaller for adults with intellectual disability (mean 1.96 vs. 0.41 children at home;  $F(2, 215) = 84.2, p < .001$ ). Otherwise, the three groups did not differ significantly in carer gender, lone carer, family income or house size.

The three groups of carers also did not differ significantly in how they received social support. Overall support was provided 28% within the home and 64% remotely, by phone (30%) or email/text

(23%), with relatively little use of video-conferencing (11%). Other means of support (28%) included outdoor conversations, social media and provision of supplies. For contact with professionals specifically, only 3% of contacts were within the home with 90% provided remotely, of which only 7% were via video-conferencing. All groups made greater use of adaptive (Problem-Solving) coping strategies than maladaptive (Wish Fulfilment) coping strategies (Table 2).

### 3.3 | Comparison of carers of children with and without intellectual disability

Carers of children with and without intellectual disability had similar use of problem-solving coping strategies, but differed on all other clinical variables (Table 2). Carers of children with intellectual disability reported significantly greater anxiety, depression, defeat/entrapment and wish fulfilment. As the two groups of children differed in age and gender, the analyses were repeated (excluding the adult group), controlling for age and gender. For all variables, the differences remained significant ( $p < .001$ ). Carers of children with intellectual disability had higher scores on all clinical variables than carers of the small group of children with autism and/or challenging behaviour but not intellectual disability, but in no case was the difference significant.

Moderate to severe levels of anxiety (GAD-7 > 10) were reported by 43% of carers of children with intellectual disability, as compared with 8% in parents of children without intellectual disability. Moderate to severe levels of depression, using a cut-off score of PHQ-9 > 10, equivalent to a diagnosis of major depression, were reported by 45% of carers of children with intellectual disability, compared with 11% of parents of children without intellectual disability. As the PHQ-9 has been reported to over-estimate the incidence of depression (Levis, Benedetti, & Ioannidis, 2020), we also implemented a higher recommended cut-off score (PHQ-9 > 14). Using this more stringent cut-off, major depression was found in 31% of carers of children with intellectual disability but only 3% of parents of children without intellectual disability. Relative to parents of children without intellectual disability, the effect size for the PHQ-9 was 0.95 (large) for carers of children with intellectual disability and 0.72

	Intellectual disability		Autism		Challenging behaviour	
	Children	Adults	Children	Adults	Children	Adults
None	11.0	2.4	18.2	12.3	5.0	12.7
Mild	15.0	13.1	15.2	16.0	25.0	17.7
Moderate	32.0	22.6	35.4	25.9	40.0	43.0
Severe	42.0	61.9	31.3	45.7	30.0	26.6

**TABLE 1** Severity of intellectual disability, autism and challenging behaviour in cared-for children and adults

Note: Values shown are percentages. Severity of intellectual disability was significantly greater in adults than in children [ $X^2 = 9.91, p < .02$ ]. The distribution of severity of autism and challenging behaviour did not differ between adults and children [ $X^2 = 4.71$  and  $4.44, p > .05$ ]. The comparison group excluded children who displayed any degree of intellectual disability, autism or challenging behaviour.

(medium) for carers of either children or adults with intellectual disability. The comparable figures for the SDES were 0.84 (large) and 0.74 (medium).

Carers of children with intellectual disability also received significantly less social support than parents of children without intellectual disability (Table 2). The sources rated as most helpful were partners, professionals and children; least helpful were neighbours, social/community groups and religious organizations. (Table 3). Relative to parents of children without intellectual disability carers of children with intellectual disability received significantly more support from professionals, but significantly less support from most other sources, particularly family (parents, children, other relatives) and friends (friends/co-workers, neighbours/local community).

Analyses of the effects of level of intellectual disability, autism and challenging behaviour on perceptions of social support by carers of children with intellectual disability showed that social support decreased as the severity of challenging behaviour increased [ $F(3, 96) = 6.90, p < .001$ ; linear trend:  $F(1, 96) = 12.28, p < .001$ ]. This relationship was not seen for severity of intellectual disability or autism [ $F(1, 96) = 1.61$  and  $0.78, p > .05$ ]. A significant decrease in some specific sources of social support as a function of the severity of challenging behaviour was also seen for family (partner, relatives) and friends (friends/co-workers, neighbours/local community) [linear trends:  $F(1, 96) = 3.11, 3.27, 4.59, 4.89, p < .05$ ].

### 3.4 | Comparison of children and adults with intellectual disability

Adults with intellectual disability were slightly more disabled than children (moderate-severe vs. moderate on average: Table 1), and their carers were somewhat less depressed (34% major depression, or 18% using the more stringent cut-off) but otherwise the two groups did not differ significantly on clinical (Table 2) or demographic variables (with the exception of family size: see above).

Social support was similar overall for carers of children and adults with intellectual disability (Table 2). Social support for adults

was unaffected by severity of intellectual disability or autism ( $F < 1$ ), but was lower in the presence of challenging behaviour. This effect was marginally significant in the overall analysis of different levels of challenging behaviour [ $F(3, 75) = 2.72, p = .051$ ] but highly significant when comparing absence versus presence of challenging behaviour [ $t(79) = 2.69, p = .009$ ]. However, unlike for children, social support did not decrease linearly with severity of challenging behaviour [linear trend:  $F(1, 75) = 3.25, p = .076$ ]: carers of adults with mild challenging behaviour were the least supported group.

Sources of social support were similar in children and adults (Table 3), with four exceptions. Carers of adults received significantly less support from day services (which were closed) than carers of children received from schools (which were open for children with special needs, albeit that fewer than 20% of children with special needs actually attended). Carers of adults also received less support from their own, presumably older, parents, and also from professionals [respectively,  $t(181-182) = 3.60, p < .001$ ;  $3.61, p < .001$ ;  $2.19, p = .030$ ]. However, they received more support from neighbours [ $t(183) = 1.97, p = .050$ ] (though still less than carers of children without intellectual disability).

### 3.5 | What determines carers' mental health outcomes and social support?

Among carers of children and adults with intellectual disability, there were strong correlations ( $r > .7$ ) between anxiety/depression (using the composite PHQ-ADS measure), defeat/entrapment and wish fulfilment. All three measures were worsened by stress and improved by social support, with anxiety/depression showing the largest effects (Tables 3 and 4). Looking separately at the stress sub-scales, carer stress weakly predicted wish fulfilment and anxiety/depression, while financial stress more strongly predicted defeat/entrapment and anxiety/depression. Additionally, total stress scores and carer stress were inversely related to social support (Table 4). None of the outcome measures differed significantly between those who were or were not sole carers (other than support

TABLE 2 Scores on clinical scales

	Children without intellectual disability		Children with intellectual disability		Adults with intellectual disability		F	df	p
	Mean	SEM	Mean	SEM	Mean	SEM			
Problem-solving	12.76	0.65	13.40	0.39	13.69	0.37	11.30	2, 221	.451
Wish fulfilment	6.11*	0.73	9.01	0.51	7.26	0.54	6.13	2, 221	.003
GAD-7	5.01*	0.67	10.02	0.61	7.97	0.63	11.02	2, 209	<.001
PHQ-9	5.17*	0.74	10.97	0.72	8.17*	0.66	12.18	2, 209	<.001
PHQ-ADS	10.18*	1.34	20.99	1.29	16.14*	1.23	12.60	2, 209	<.001
SDES	4.19*	0.85	10.69	0.92	9.43	0.93	8.48	2, 200	<.001
Social support	22.19*	1.06	16.31	0.81	14.42	0.73	14.47	2, 221	<.001

Note: GAD-7: anxiety; PHQ-9: depression; PHQ-ADS: anxiety and depression; SDES: defeat/entrapment.

\*Significantly different from children with intellectual disability.



	Children without intellectual disability		Children with intellectual disability		Adults with intellectual disability	
	Mean	SEM	Mean	SEM	Mean	SEM
Partner or spouse	3.43	0.24	2.89	0.18	2.76	0.23
Professional helpers	1.25**	0.25	2.11	0.15	1.68*	0.14
Your children	3.11***	0.18	1.90	0.13	1.93	0.19
School/day-care centre	1.57	0.28	1.81	0.17	0.95***	0.18
Friends/co-workers	3.24***	0.16	1.68	0.16	1.52	0.16
Parent groups or other parents	1.29	0.23	1.45	0.14	1.27	0.16
Your parents	2.30**	0.28	1.42	0.17	0.64***	0.16
Other relatives/kin	2.05***	0.26	0.95	0.13	1.18	0.15
Neighbours/local community	1.81***	0.25	0.93	0.12	1.25*	0.14
Social groups/clubs	1.29*	0.25	0.57	0.12	0.51	0.11
Place of worship/religious organisation	0.59*	0.20	0.24	0.08	0.41	0.17

**TABLE 3** Sources of social support for carers

Note: Sources of support are listed in decreasing order for carers of children with intellectual disability (middle column). Scores represent the helpfulness of each source of support, rated from 0 (not available or not at all helpful) to 4 (extremely helpful). \* $p < .05$ . \*\* $p < .01$ . \*\*\* $p < .001$  relative to children with intellectual disability: professional helpers, with > without; other sources, without > with.

**TABLE 4** Factors associated with mental health outcomes and social support

	Social support	Total stress	Carer stress	Financial stress	Lockdown stress	Household income	No. of bedrooms
Wish fulfilment	-.18*	.25***	.20*	.13	.13	-.19*	-.27***
SDES	-.13	.20*	.10	.24**	.09	-.27***	-.18*
PHQ-ADS	-.27***	.28***	.18*	.25**	.13	-.27***	-.22**
PHQ-ADS		.24**	.14			-.25**	-.20*
Social support		-.20*	-.18*	-.11	-.03	.18*	.18*
Social support		-.14	-.14			.12	.14

Note: Combined data for children and adults with intellectual disability. Partial correlations controlling for group: \* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$ ;  $df = 152-159$ . Values in italics show partial correlations of objective measures with PHQ-ADS after controlling for Social Support, and vice versa. SDES: hopelessness; PHQ-ADS: anxiety and depression.

from a partner, which, obviously, was lacking in sole carers; results not shown).

Further correlational analyses were undertaken to understand the effects of carer stress and financial stress.

To better understand the effect of carer stress, we examined the effects of the three components of the carer's clinical profile on anxiety/depression, defeat/entrapment and wish fulfilment. An initial analysis found that severity of autism weakly predicted all three measures [ $r(156) = .17$  to  $.19$ ,  $p < .05$ ], while correlations with severity of intellectual disability or challenging behaviour were not significant. However, intellectual disability, autism and challenging behaviour were quite strongly inter-correlated [ $r(174) = .35$  to  $.55$ ,  $p < .001$ ]: when this was taken into account (by computing partial correlations for each variable while controlling for the other two),

the effects of autism on mental health measures were no longer significant. This suggests that it is the overall burden of carer stress that impacts on carers' mental health. The same analysis revealed that social support to carers increased with severity of intellectual disability [ $r(172) = .18$ ,  $p = .017$ ], and decreased with severity of challenging behaviour [ $r(172) = -.27$ ,  $p < .001$ ].

Financial stress scores comprised two variables, low household income and family size. In order to understand the role of poverty per se, we examined the relationships between mental health measures and household income specifically, as well as another proxy measure of affluence, house size (number of bedrooms). Household income alone was more strongly related to all three mental health outcomes than the composite measure of financial stress, and the same relationships were seen for house

size. Additionally, both measures were positively correlated with social support (Table 4).

Finally, given that four objective variables (total stress, carer stress, low household income, small house size) were all associated with both poor mental health and decreased social support (Table 4), we considered whether these effects on mental health might be partially explained by a loss of social support. Correlations between the four objective measures and PHQ-ADS scores were only slightly reduced after controlling for social support (shown in italics in Table 4), confirming that carer burden impaired mental health independently of the level of social support. We also considered the opposite hypothesis that carers' mental health might alter the relationship between the objective stress measures and the social support they receive. Controlling for PHQ-ADS scores led to a somewhat larger decrease—albeit still quite small—in the correlations between total stress or household income and social support (shown in italics in Table 4), which were no longer statistically significant. This suggests that the social support that carers receive may to some extent depends on the state of their mental health.

## 4 | DISCUSSION

This study compared the carers of children and adults with intellectual disability with a group of carers of children without intellectual disability. The data were collected in the second half of the period of strict lockdown occasioned by the COVID-19 pandemic. Because of difficulties in recruitment, the comparison group was smaller, their data were collected later, and the two groups of children were not well matched on age or gender. Nevertheless, the loss of statistical power did not prevent the identification of major differences between the carers of children with intellectual disability and those without, and the differences in demographics and timing of data collection did not affect the outcomes. Despite the fact that over half of adults in the UK have experienced a worsening of their mental health during the lockdown (Mind, 2020), the prevalence of mental health problems in the comparison group in this study, at 8% for severe anxiety and 3%–11% for major depression (depending on the cut-off score used) was little worse than the national average pre-pandemic (5%–6% for generalized anxiety disorder; 3%–4% for major depression: Stansfeld et al., 2016).

In contrast, the major finding of this study is the extremely high level of mental health problems in the carers of adults and, particularly, children with intellectual disability, who had a 5-fold increase in rates of severe anxiety and a 4- to 10-fold increase (depending on the PHQ-9 cut-off used) in rates of major depression, relative to parents of children without intellectual disability. Because data collection for the study began several weeks after the start of lockdown, we cannot directly estimate whether, or to what extent, these rates of severe mental health problems exceed those experienced by carers independently of the pandemic. However, comparisons are possible with data from other studies. For example, Olsson and Hwang (2001) reported major depression (scores of > 20 on the

Beck Depression Inventory) in 8% of mothers and 2% of fathers of children with intellectual disabilities, compared with our estimates of 31%–45% depending on the PHQ-9 cut-off used. The issue of what cut-off value to use with the PHQ-9 (Levis et al., 2020) can be avoided by looking at the effect size for the difference between carers with and without intellectual disability. A meta-analysis of 18 pre-pandemic studies comparing carers of people with and without intellectual disability (mainly children, but including some studies of adults) on validated depression scales reported a mean effect size of 0.35 (Singer, 2006). This is half the effect size seen here for children and adults combined (0.72) and well under half the effect size for children alone (0.95). It is likely from these data that the mental health of carers of children and adults with intellectual disability has been adversely affected by the pandemic over and above any pre-existing mental health problems, and to a greater extent than parents of people without disabilities, in line with the general picture that the pandemic has amplified existing inequalities (Bourquin, Delestre, Joyce, Rasul, & Waters, 2020; Mind, 2020).

Carers of children and adults with intellectual disability also had elevated scores on the defeat/entrapment scale, with an effect size similar to that seen for their depression scores. Wishful thinking was also elevated in carers of children and adults with intellectual disability, and strongly related to both mental health (anxiety and depression) and defeat/entrapment. The high scores of carers of children and adults with intellectual disability on these two measures add further concern for their mental health and overall well-being.

The need to act quickly in designing this study required us to compose a scale to capture the burden caused by the sudden onset of the pandemic, with no opportunity for piloting or validation. Nevertheless, this crude measure of objective stress was systematically related to all the mental health outcome measures studied, suggesting that it may have some validity. The elements that were particularly adverse for the mental health of carers of children and adults with intellectual disability were greater care needs, especially in relation to challenging behaviour, and financial pressures, in agreement with earlier data (Meppelder, Hodes, Kef, & Schuengel, 2015). Less intuitively, challenging behaviour and poverty were associated with lower levels of social support among carers of children and adults with intellectual disability. This suggests that social support is less readily available to those whose children are more challenging, as previously reported (Cooper, Emerson, & Glover, 2014) and those with fewer financial resources, which in turn raises a question about the relationships between stress, social support and mental health. The data suggest, albeit weakly, that the deterioration of mental health associated with stress was to some extent responsible for a decreased level of social support from family and friends, consistent with a number of studies that have found that the behaviour of depressed people discourages others from offering support (Ren, Qin, Zhang, & Zhang, 2018; Stice, Ragan, & Randall, 2004; Stice, Rohde, Gau, & Ochner, 2011).

Carers of people with intellectual disability, particularly those with challenging behaviour, reported that they received less support despite their greater needs. For carers of children with intellectual disability, the dilution of social support increased with the severity



of challenging behaviour. Recent surveys reported that carers of people with intellectual disability were particularly concerned that pressures arising from the pandemic had created a loss of support from care providers (Harris, 2020; Scottish Commission for Learning Disability, 2020). Our findings suggest that they also receive considerably less support from family and friends than parents whose child does not have intellectual disability.

The very high levels of mental health difficulties in carers of children and adults with intellectual disability are of particular concern considering that the participants in this study were relatively affluent (probably as a result of the exclusively online recruitment procedure): most respondents reported professional or white-collar occupations; their homes were relatively spacious; and their average household income was close to the pre-pandemic median at a time when the national lockdown had caused the median household income to decrease by 8% (Bourquin et al., 2020). This is not typical. The average family supporting a child or adult with intellectual disability is poor (Emerson, 2007), and is also more likely to fall into poverty in response to stressful events, and less likely to escape from poverty (Emerson, Shahtahmasebi, Lancaster, & Berridge, 2010). The greatest impact of the pandemic has been on the on poorest households and pre-existing inequalities have worsened (Bourquin et al., 2020; Mind, 2020). Consequently, the present results, being based on a relatively affluent sample, almost certainly under-state the extent of the mental health problems that carers of people with intellectual disability are facing.

Because this study is a cross-sectional survey and of necessity commenced after the onset of the pandemic, we cannot be certain of the extent to which the results reflect effects of the pandemic as distinct from existing inequalities. However, relative to earlier pre-pandemic studies, the higher incidence of major depression in this sample, as well as the considerably larger effect size for the difference in mental ill health between families with or without intellectual disability, suggests strongly that the pandemic has substantially worsened the mental health of carers of children and adults with intellectual disability and the associated risks. An ongoing qualitative study and a planned longitudinal follow-up of the same cohort may shed further light on this issue.

#### 4.1 | Implications

The major findings of this study are that carers of children and adults with intellectual disability reported mental health problems well in excess of what might have been expected on the basis of the pre-pandemic literature, particularly in households with more severe challenging behaviour and greater financial pressures, and at the same time experienced lower levels of social support relative to parents of children without intellectual disability. The greater need for professional support combined with reduced levels of informal support creates serious risk for both carers and the children and adults with intellectual disability for whom they care.

Families provide long-term support, care and advocacy for their relative, often on a 24/7 basis. The COVID-19 crisis has

demonstrated how families provide the safety net when the system around them shuts down, highlighting the need to ensure they are adequately informed, supported, valued and prioritized. Family carers need support that is long-term and consistent over time. But the provision of consistent long-term support implies a reversal of the trend for community teams to engage with clients for brief episodes of care focused on specific issues. As this reflects the increasing financial pressures on community teams, it would be difficult to return to the earlier practice of long-term engagement. Nevertheless, there is a balance to be struck, in relation to a potential alleviation of pressures on teams if carers become unable to cope, which is a significant current risk (Coughlan, 2020; Hill, 2020; Scottish Commission for Learning Disability, 2020; Youssef, 2020). The NHS long-term plan includes a commitment to identify a key-worker for children and young adults with the most complex needs (NHS, 2019/20): this scheme should be extended to young people with less complex needs, and reinstated for adults. A reversal of the decline in training of learning disabilities nursing would also help, as would an effective implementation of early interventions (Cooper et al., 2014) and an increase in respite provision. There is an opportunity now to acknowledge the essential role that informal carers play and to ensure that they are appropriately and proactively supported. Not to do so creates a significant cost not only to carers, but potentially to society if mental ill health deprives them of the ability to continue in their caring role, leaving others to pick up the pieces.

There is also a need for support to be available more flexibly, such that services are prepared, under pandemic conditions, to offer support remotely via phone or electronic media, with a lesser reliance on traditional face-to-face contact. As in society more generally, the pandemic has forced mental health services to scale up their use of remote technologies (Rauschenberg et al., 2020). There are particular difficulties for people with intellectual disability, in relation to the feasibility and acceptability of remote contact, access to equipment, and confidentiality issues if carers are needed to mediate contact with services (Courtenay & Perera, 2020; Lussier-Desrochers et al., 2017). But these difficulties are much reduced in relation to contact between services and carers. Indeed, almost all of the support to the present sample of carers was provided remotely. However, it is notable that only 7% of contacts between professionals and carers, across all groups of participants, were by video. This to some extent reflects the fact that many UK adults (10% in 2018) are still internet non-users (Office for National Statistics, 2019), which is potentially problematic for poorer families caring for children and adults with intellectual disability.

The low usage of video-based contact may also reflect a poor availability of video-conferencing platforms to community teams and other professional supports. This issue also extends to interactions with other services during the pandemic. As reported from one learning disability service:

Generally, as a service, there is a lot of face-to-face contact with other agencies. This is not possible at present. Advice is to use teleconferencing where

possible. This is not as easy as it sounds. While there is access to certain options, colleagues in other agencies are using different platforms. Any proposed flexibility is likely to compromise confidentiality. To now try and become familiar with the technology and obtain the relevant headsets and webcams with brains already overloaded by the surge of changing information is a huge pressure

(Hughes & Anderson, 2020).

Hopefully, these practical problems are being resolved, and services will be better prepared for remote working the next time it is needed.

The extent of serious mental health problems among carers of people with intellectual disability also suggests that many carers would benefit from access to specialist mental health support, over and above that which can be provided by community learning disability teams. But the mental health of carers is not seen as falling within the remit of learning disability specialists, who typically would not take a professional interest in carers' mental health (other than in an initial carer's assessment), and would not be alert to the need for a referral to mental health services. Learning disability nurses in particular should be made aware of the risks to carers' mental health and encouraged to address them more proactively. This could be either by offering direct mental health support to carers from within the team, which would probably require changes to commissioning arrangements, or, more usually, by making onward referrals. There may also be scope to provide assistance to carers of people with intellectual disability through the medium of peer support groups (Wei et al., 2012), as has proved successful for carers of people with dementia (Chien et al., 2011).

The extremely high level of unmet mental health needs among informal carers of children and adults with intellectual disability represents a risk both to themselves and to those for whom they care. While community teams represent the front line of support, there is a wider responsibility for addressing those needs. Alongside a rethink of their strategy for supporting care homes during a pandemic, the UK government also needs to consider how better to support informal carers of people with intellectual disability, and to consider them as a priority group for support. For example, carefully planned and funded arrangements should be in place for day services for adults to stay open during a pandemic and provide more individually tailored and flexible support, and respite care should remain available to give carers a break. Strict lockdown is likely to be particularly difficult, so families with children and adults with intellectual disability need to be allowed more leeway than non-intellectually disabled families. This did happen to some extent during the pandemic, in that, following legal challenge, families with children and adults with intellectual disability were allowed out more than once a day after the first few weeks of lockdown (Walker, 2020). However this should not have required a legal challenge. Another strategy that might be considered by government is to publicize the need for support for such families. Neighbours were encouraged to support older

people during the pandemic: support for families caring for children and adults with intellectual disability should also be similarly encouraged (particularly considering that they currently receive less support than comparable families without intellectual disability). Finally and importantly, it will be essential to consult families as to what else might help, so that support can be planned and implemented well in advance of it next being needed.

## ORCID

Paul Willner  <https://orcid.org/0000-0001-5576-5260>

John Rose  <https://orcid.org/0000-0003-2672-9767>

Glynis H Murphy  <https://orcid.org/0000-0001-7817-5861>

Peter E Langdon  <https://orcid.org/0000-0002-7745-1825>

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