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The cost of mental health disability to families in childhood and adolescence in the United Kingdom: findings from a repeated cross-sectional survey using propensity score matching

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3 1 **The cost of mental health disability to families in childhood and adolescence in the United**
4 2 **Kingdom: findings from a repeated cross-sectional survey using propensity score matching**

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28 19 score matching.
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ABSTRACT

Objective: Since 1992, UK families of disabled children have been entitled to receive disability benefits to help meet costs associated with caring for their disabled child. Evidence of actual costs incurred is scant, especially for mental health disability. The aim of this study was to quantify the cost of mental health disability in childhood and adolescence to families in the UK using the concept of compensating variation (CV).

Design: Repeated cross-sectional survey.

Setting: UK general population

Participants: 85,627 children drawn from eight waves of the Family Resources Survey.

Outcomes: We used propensity score matching to match families with a disabled child to similar families without a disabled child and calculated the extra income the former require to achieve the same living standards as the latter, i.e. their CV. We calculated the costs specifically associated with mental health and physical health disability, using several definitions of each.

Results Families of a child with any mental health disability, regardless of the presence of physical health comorbidity, needed an additional £33 per week to achieve the same living standards as matched families without a disabled child. This difference was greater for more deprived families, who needed £42 to £61 more per week depending on the extent of mental health disability. Economically deprived families of a child with a physical health disability required an additional £25 per week to meet the same living standards of a family without a disabled child. More deprived families with a child with mental health disabilities were undercompensated by £8-£15 per week under the current benefits system.

Conclusions Mental health disability among children and adolescents was associated with relatively high costs for the family compared with physical health disability, especially for those from deprived economic backgrounds. Means testing could help achieving a more equitable redistribution of disability benefit.

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3 62 **Strengths and Limitations**
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- 5 63 • Strengths of this study are the use of: (i) large and rich dataset representative of the UK
6 64 population; (ii) disability domains employed in the Disability Discrimination Act (DDA) consistent
7 65 with definitions applicable to policy settings; and, (iii) novel analytical approach based on
8 66 propensity score matching.
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11 67 • Limitations of this study are: (i) its cross-sectional design; (ii) difficulties in disentangling physical
12 68 and mental health disabilities (which are often co-occurring); and, (iii) data limitations making it
13 69 problematic to account for severity of disability and to measure living standards.
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INTRODUCTION

Families of children suffering from chronic conditions and physical and mental health disabilities incur significantly higher costs than those of their healthy counterparts.¹⁻⁵ These costs are primarily accounted for by more frequent visits to inpatient and outpatient departments and by greater use of prescribed drugs,¹⁻³ although evidence also suggests that the need to provide or secure informal care adds to the financial burden of child disability for these families.^{4,5} Previously, UK studies have estimated the cost of having a disabled child at about £79-£100 per week⁴ and that under the benefits arrangements at the time (1997) families of disabled children were undercompensated by £30-£80 per week⁴ and by £28 in 2001.⁵ More recent evidence has estimated that in the UK families of severely disabled children require up to an additional £79 per week to be able to meet the same living standards of those without disabled children, a figure that does not find correspondence in disability benefits that these families receive (i.e., up to £71 per week).⁶

Mental health conditions account for a great portion of the burden of disease among children and adolescents below the age of 16 years.⁷ Onset of most mental health conditions occurs at different stages of childhood and adolescence: developmental and hyperkinetic disorders become manifest in early childhood, whilst depressive (including suicide and self-harm), psychotic, anxiety, conduct, and eating disorders most commonly arise in adolescence and young adulthood.⁸ Evidence suggests that in the UK there has been a trend towards increasing rates of children and young people suffering from mental health conditions since the 1980s.⁹ The 2004 British Child and Adolescent Mental Health Survey (B-CAMHS) conducted by the Office of National Statistics (ONS) reported that 10% of children aged 5 – 16 years met diagnostic criteria for a mental health disorder.¹⁰

A socio-economic gradient exists in the distribution of child mental health disorders¹¹⁻¹³. In the 2004 B-CAMHS, prevalence of diagnosable child mental health conditions was higher among single-parent (15.6%) compared to married or co-habiting (7.7%) households; among families with low (16.1%) compared to high (5.3%) income; and among families whose parents had no academic qualifications (17.0%) compared to those with university degrees (4.4%)¹⁴. Evidence exists that life adversities are a risk factor for the onset of mental health conditions as well as that mental health problems of the child can lead to family breakdown and unemployment¹⁴.

Both mental health problems and socio-economic disadvantage in childhood and adolescence can have enduring effects and significantly impact on a young person's future. Children and adolescents suffering from mental health problems more often report low levels of academic achievement, and

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3 104 engage in risk-behaviours such as alcohol and drug use with detrimental effects on employment
4 105 prospects¹⁵. Similarly, childhood experience of economic hardship can result in long-term adverse
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6 106 health outcomes via the persistence of lower socio-economic status¹⁵.
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10 108 Since 1992, in the UK, families of children affected by disability have been eligible to receive a non-
11 109 means-tested weekly Disability Living Allowance (DLA).¹⁶ The rationale for these benefits is that
12 110 they “*may help with the extra costs of looking after a child who: is under 16; has difficulties walking*
13 111 *or needs more looking after than a child of the same age who doesn’t have a disability*”.¹⁶ The
14 112 amount of benefits that the family is entitled to receive largely depends on the severity of the child’s
15 113 condition, which is determined by the disability service centre often in conjunction with external
16 114 assessments. In 2014, under the care component of DLA, children could receive either £21.80 (if
17 115 they needed a little help during the day or night), £55.10 (if they needed frequent supervision), or
18 116 £82.30 (if they needed constant help day and night, or were terminally ill) per week. Under the
19 117 mobility component of DLA, children were entitled to receive between £21.80 (if they could walk but
20 118 needed supervision outdoors) and £57.45 (if they could not walk, if walking represented a health
21 119 risk, or if they were blind) per week.
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31 121 Previous UK studies have shown that families of disabled children incur high costs, but were
32 122 however unable to attribute these extra expenditures to either physical or mental health disability,
33 123 which has been shown to inflict a substantial economic burden in other settings.^{2,3} In the absence of
34 124 literature exploring the cost of child mental health disability to families, and the rising prevalence of
35 125 these problems, the aims of this study are to: (1) investigate the cost to families of having a child
36 126 with a mental health disability; (2) compare the costs of mental health versus physical health
37 127 disability; and, (3) examine how these costs vary by economic deprivation. We use repeated cross-
38 128 sectional data from the Family Resources Survey (2004/05 – 2011/12).
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47 131 MATERIALS AND METHODS

48 132 Sample

49 133 We employed data from eight consecutive rounds of data collection from the Family Resources
50 134 Survey (FRS) covering the financial years 2004/05 to 2011/12. The FRS is a repeated cross-sectional
51 135 survey of private households in the UK undertaken by the Department of Work and Pensions (DWP)
52 136 with the aim of collecting data on the financial and social circumstances of private households.
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54 137 Although representativeness of the older age groups within the population might be limited in FRS
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3 138 due to the focus on private households (nursing and retirement homes are not included), the overall
4 139 sample, used in this study, is representative of the UK population ¹⁸, and our focus on families with
5 140 children under 16 years of age means this is unlikely to introduce a bias.
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9 142 Our sample includes all children aged 0-15 years and their families with complete data on all
10 143 variables included in the model covariates and necessary to estimate the CV (i.e. income and living
11 144 standards). We excluded families with more than one disabled child because of difficulties
12 145 separating the effects of multiple disabled children in the same family (2.7% of total children).
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17 147 **Child mental and physical health disability**

18 148 In line with the definition of disability included in the Disability Discrimination Act (DDA) 1995 and
19 149 2005, the FRS defines a child as having a disability if they have a longstanding illness lasting longer
20 150 than 6 months and affecting their ability to undertake daily activities. Families were asked if their
21 151 child had any longstanding illness, disability or infirmity. Families responding 'yes' were directed to a
22 152 set of follow up questions asking which area of the child's life was affected by their disability.
23 153 Possible answers were: mobility; lifting; manual dexterity; continence (i.e. bladder control);
24 154 communication (i.e. speech, hearing, or eyesight); memory and learning; recognition of physical
25 155 danger; physical coordination; other; or, none of these areas. As we were not able to define their
26 156 disability either as affecting physical or mental health, we excluded children whose family claimed
27 157 had a disability but subsequently said that none of these areas were affected by disability (3.4% of
28 158 total children).
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38 160 Of these eight disability domains, we assume that memory and learning, and recognition of physical
39 161 danger can be attributable solely to mental health problems, as they are related to cognitive
40 162 impairment. We assume all other areas primarily reflect physical health problems ¹⁹, but
41 163 acknowledge these domains could also be affected by, or affect, mental health status. For ease of
42 164 explanation, we will hereafter refer to memory and learning, and recognition of physical danger as
43 165 'mental health' disability areas, and mobility, lifting, manual dexterity, continence, communication,
44 166 and physical coordination as 'physical health' disability areas.
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51 168 Using this distinction we defined disability accounting for: 1) presence of comorbidity between
52 169 mental and physical disability; 2) number and type of areas affected by disability. Therefore we
53 170 created 6 disability groups defined as follows:
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- 56 171 • Group 1: Any (either or both domains) mental disability (no physical disability);
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3 172 • Group 2: Any physical disability (no mental disability) (group 1 & 2 are mutually exclusive);
4 173 • Group 3: Any mental disability (either domains, with or without physical disability);
5 174 • Group 4: Both mental disability (both domains, with or without physical disability);
6 175 • Group 5: Any physical disability (with or without mental disability);
7 176 • Group 6: No disability.

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13 178 We did not create a separate group for children with both mental health domains affected by
14 179 disabilities, but no physical disability as the numbers were too low. Under the same rationale we did
15 180 not include a group with children affected by disability in all of the physical health domains due to
16 181 low numbers. We compared these groups as follows:

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19 182 • Comparison A: Group 1 versus Group 6;
20 183 • Comparison B: Group 2 versus Group 6;
21 184 • Comparison C: Group 3 versus Group 6;
22 185 • Comparison D: Group 4 versus Group 6;
23 186 • Comparison E: Group 5 versus Group 6.

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29 188 By allowing for comorbidity between mental and physical health disability in groups 3, 4, and 5, we
30 189 attempt to explore whether these disability groups could represent more severe conditions
31 190 compared to groups 1 and 2. Physical health impairments are more common in children with mental
32 191 health problems ¹⁴ similarly, physical health disability can adversely affect mental health ²⁰. We
33 192 hypothesise that if the cost of mental health disability is greater than that of physical health
34 193 disability we should see a positive CV for groups 1, 3, and 4 and this will be greater in magnitude
35 194 than that observed in groups 2 and 5.

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42 196 It is possible, however, that both physical and mental health have a positive and significant impact
43 197 and, although the magnitude of the CV across the previously defined groups can give an indication of
44 198 the overall impact of mental and physical health disability on the costs borne by the family, it is
45 199 important to attempt to quantify their relative impact. Therefore, in order to investigate our second
46 200 aim we ran three additional models comparing the exposed group against both children without
47 201 disabilities and children who had a disability 'other' than that employed to define the main
48 202 exposure. For example, children with any or both (all) 'mental (physical) health disabilities' plus
49 203 other physical (mental) health comorbidities were compared with children with no disabilities and
50 204 children with only physical (mental) health comorbidities. We defined these models as:

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55 205 • Comparison F: Group 3 versus Group 6 and Group 2;

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- 206 • Comparison G: Group 4 versus Group 6 and Group 2;
207 • Comparison H: Group 5 versus Group 6 and Group 1

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209 **Living standards**

210 Material deprivation is measured in the FRS through a set of 21 questions asking whether the family:
211 (i) can afford and has; (ii) would like to have, but cannot afford; or (iii) can afford, but does not want
212 a number of goods previously identified as necessities by families without (10 questions) and with
213 (11 questions) children²¹. We employed a sub-set of these questions (M= 12) asked to the whole
214 sample at each survey wave included in our study and developed a living standards index (*LSI*) using
215 prevalence weighting²² with weights representing the proportion of families considering the item a
216 necessity. We calculated the *LSI* as follows:

$$217 \quad LSI = \frac{\sum_{i=1}^M x_i w_i}{\sum_{i=1}^M w_i} \quad (1)$$

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219 In Eq.(1), x_i is a binary variable indicating whether the family can afford each item (1='yes, can afford
220 and has it'; or 'yes, can afford, but does not want', 0='would like to have, but cannot afford), w_i is the
221 proportion (i.e. weight) of respondents who consider the item desirable, as defined above²² and M
222 is the number of items.

223 A total of 10% of families in our sample had missing data for one or more of these questions. In
224 order to derive a *LSI* value for these families, we scaled the score they obtained from the questions
225 they answered on the total score they could have obtained if they had could afford each of the items
226 they were asked about ($\sum_{i=1}^M w_i$).

227 Finally, from the continuous *LSI* ranging from 0 to 1 (distribution in Figure 1) we defined families with
228 a $LSI=1$ as having 'high living standards', since they could afford each item included, and families with
229 $LSI<1$ as having 'low living standards' as they could not afford one or more of the items. We
230 employed continuous values of the *LSI* to match families using propensity scores and the derived
231 binary variable to conduct sub-group analyses.

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233 **Income**

234 We derived a measure of income accounting for all available resources affecting living standards^{17,23},
235 including net income from all sources (i.e. earnings, self-employment, investments, and pensions) as
236 well as from any benefits, including disability benefits, received by the family. Disability benefits
237 were included because if a family receives benefits, its ability to achieve a given level of living

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3 238 standards is dependent upon their receipt. We inflated incomes to 2011/12 prices. We did not
4 239 employ an equivalised measure of income for ease of interpretation of the results (i.e., our unit of
5 240 analysis is the benefit unit and equivalised income is a measure of income per person); however, in
6 241 order to account for family composition we included variables indicating number of adults and ages
7 242 of children in the matching stage of the analyses (see below), in line with previous literature ^{23,24}.
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9 243 Values of net income are reported 'per week' in the FRS.
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14 **Other variables**

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16 246 In our analyses we match families with and without a disabled child on a number of socio-
17 247 demographic and socio-economic characteristics of the families and their children. We included
18 248 indicators of the child's age (linear term) and gender (male/female); two linear terms for number of
19 249 dependent children in the family (range 1-8) and number of years of schooling after the age of 18
20 250 years (i.e. the age at which compulsory education ends in the UK) of the head of the household and
21 251 their marital status (single/couple); presence of a disabled adult (yes/no), and to account for family
22 252 wealth, a categorical variable indicating family savings banded in five categories.
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29 254 We also included a categorical indicator for survey year and UK Government Office Region (London;
30 255 South East; Rest of England; Northern Ireland, Wales and Scotland¹).
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33 **Data analysis**

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35 258 We described how sample characteristics vary by disability group using cross-tabulations with Chi-
36 259 Square tests and ANOVAs for categorical and continuous variables, respectively.
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40 261 We employed the 'compensating variation' (CV) approach to calculate the cost of child disability,
41 262 which has been previously used in studies of disability in adults ¹⁷. The CV can be defined as the
42 263 additional income that a family with a disabled child needs to be able to achieve the same living
43 264 standards of a family that is similar in all other respects but without a disabled child. More details on
44 265 the theoretical approach can be found in the supplementary material. We used Propensity Score
45 266 Matching (PSM) ^{25,26} to match families according to comparisons A – F and calculate the CV (i.e. the
46 267 mean income difference). It has been suggested that this approach, by simulating a randomised
47 268 controlled trial setting, can provide a more unbiased estimate of the income difference than
48 269 parametric models in observational studies ¹⁷.
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57 ¹ Rest of England includes: North East, North West & Merseyside, Yorkshire & Humberside, East Midlands,
58 West Midlands, and South West.
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3 271 We calculated propensity scores (i.e. predicted probabilities) from multivariate probit regression
4 272 models with each of our group allocations in the comparisons defined above (Comparisons A to H) as
5 273 the outcome (e.g., for Comparison A, participation in Group 1 is coded 1 and Group 6 is coded 0, all
6 274 other groups are coded as missing). In all models the independent variables were child age and
7 275 gender, number of children and disabled adults in the family, years of schooling of the main
8 276 respondent, marital status, family savings, government region and survey year. Additionally, for
9 277 comparisons F, G, and H we also controlled for areas of disability (other than those defining the
10 278 Group) as covariates. For all models we calculated areas under the receiver operating characteristic
11 279 (ROC) to estimate goodness of fit of the model. More details on the PSM theoretical approach are in
12 280 the supplementary material.

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16 281 For each matching pair obtained with this matching approach we calculated the CV and 95% CI²⁸.
17 282 Finally, we compared the CV with the mean (SD) amount of disability benefits received by each
18 283 group. All our analyses were run using Stata13.²⁹

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285 RESULTS

286 Sample characteristics

287 From an initial sample of 99,142 children, we excluded families with a disabled child whose disability
288 could not be described in terms of one of the 9 main disability areas (N=3,460, 3.4%) and those with
289 more than one disabled child (N= 2,600 children, 2.7%) . After excluding children with any missing
290 data on the variables of interest the final sample consisted of 85,627 children.

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292 The majority of children included in our sample were male (51.05%), lived in a two-parent family
293 (74.79%), did not live with an adult with a disability (84.13%), lived in a family whose total savings
294 were less than £1,500 (53.41%), and lived in the 'rest of England' (50.50%) (Table 1). Mean child age
295 was 7.42 years (standard deviation (SD) = 4.69), mean number of dependent children in the
296 household was 2.19 (SD=0.99), and mean number of years spent in education past the age of 18
297 years by the main respondent was 1.08 (SD=2.15).

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299 Child disability

300 In total, 1,794 (2.1%) children had some type of mental health disability, irrespective of the presence
301 of physical disabilities, and 356 children (0.4%) had mental health disability without physical health
302 disability (Table 1). A greater number of children had physical health disability, either with (2,703,
303 3.2%) or without (1,135, 1.3%) mental health problems, respectively.

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5 305 Compared to children without any disabilities, and for all definitions of disabilities, more children
6 306 with disabilities were male, lived in a single parent household and with an adult also affected by
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8 307 disability, had a parent who spent less time in education and had fewer savings, and were older
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10 308 (Table 1).

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13 310 Across low and high living standards, families of children with any type of disability had lower
14 311 income than those of children without disabilities (Table 2); in every disability group income was
15 312 higher in families with higher living standards. Among families with low living standards, families of
16 313 children with both mental health areas affected by disability had higher income than those without
17 314 disability, whereas families of children with any mental or physical health only had lower income.
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19 315 Among families with high living standards, families of children affected in any of the physical or
20 316 mental health disability areas or in both the mental health areas, regardless of other areas affected,
21 317 had lower income compared to families of children without disabilities.

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27 319 **Compensating variation**

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29 320 Families of children with any or both mental health disabilities (Group 3) needed an additional
30 321 £33.20 in order to achieve the same living standards of similar families without a disabled child
31 322 (Group 6; Comparison C), across both levels of LS (Table 3). When pooling across living standards, we
32 323 did not find any other differences in any of the other disability groups.

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37 325 When we split the sample by low and high levels of living standards, we found that in some cases
38 326 families of a disabled child needed a higher net income to meet the same LS of families without a
39 327 disabled child. Specifically, we found that families of a child with any mental health disability or both
40 328 mental health disabilities (with or without physical disabilities) required £42.03 (Group 3,
41 329 Comparison C) and £60.62 (Group 4, Comparison D) more than a family without a disabled child
42 330 (Table 3). We also found an income difference, albeit smaller, for families of children with disability
43 331 affecting physical health areas compared to families of non-disabled children, with the former
44 332 needing £25.31 (Group 5, Comparison E) more to achieve the same LS.

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51 334 When we compared children affected by disability in any, or both mental health areas and in any
52 335 physical health areas, regardless of the presence of other disabilities, against children without
53 336 disabilities and other with physical and mental health disabilities respectively (i.e., in groups 6-8), we
54
55 337 found that families of children with both mental health areas affected by disabilities needed £52.38

338 more per week to achieve the same LS if in the low LS category (Table 3). We did not find any
339 differences for the other groups, in particular those with high living standards.

340

341 **Benefits**

342 Families of children with both mental health disabilities received the highest amount of weekly
343 benefits (mean value £45.84), followed by those with any mental health disabilities (£34.44), and
344 those with any physical health disabilities (£26.21) (Table 4). Children only affected in either or both
345 mental health areas received on average £17.24 per week whilst those affected in any or all physical
346 health domains only received £10.64. The amount of benefits received did not vary by LS, reflecting
347 the absence of means testing for disability benefits.

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349 Families of children with mental disabilities, regardless of presence of physical disabilities (group 3)
350 on average received £34.44 per week in benefits, which closely matches the extra income needed to
351 provide for their child (£33.20). However, when grouping these families according to LS the amount
352 needed by families with low LS (£42.03) exceeded that which they received as benefits (£34.26),
353 suggesting these families were undercompensated by the current benefits system. Similarly,
354 although no overall income differences were seen for families with children with both areas of
355 mental health disability affected (regardless of other physical disabilities, group 4), families with low
356 LS needed a higher weekly income (£60.62 extra) to provide for their child, whereas they only
357 received (£46.05) through benefits. Finally, families of children with physical disability (regardless of
358 mental disability) living in low LS seemed to be adequately compensated as they received £26.07
359 whilst needed an extra £25.31. No other significant income differences were noted for the remaining
360 groups, although all of them were in receipt of benefits, suggesting that, potentially, these families
361 were overcompensated for their child's disability.

362

363 **DISCUSSION**

364 Little evidence exists on the costs borne by families of children affected by mental health disability in
365 the UK. To the best of our knowledge, this is the first UK study aiming to quantify these costs using
366 propensity score matching and a compensating variation approach to estimate cost of mental health
367 disability.

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369 We found no difference in income between families of children with a disability affecting any or all
370 areas associated with mental health problems only and families of non-disabled children. When we
371 allowed for existence of physical health comorbidities, we found that these families needed an

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3 372 additional £33 per week compared to families of non-disabled children to achieve the same living
4 373 standards. This difference was even greater for families with low living standards (£42). When we
5 374 compared children with both mental health areas affected by disability as well as possible comorbid
6 375 conditions related to physical health we did not find an overall difference in income, however we
7 376 found a high and positive CV of approximately £61 for children of families with low LS. In
8 377 comparison, families in the same LS group, with children affected by physical health had a positive,
9 378 but smaller in magnitude, CV (£25). When we tested the relative impact of mental and physical
10 379 health on the CV, by allowing our comparator group to have disabilities in the opposite domains of
11 380 the one under investigation, we found a positive and significant CV for children affected in both
12 381 mental health disabilities who live in families with low LS (£53).
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21 383 We compared these amounts against benefits received, in order to investigate if these families were
22 384 adequately compensated for the costs associated with their child's disability. We found that overall
23 385 children with any mental health disabilities were adequately compensated (CV=£33, mean
24 386 benefits=£34) and so were families of children with physical health disabilities with low LS (CV=£25,
25 387 mean benefits= £26). We also found, however, that families of children with any or both mental
26 388 health disabilities with low LS were undercompensated under the current benefit scheme (any
27 389 mental health: CV=£42, mean benefit=£34; both mental health: CV=£61, mean benefits=£46).
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34 391 These results suggest that mental health disabilities in childhood are associated with substantial
35 392 costs, which need to be borne by their families. In other words, families of children with mental
36 393 health disabilities need to have higher income in order to achieve the same living standards of a
37 394 family without a disabled child. These costs appear to be higher when there are co-occurring mental
38 395 and physical disabilities, possibly an indicator of severity of the condition, and for more economically
39 396 deprived families. These families also appear to be undercompensated under current benefit
40 397 arrangements.
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47 399 Our findings on the cost of child disability are lower from those found by Dobson and colleagues
48 400 estimating the cost of child disability to the family at £100 per week^{4,5}. Compared to these studies,
49 401 we also found that undercompensation occurred to a lower extent, in the range of £8-£15 and only
50 402 for deprived families with children with mental health disabilities, as opposed to £30-£80⁴ and £24⁵.
51 403 One reason for this difference could be that these studies employed convenience sampling (i.e.
52 404 selecting children with more severe disabilities and living in more deprived settings) and different
53 405 definitions of disability, which did not clearly distinguish between mental and physical health.
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4 407 This study had several strengths. It employed a large and rich dataset representative of the UK
5 408 population. The FRS also makes use of the disability domains employed in the DDA to define areas
6 409 affected by disability, which makes it consistent with definitions applicable to policy settings. We
7 410 also employed a novel approach which allowed us to match families not only based on their
8 411 propensity scores distribution, but also on the values of living standards with exact matching to the
9 412 first decimal digit. Nevertheless, several limitations should be accounted for. First, we could only
10 413 give an approximate definition of mental and physical health disability, knowing that areas which we
11 414 have considered as physical health could be affected as a result of mental health disability only.
12 415 Nevertheless, our approach represents a first attempt at both costing the impact of mental health
13 416 disabilities on families and disentangling the relative effect of mental and physical health disability.
14 417 We were also unable to explore the effect of severity of disability or of different types of disabilities
15 418 given the nature of the available variables. Future studies should attempt to include specific
16 419 diagnoses, perhaps including sub-clinical presentations as separate categories in order to account for
17 420 varying degrees of severity. A total of 10% had missing data on LS measures; although we calculated
18 421 our index re-scaling the latter to the number of questions each family had answered, it is not
19 422 possible to rule out the possibility that under/over-estimation of the LSI value for these families
20 423 could have occurred. Moreover, our living standards measure provides an indication of what goods
21 424 the family can afford, but not of their quality. However, values of mean income by low/high LSI
22 425 seemed to suggest that the latter adequately describes the intended groups. The sample size for
23 426 some of our disability definitions was small meaning that we could have incurred in type II error and
24 427 failed to observe an income difference when indeed there was one. Due to the cross-sectional
25 428 nature of the study, it was not possible to estimate the CV in the absence of benefits, as the latter
26 429 contribute, when received, to the LS achieved by the family. This approach would have given a
27 430 clearer indication of the income difference between families with and without a disabled child. In
28 431 fact, based on our estimates, we are not able to tell, if we do not observe a difference in income,
29 432 whether an actual difference would have occurred in the absence of the benefits system. By
30 433 comparing the CV to the amount of benefits received, we however attempted to estimate whether
31 434 the family was currently over or undercompensated. Finally, our propensity score model could have
32 435 been improved by including more precise indications of family structure and parental education, as
33 436 well as a greater number of family and child characteristics, such as parental employment, child
34 437 emotional problems or school attainment. Future studies should endeavor to be more inclusive in
35 438 order to improve model prediction.

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3 440 In conclusion, we found that mental health in childhood and adolescence is associated with high
4 441 costs, which need to be borne by the family. Our findings indicate that families of children from
5 442 more disadvantaged backgrounds are currently undercompensated by the disability benefits system.
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7 443 Based on these findings we suggest that mental health should be better defined as a criterion for
8 444 receiving benefits and that the amount of disability benefits that a family is entitled to receive are
9 445 subject to means testing, so that families from more deprived socio-economic backgrounds could be
10 446 entitled to higher benefits amounts.
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21 451 Helen Roberts, Cathy Street, Russell Viner and Miranda Wolpert.
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453 **Authors' contributions**

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29 454 Francesca Solmi: Contributed to designing research question and study designed, analyzed data,
30 455 wrote manuscript.
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32 456 Maria Melnychuk: Contributed to designing research question and study designed, analyzed data,
33 457 contributed to manuscript revision.
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35 458 Steve Morris: Contributed to designing research question and study designed, contributed to
36 459 manuscript revision, supervised data analyses and the overall project.
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527 **TABLES and FIGURES**

528 **Figure 1. Distribution of LSI**



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Peer review only

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Table 1: sample characteristics

Group	All, N (%)	Child disability					
		No disability N (%)	Any Mental Health only N(%);P (χ^2)	Any Physical Health only N (%);P (χ^2)	Any Mental Health N (%); P (χ^2)	Both Mental Health N (%); P (χ^2)	Any Physical Health N (%); P (χ^2)
		6	1	2	3	4	5
Total	85,627(100%)	81,307(94.95%)	356(0.4%)	1,135(1.3%)	1,794(2.1%)	986(1.2%)	2,703(3.2%)
Gender of child			$p < 0.0001$	$p < 0.0001$	$p < 0.0001$	$p < 0.0001$	$p < 0.0001$
<i>Male</i>	43,711(51.05%)	40,970(50.39%)	273(76.69%)	642(56.56%)	1,307(72.85%)	726(73.63%)	1,742(64.45%)
<i>Female</i>	41,916(48.95%)	40,337(49.61%)	83(23.31%)	493(43.44%)	487 (27.15%)	260(26.37%)	961(35.55%)
Government Region			$p=0.09$	$p=0.276$	$p=0.02$	$p=0.01$	$p=0.029$
<i>London</i>	8,743(10.21%)	8,365(10.29%)	26(7.30%)	101(8.90%)	164(9.14%)	85(8.62%)	252(9.32%)
<i>South East</i>	9,996(11.67%)	9,498(11.68%)	52(14.61%)	145(1.78%)	217(12.10%)	134(13.59%)	330(12.21%)
<i>Wales, Scotland, Northern Ireland</i>	23,566(27.52%)	22,420(27.57%)	91.25.56%	303(26.70%)	451(25.14%)	240(24.34%)	695(25.71%)
<i>Rest of England</i>	43,332(50.59%)	41,024(50.36%)	187(52.53%)	586(51.63%)	962(53.62%)	527(53.45%)	1,426(52.76%)
Marital status			$p < 0.0001$	$p < 0.0001$	$p < 0.0001$	$p < 0.0001$	$p < 0.0001$
<i>Single</i>	21,586(25.21%)	19,934(24.52%)	159(44.66%)	434(38.24%)	685(38.18%)	368(37.32%)	1,012(37.44%)
<i>Couple</i>	64,041(74.79%)	61,373(75.48%)	197(55.34%)	701(61.76%)	1,109(61.82%)	618(62.68%)	1,691(62.56%)
Adult with disability in BU			$p < 0.0001$	$p < 0.0001$	$p < 0.0001$	$p < 0.0001$	$p < 0.0001$
<i>No</i>	72,040(84.13%)	69,231(85.15%)	252(70.79%)	745(65.64%)	1,220(68.00%)	655(66.43%)	1,793(66.33%)
<i>Yes (at least one parent)</i>	13,587(15.87%)	12,076(14.85%)	104(29.21%)	390(34.36%)	574(32.00%)	331(33.57%)	910(33.67%)
Year			$p=0.057$	$p=0.563$	$p=0.35$	$p=0.23$	$p=0.789$
2004/05	12,822(14.97%)	12,232(15.04%)	64(17.98%)	166(14.63%)	262(14.60%)	130(13.18%)	385(14.24%)
2005/06	11,640(13.59%)	11,044(13.58%)	46(12.92%)	167(14.71%)	241(13.43%)	119(12.07%)	379(14.02%)
2006/07	11,150(13.02%)	10,603(13.04%)	34(9.55%)	160(14.10%)	208(11.59%)	120(12.17%)	357(13.21%)
2007/08	10,411(12.16%)	9,857(12.12%)	51(14.33%)	125(11.01%)	247(13.77%)	135(13.69%)	346(12.80%)
2008/09	10,414(12.16%)	9,888(12.16%)	54(15.17%)	127(11.19%)	226(12.60%)	120(12.17%)	311(11.91%)
2009/10	10,279(12.00%)	9,744(11.98%)	46(12.92%)	134(11.81%)	223(12.43%)	121(12.27%)	322(11.91%)
2010/11	10,353(12.09%)	9,829(12.09%)	34(9.55%)	150(13.22%)	211(11.76%)	136(13.79%)	338(12.50%)
2011/12	8,558(9.99%)	8,110(9.97%)	27(7.58%)	106(9.34%)	176(9.81%)	105(10.65%)	265(9.80%)

Table 1 (continued)

Group	Child disability						
	All, N (%)	No disability N (%)	Any Mental Health only N(%);P (χ^2)	Any Physical Health only N (%);P (χ^2)	Any Mental Health N (%); P (χ^2)	Both Mental Health N (%); P (χ^2)	Any Physical Health N (%); P (χ^2)
	6	1	2	3	4	5	
Total savings			<i>p</i> <0.0001	<i>p</i> <0.0001	<i>p</i> <0.0001	<i>p</i> <0.0001	<i>p</i> <0.0001
No savings	4,116(4.81%)	3,857(4.74%)	24(6.74%)	63(5.55%)	95(5.30%)	48(4.87%)	146(5.40%)
Savings less than £1,500	46,241(54%)	43,428(53.41%)	224(62.92%)	730(64.32%)	1,164(64.88%)	634(64.30%)	1,756(64.96%)
Savings over £1,500 and up to £20,000	22,001(25.69%)	21,198(26.07%)	69(19.38%)	218(19.21%)	352(19.62%)	210(21.30%)	516(19.09%)
Savings over £20,000	10,609(12.39%)	10,240(12.59%)	34(9.55%)	99(8.72%)	154(8.58%)	79(8.01%)	234(8.66%)
Did not want to say	2,660(3.11%)	2,584(3.18%)	5(1.40%)	25(2.20%)	29(1.62%)	15(1.52%)	51(1.89%)
	Mean (SD)	Mean(SD)	Mean(SD) P(F)	Mean(SD) P(F)	Mean(SD) P(F)	Mean(SD) P(F)	Mean(SD) P(F)
Child's age	7.42(4.67)	7.34(4.69)	10.96(3.32) <i>p</i> <0.0001	8.48(4.30) <i>p</i> <0.0001	9.71(3.69) <i>p</i> <0.0001	9.42(3.64) <i>p</i> <0.0001	8.88(4.03) <i>p</i> <0.0001
Age main respondent left full time education (years above 18)	1.08(2.15)	1.10(2.17)	0.53(1.74) <i>p</i> <0.0001	0.71(1.73) <i>p</i> <0.0001	0.64(1.77) <i>p</i> <0.0001	0.71(1.96) <i>p</i> <0.0001	0.70(1.78) <i>p</i> <0.0001
Number of dependent children in household	2.19(0.99)	2.19(0.99)	2.15(1.07) <i>p</i> =0.41	2.12(0.99) <i>p</i> =0.034	2.14(1.01) <i>p</i> =0.035	2.13(1.01) <i>p</i> =0.05	2.11(0.98) <i>P</i> =0.0001

Abbreviations: SD = standard deviation

Table 2: Mean (standard deviation) net income by definition of disability and living standards group

Groups	Mean net income (SD), Median (IQR) [N]		
	All LS	Low Living Standards (LS <1)	High Living Standards (LS 1)
No disability (Group 6)	715.18 (671.80) 587.09 (403.77 – 856.08) [81,307]	531.25 (329.38) 475.78 (349.20 – 647.54) [48,833]	991.76 (916.22) 831.86 (605.56 – 1,153.74) [32,474]
(Group 1) Any mental disability (no physical disability)	588.79 (359.53)* 520.51 (375.77 – 674.26) [356]	482.52 (193.92)* 454.98 (348.54 – 593.10) [261]	880.75 (516.39) 736.07 (583.49 – 1,113.45) [95]
(Group 2) Any physical disability (no mental disability)	612.34 (616.40)* 515.96 (357.79 – 709.71) [1,135]	490.59 (246.23)* 451.06 (324.45 – 600.59) [827]	939.24 (1045.55) 747.07 (570.19 – 1,014.49) [308]
(group 3) Any mental disability (+/- physical disability)	631.17 (464.62)* 550.738 (415.27 – 736.64) [1,794]	533.95 (263.82) 497.39 (386.05 – 624.08) [1,301]	887.69 (715.45)* 771.28 (576.90 – 1,015.50) [493]
(Group 4) Both mental disability (+/- physical disability)	642.11 (462.01)* 565.41 (435.22 – 742.62) [986]	559.21(285.90)* 515.11 (415.83 – 651.32) [713]	858.62(702.82)* 768.50 (577.16 – 947.93) [273]
(Group 5) Any physical disability (+/- mental disability)	624.90 (539.84)* 533.86 (394.67 – 729.66) [2,703]	520.67 (263.62) 483.32 (360.12 – 623.00) [1,970]	905.01 (883.75)* 758.30 (567.79 – 1,003.62) [733]

* p ≤ 0.05 (reference group = no disability (Group 6))

Abbreviations: IQR = inter-quartile range; LS = living standards, SD = standard deviation. Numbers in squared brackets are sample sizes.

Table 3: Compensating variation

Comparisons	Mean income difference (95%CI) [N]		
	All LS	Low Living Standards (LS <1)	High Living Standards (LS=1)
(A) Any mental disability (no physical disability)	-6.27 (-52.90;40.34) [356]	5.13 (-29.67; 39.94) [260/261]	-36.62 (-184.37; 111.13) [95]
(B) Any physical disability (no mental disability)	-8.45 (-48.54;31.57) [1135]	-10.74 (-32.37; 10.89) [827]	-2.40 (-138.50; 133.71) [308]
(C) Any mental disability (+/- physical disability)	33.20 (8.33; 58.07)** [1791/1794]	42.03 (22.98; 61.08)** [1,299/1,301]	9.32(-66.24;84.89) [491/493]
(D) Both mental disability (+/- physical disability)	31.71 (-7.79; 71.20) [984/986]	60.62 (21.02; 100.23)** [713]	-44.37 (-143.27;54.53) [271]
(E) Any physical disability (+/- mental disability)	19.13 (-2.51;40.76) [2698/2703]	25.31 (10.14; 40.48)** [1968/1970]	2.47 (-66.33; 71.26) [730/ 733]
(F) Any mental disability (+/- physical disability)	39.83 (-12.75; 92.41) [1645/1794]	25.56 (-23.35; 76.47) [1194/1301]	66.78 (-74.99; 208.55) [440/493]
(G) Both mental disability (+/- physical disability)	34.90 (-31.75; 101.55) [836/986]	52.38 (11.49; 93.27)** [579/713]	-5.97(-205.03; 193.08) [254/273]
(H) Any physical disability (+/- mental disability)	15.33 (-19.01; 49.67) [2646/ 2703]	6.30 (-23.64; 36.24) [1916/ 1970]	37.37 (-60.04; 134.78) [724/ 733]

** p<=0.05 *0.1>p>0.05

Abbreviations: LS = living standards. Numbers in squared brackets are sample sizes .

Table 4: Mean value of benefits received by disability and living standards group

Groups	Mean benefit received (SD)		
	Median (IQR)		
	[N]		
	All LS	Low Living Standards (LS <1)	High Living Standards (LS 1)
(1) Any mental disability (no physical disability)	17.24 (31.68) 0.00 (0.00 – 0.00) [319]	16.64 (30.72) 0.00 (0.00 – 0.00) [229]	18.78 (34.13) 0.00 (0.00 – 39.63) [90]
(2) Any physical disability (no mental disability)	10.64 (28.14) 0.00 (0.00 – 0.00) [1043]	11.03 (28.64) 0.00 (0.00 – 0.00) [744]	9.67 (26.85) 0.00 (0.00 – 0.00) [299]
(3) Any mental disability (+/- physical disability)	34.44 (43.29) 0.00 (0.00 – 70.68) [1579]	34.26 (42.79) 0.00 (0.00 – 70.68) [1121]	34.88 (44.52) 0.00 (0.00 – 70.52) [458]
(4) Both mental disability (+/- physical disability)	45.84 (45.61) 50.42 (0.00 – 75.36) [856]	46.05 (45.11) 50.42 (0.00 – 75.36) [609]	45.31 (46.90) 50.15 (0.00 – 75.51) [247]
(5) Any physical disability (+/- mental disability)	26.21 (40.84) 0.00 (0.00 – 51.29) [2420]	26.07 (40.45) 0.00 (0.00 – 51.95) [1725]	26.58 (41.83) 0.00 (0.00 – 50.61) [695]

Abbreviations: IQR = inter-quartile range; LS = living standards, SD = standard deviation. Numbers in squared brackets are sample size

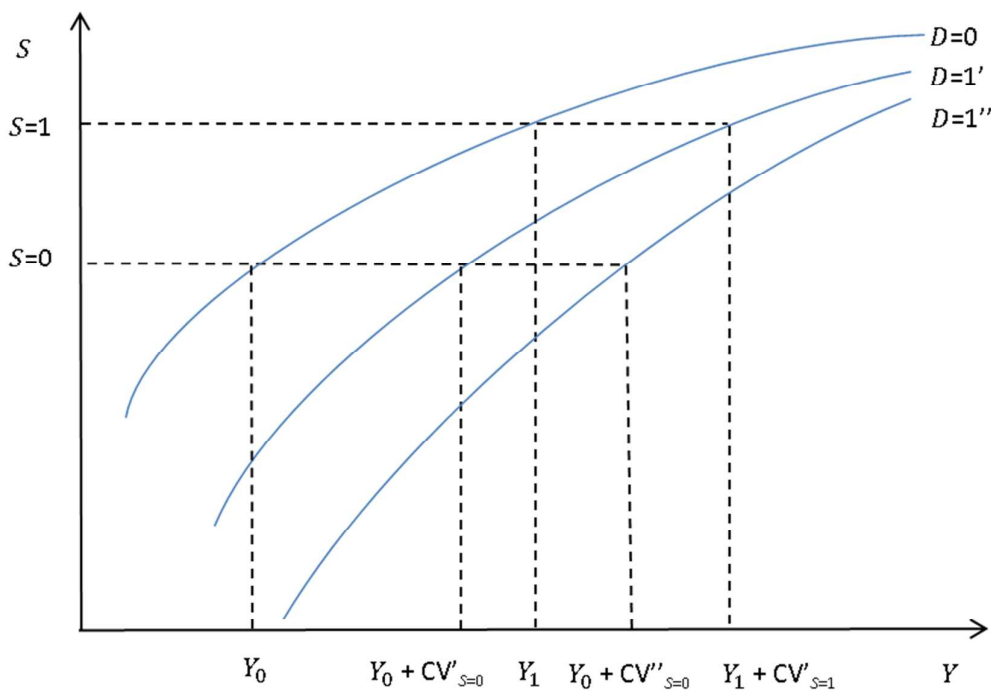
Theoretical approach: Compensating Variation

In Figure S1 we illustrate the concept of CV by plotting curves relating the income (Y , on the horizontal axis) and the living standards (S , on the vertical axis) of families without a disabled child ($D=0$) and with a disabled child ($D=1'$). We assume that: (i) the curves are upward sloping from left to right, due to diminishing returns to S as Y increases; and, (ii) $D=1'$ lies below $D=0$ though they tend towards one another at higher levels of Y . At a given level of living standards such as $S=0$ the CV is the difference between the income that a family with a disabled child ($D=1'$) needs to have ($= Y_0 + CV'_{S=0}$) compared to the income of a family without a disabled child ($D=0$) ($=Y_0$) to achieve the same living standard ($S=0$). Based on our assumptions this difference will decrease at higher levels of living standards. For instance, the CV between $D=1'$ and $D=0$ for $S=1$ (where $S=1 > S=0$) will correspond to $Y_1 + CV'_{S=1}$, which is smaller than $Y_0 + CV'_{S=0}$.

We hypothesize that families of children with more severe disabilities incur higher costs to achieve the same living standards as families with less severely disabled children. Suppose $D=1''$ denotes more severe disabilities than $D=1'$; this is shown in Figure 1 as curve $D=1''$ lying below curve $D=1'$. In this case the CV for $S=0$, corresponds to $Y_0 + CV''_{S=0}$, which is greater than $Y_0 + CV'_{S=0}$.

In order to employ this approach to investigate our aims, three measures are needed: 1) a definition of child mental and physical health disability; 2) a measure of living standards (LS); and 3) a measure of income.

Figure S1: Compensating variation



Theoretical Approach: Propensity Score Matching

If we assume that the probability of having a disabled child is adequately explained by the set of observed characteristics X , we can select from the sample of families with non-disabled children a control (i.e. non-treated) group, which is similar to the treated group with respect to X , but different with respect to disability D ²⁷. We therefore calculated the CV as the average treatment effect on the treated (*ATT*), as follows:

$$ATT = E[Y_1 - Y_0 | D=1] = E[Y_1 - Y_0 | D=1, p(X)] = E[Y_1 | D=1, p(X)] - E[Y_0 | D=0, p(X)] \quad (1)$$

We matched families using nearest neighbor matching within a caliper, defined to be one quarter of the standard deviation of the propensity score²⁵. Families are matched based on similar distributions of propensity scores, which might not arise from identical values of X . Since one of our aims is to estimate the income difference for families with and without a disabled child for the same value of living standards (S), we included values of our *LSI* rounded to the first decimal point as external to X and matched on both, so that the CV is given by:

$$ATT = E[Y_1 - Y_0 | D=1] = E[Y_1 - Y_0 | D=1, L, p(X)] = E[Y_1 | D=1, L, p(X)] - E[Y_0 | D=0, L, p(X)] \quad (2)$$

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STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No	Recommendation	PAGE
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	2
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	4-5
Objectives	3	State specific objectives, including any prespecified hypotheses	5
Methods			
Study design	4	Present key elements of study design early in the paper	6
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	6
Participants	6	(a) <i>Cohort study</i> —Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up	
		<i>Case-control study</i> —Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls	
		<i>Cross-sectional study</i> —Give the eligibility criteria, and the sources and methods of selection of participants	6
		(b) <i>Cohort study</i> —For matched studies, give matching criteria and number of exposed and unexposed	
		<i>Case-control study</i> —For matched studies, give matching criteria and the number of controls per case	
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6-9
Data sources/measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	6-9
Bias	9	Describe any efforts to address potential sources of bias	14
Study size	10	Explain how the study size was arrived at	6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	6-9
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	9-10
		(b) Describe any methods used to examine subgroups and interactions	9-10 9-10
		(c) Explain how missing data were addressed	9-10
		(d) <i>Cohort study</i> —If applicable, explain how loss to follow-up was addressed	
		<i>Case-control study</i> —If applicable, explain how matching of cases and controls was addressed	
		<i>Cross-sectional study</i> —If applicable, describe analytical methods taking account of sampling strategy	N/A
		(e) Describe any sensitivity analyses	N/A

Continued on next page

Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	10
		(b) Give reasons for non-participation at each stage	N/A
		(c) Consider use of a flow diagram	N/A
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	10
		(b) Indicate number of participants with missing data for each variable of interest	10
		(c) <i>Cohort study</i> —Summarise follow-up time (eg, average and total amount)	
Outcome data	15*	<i>Cohort study</i> —Report numbers of outcome events or summary measures over time	
		<i>Case-control study</i> —Report numbers in each exposure category, or summary measures of exposure	
		<i>Cross-sectional study</i> —Report numbers of outcome events or summary measures	10-11
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	11-12
		(b) Report category boundaries when continuous variables were categorized	11-12
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	N/A
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	12
Discussion			
Key results	18	Summarise key results with reference to study objectives	12-13
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	14
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	14
Generalisability	21	Discuss the generalisability (external validity) of the study results	14
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	1

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.

BMJ Open

The cost of mental and physical health disability in childhood and adolescence to families in the United Kingdom: findings from a repeated cross-sectional survey using propensity score matching

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Secondary Subject Heading:	Health economics, Epidemiology
Keywords:	Child disability, living standards, compensating variation, propensity score matching, disability benefits

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3 1 **The cost of mental and physical health disability in childhood and adolescence to families in the**
4 2 **United Kingdom: findings from a repeated cross-sectional survey using propensity score matching**

5
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27 18 **Keywords:** Child disability; living standards; disability benefits; compensating variation; propensity
28 19 score matching.
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33 21 **Competing interests:**

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35 22 The authors declare no competing interests.
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ABSTRACT

Objective: UK families of disabled children are entitled to receive disability benefits to help meet costs associated with caring for their child. Evidence of actual costs incurred is scant, especially for mental health disability. In this study we aimed to quantify the cost of mental and physical health disability in childhood and adolescence to families in the UK using the concept of compensating variation (CV).

Design: Repeated cross-sectional survey.

Setting: UK general population

Participants: 85,212 children drawn from eight waves of the Family Resources Survey.

Outcomes: Using propensity score matching we matched families with a disabled child to similar families without a disabled child and calculated the extra income the former require to achieve the same living standards as the latter, i.e. their CV. We calculated the additional costs specifically associated with several definitions of mental health and physical health disability.

Results Families of a child with any mental health disability, regardless of the presence of physical health comorbidity, needed an additional £49.31 (either mental health disability, 95% confidence interval (CI): 21.95; 76.67) or £57.56 (both mental health disabilities, 95%CI: 17.69; 97.44) per week to achieve the same living standards of families without a disabled child. This difference was greater for more deprived families, who needed between £59.28 (95%CI: 41.38; 77.18) and £81.26 (95%CI: 53.35; 109.38) more per week depending on the extent of mental health disability. Families of children with physical health disabilities, with or without mental health disabilities, required an additional £35.86 (95%CI: 13.77; 57.96) per week, with economically deprived families requiring an extra £42.18 (95%CI: 26.38; 57.97) per week.

Conclusions Mental and physical health disabilities among children and adolescents were associated with high additional costs for the family, especially for those from deprived economic backgrounds. Means testing could help achieve a more equitable redistribution of disability benefit.

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3 64 **Strengths and Limitations**
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- 5 65 • Strengths of this study are the use of: (i) a large and rich dataset representative of the UK
6 66 population; (ii) disability domains employed in the Disability Discrimination Act (DDA) consistent
7 67 with definitions applicable to policy settings; and, (iii) novel analytical approach based on
8 68 propensity score matching.
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11 69 • Limitations of this study are: (i) its cross-sectional design; (ii) difficulties in disentangling physical
12 70 and mental health disabilities (which are often co-occurring); and, (iii) data limitations making it
13 71 problematic to account for severity of disability and to measure living standards, and only
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15 72 covering the period 2004/05 up to 2011/12.
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INTRODUCTION

Families of children suffering from chronic conditions and physical and mental health disabilities incur significantly higher costs than those of their healthy counterparts.¹⁻⁵ These costs are primarily accounted for by more frequent visits to inpatient and outpatient departments and by greater use of prescribed drugs,¹⁻³ although evidence also suggests that the need to provide or secure informal care adds to the financial burden of child disability for these families.^{4,5} Previously, UK studies have estimated the cost of having a disabled child at about £79-£100 per week⁴ and that under the benefits arrangements at the time (1997) families of disabled children were undercompensated by £30-£80 per week⁴ and by £28 in 2001.⁵ More recent evidence has estimated that in the UK families of severely disabled children require up to an additional £79 per week to be able to meet the same living standards of those without disabled children.⁶

Mental health conditions account for a great portion of the burden of disease among children and adolescents below the age of 16 years.⁷ Onset of most mental health conditions occurs at different stages of childhood and adolescence: developmental and hyperkinetic disorders become manifest in early childhood, whilst depressive (including suicide and self-harm), psychotic, anxiety, conduct, and eating disorders most commonly arise in adolescence and young adulthood.⁸ Evidence suggests that in the UK there has been a trend towards increasing rates of children and young people suffering from mental health conditions since the 1980s.⁹ The 2004 British Child and Adolescent Mental Health Survey (B-CAMHS) conducted by the Office of National Statistics (ONS) reported that 10% of children aged 5 – 16 years met diagnostic criteria for a mental health disorder.¹⁰

A socio-economic gradient exists in the distribution of child mental health disorders¹¹⁻¹³. In the 2004 B-CAMHS, prevalence of diagnosable child mental health conditions was higher among single-parent (15.6%) compared to married or co-habiting (7.7%) households; among families with low (16.1%) compared to high (5.3%) income; and among families whose parents had no academic qualifications (17.0%) compared to those with university degrees (4.4%)¹⁴. Evidence exists that life adversities are a risk factor for the onset of mental health conditions as well as that mental health problems of the child can lead to family breakdown and unemployment¹⁴.

Both mental health problems and socio-economic disadvantage in childhood and adolescence can have enduring effects and significantly impact on a young person's future. Children and adolescents suffering from mental health problems more often report low levels of academic achievement, and engage in risky behaviours such as alcohol and drug use with detrimental effects on employment

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3 107 prospects¹⁵. Similarly, childhood experience of economic hardship can result in long-term adverse
4 108 health outcomes via the persistence of lower socio-economic status¹⁵.

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8 110 Since 1992, in the UK, families of children affected by disability have been eligible to receive a non-
9 111 means-tested weekly Disability Living Allowance (DLA).¹⁶ The rationale for these benefits is that
10 112 they “*may help with the extra costs of looking after a child who: is under 16; has difficulties walking*
11 113 *or needs more looking after than a child of the same age who doesn’t have a disability*”.¹⁶ The
12 114 amount of benefits that the family is entitled to receive largely depends on the severity of the child’s
13 115 condition, which is determined by the disability service centre often in conjunction with external
14 116 assessments. In 2017, under the care component of DLA, children could receive either £22 (if they
15 117 needed a little help during the day or night), £55.65 (if they needed frequent supervision), or £83.10
16 118 (if they needed constant help day and night, or were terminally ill) per week. Under the mobility
17 119 component of DLA, children were entitled to receive between £22 (if they could walk but needed
18 120 supervision outdoors) and £58 (if they could not walk, if walking represented a health risk, or if they
19 121 were blind) per week.

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22 123 Previous UK studies have shown that families of disabled children incur high costs, but were
23 124 however unable to attribute these extra expenditures to either physical or mental health disability,
24 125 which has been shown to inflict a substantial economic burden in other settings.^{2,3} In the absence of
25 126 literature exploring the cost of child mental health disability to families, and the rising prevalence of
26 127 these problems, the aims of this study are to: (1) investigate the cost to families of having a child
27 128 with a mental health disability; (2) compare the costs of mental health versus physical health
28 129 disability to assess whether such stratification is needed when considering disability benefits; and,
29 130 (3) examine how these costs vary by economic deprivation in order to assess whether means testing
30 131 of DLA should be considered.

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MATERIALS AND METHODS

Sample

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38 136 We employed data from eight consecutive rounds of data collection from the Family Resources
39 137 Survey (FRS) covering the financial years 2004/05 to 2011/12. The FRS is a repeated cross-sectional
40 138 survey undertaken by the Department of Work and Pensions (DWP) whose aim is to collect data on
41 139 the financial and social circumstances of individuals living within private UK households. Although
42 140 representativeness of the older age groups within the population might be limited in FRS due to the

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3 141 focus on private households (nursing and retirement homes are not included), the overall sample,
4 142 used in this study, is representative of the UK population¹⁷, and our focus on families with children
5 143 under 16 years of age means this is unlikely to introduce a bias.
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9 145 In the FRS households are defined as 'a single person or group of people living at the same address
10 146 who either share one meal a day or share the living accommodation, i.e. a living room'. Each
11 147 household may include one or more benefit unit, 'a single adult or couple living as married and any
12 148 dependent children'. A dependent child is a 'child younger than 16 years or an unmarried 16 to 19-
13 149 year-old in full time non-advanced education'.¹⁸ In this study, for simplicity we refer to benefit units
14 150 as 'families' and consider children as our main unit of analyses, as matching was done at child-level.
15 151 Our sample includes children aged 0-15 years and their families who had complete data on all
16 152 variables included in the model covariates and necessary to estimate the CV (i.e. income and living
17 153 standards). We excluded all the children from families with more than one disabled child because of
18 154 difficulties separating the effects of multiple disabled children in the same family (2.7% of total
19 155 children). In families with only one disabled child who had siblings we excluded the siblings to avoid
20 156 within-family matching.
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32 159 **Child mental and physical health disability**

33 160 In line with the definition of disability included in the Disability Discrimination Act (DDA) 1995 and
34 161 2005, the FRS defines a child as having a disability if they have a longstanding illness lasting longer
35 162 than 6 months and affecting their ability to undertake daily activities. Families were asked if their
36 163 child had any longstanding illness, disability or infirmity. Families responding 'yes' were directed to a
37 164 set of follow up questions asking which area of the child's life was affected by their disability.
38 165 Possible answers were: mobility; lifting; manual dexterity; continence (i.e. bladder control);
39 166 communication (i.e. speech, hearing, or eyesight); memory and learning; recognition of physical
40 167 danger; physical coordination; other; or, none of these areas. As we were not able to define their
41 168 disability either as affecting physical or mental health, we excluded children whose family claimed
42 169 had a disability but subsequently said that none of these areas were affected by disability (3.4% of
43 170 total children).
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53 172 Of these eight disability domains, we assume that memory and learning, and recognition of physical
54 173 danger can be attributable solely to mental health problems, as they are related to cognitive
55 174 impairment. We assume all other areas primarily reflect physical health problems¹⁹, but
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3 175 acknowledge these domains could also be affected by, or affect, mental health status. For ease of
4 176 explanation, we will hereafter refer to memory and learning, and recognition of physical danger as
5 177 'mental health' disability areas, and mobility, lifting, manual dexterity, continence, communication,
6 178 and physical coordination as 'physical health' disability areas.
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11 180 Using this distinction we defined disability accounting for: 1) presence of comorbidity between
12 181 mental and physical disability; 2) number and type of areas affected by disability. Therefore we
13 182 created 6 disability groups defined as follows:

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 - 17 184 • Group 1: Any mental disability (either or both domains), no physical disability;
 - 18 185 • Group 2: Any physical disability, no mental disability (group 1 & 2 are mutually exclusive);
 - 19 186 • Group 3: Any mental disability (either or both domains), with or without physical disability;
 - 20 187 • Group 4: Both mental disabilities (both domains), with or without physical disability;
 - 21 188 • Group 5: Any physical disability, with or without mental disability;
 - 22 189 • Group 6: No disability.

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24 190 **Supplemental table 1** provides a summary of our groups. We did not create a separate group for
25 191 children with both mental health domains affected by disabilities, but no physical disability as the
26 192 numbers were too low. Under the same rationale we did not include a group with children affected
27 193 by disability in all of the physical health domains due to low numbers. We compared these groups as
28 194 follows:

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 - 32 196 • Comparison A: Group 1 versus Group 6;
 - 33 197 • Comparison B: Group 2 versus Group 6;
 - 34 198 • Comparison C: Group 3 versus Group 6;
 - 35 199 • Comparison D: Group 4 versus Group 6;
 - 36 200 • Comparison E: Group 5 versus Group 6.

37 200

38 201 By allowing for comorbidity between mental and physical health disability in groups 3, 4, and 5, we
39 202 attempt to explore whether these disability groups could represent more severe conditions
40 203 compared to groups 1 and 2. Physical health impairments are more common in children with mental
41 204 health problems¹⁴ similarly, physical health disability can adversely affect mental health²⁰. We
42 205 hypothesise that if the cost of mental health disability is greater than that of physical health
43 206 disability we should see a positive CV for groups 1, 3, and 4 and this will be greater in magnitude
44 207 than that observed in groups 2 and 5.
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209 It is possible, however, that both physical and mental health have a positive and significant impact
210 and, although the magnitude of the CV across the previously defined groups can give an indication of
211 the overall impact of mental and physical health disability on the costs borne by the family, it is
212 important to attempt to quantify their relative impact. Therefore, in order to investigate our second
213 aim we ran three additional models comparing the exposed group against both children without
214 disabilities and children who had a disability 'other' than that employed to define the main
215 exposure. For example, children with any or both (all) 'mental (physical) health disabilities' plus
216 other physical (mental) health comorbidities were compared with children with no disabilities and
217 children with only physical (mental) health comorbidities. We defined these models as:

- 218 • Comparison F: Group 3 versus Group 6 and Group 2;
- 219 • Comparison G: Group 4 versus Group 6 and Group 2;
- 220 • Comparison H: Group 5 versus Group 6 and Group 1

222 Living standards

223 Material deprivation is measured in the FRS through a set of 21 questions asking whether the family:
224 (i) can afford and has; (ii) would like to have, but cannot afford; or (iii) can afford, but does not want
225 a number of goods previously identified as necessities by families. Ten of the 21 questions were
226 relevant for families without children; all 21 were relevant for families with children.²¹ We employed
227 a sub-set of 12 questions asked to the whole sample at each survey wave included in our study.
228 These questions were selected on the basis of their relevance for families with children, irrespective
229 of whether or not the child was disabled. For instance, a question about taking children to swim at
230 least monthly was not included as this might not have been a relevant domain for families with
231 children with disabilities affecting mobility, irrespective of whether or not it was affordable. In
232 **Supplemental Table 2** we provide a list of all questions we did and did not include with a rationale
233 for the latter.

234
235 From these questions we developed a living standards index (*LSI*) using prevalence weighting²² with
236 weights representing the proportion of families considering the item a necessity. We calculated the
237 *LSI* as follows:

$$238 \quad LSI = \frac{\sum_{i=1}^M x_i w_i}{\sum_{i=1}^M w_i} \quad (1)$$

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240 In Eq.(1), x_i is a binary variable indicating whether the family can afford each item (1='yes, can afford
241 and has it'; or 'yes, can afford, but does not want', 0='would like to have, but cannot afford), w_i is the

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3 242 proportion (i.e. weight) of respondents who consider the item desirable, as defined above²² and M
4 243 is the number of items.

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7 244 A total of 10% of families in our sample had missing data for one or more of these questions. In
8 245 order to derive a LSI value for these families, we scaled the score they obtained from the questions
9 246 they answered on the total score they could have obtained if they had could afford each of the items
10 247 they were asked about ($\sum_{i=1}^M w_i$).

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14 248 Finally, from the continuous *LSI* ranging from 0 to 1 (distribution in Figure 1) we defined families with
15 249 a *LSI*=1 as having 'high living standards', since they could afford each item included, and families with
16 250 *LSI*<1 as having 'low living standards' as they could not afford one or more of the items. We
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18 251 employed continuous values of the *LSI* to match families using propensity scores and the derived
19 252 binary variable to conduct stratified analyses (see Data Analysis section).
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24 254 **Income**

25 255 We derived a measure of income accounting for all available resources affecting living standards^{23,24},
26 256 including net income from all sources (i.e. earnings, self-employment, investments, and pensions) as
27 257 well as from any benefits, including disability benefits, received by the family. Disability and other
28 258 benefits were included because these affect living standards. We inflated incomes to 2011/12 prices.
29 259 We did not employ an equivalised measure of income for ease of interpretation of the results (i.e.,
30 260 our unit of analysis is the family and equivalised income is a measure of income per person);
31 261 however, in order to account for family composition we included variables indicating number of
32 262 adults and ages of children in the matching stage of the analyses (see below), in line with previous
33 263 literature^{23,25}. Values of net income are reported 'per week' in the FRS.
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42 265 **Other variables**

43 266 In our analyses we match families with and without a disabled child on a number of socio-
44 267 demographic and socio-economic characteristics of the families and their children. We included
45 268 indicators of the child's age (linear term) and gender (male/female); two linear terms for number of
46 269 dependent children in the family (range 1-8) and number of years of schooling after the age of 18
47 270 years (i.e. the age at which compulsory education ends in the UK) of the head of the household and
48 271 their marital status (single/couple); presence of a disabled adult (yes/no), and to account for family
49 272 wealth, a categorical variable indicating family savings banded in five categories and an indicator of
50 273 parental (i.e. main respondent's) employment (employed/unemployed/inactive).
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3 275 We also included a categorical indicator for survey year and UK Government Office Region (London;
4 276 South East; Rest of England; Northern Ireland, Wales and Scotland¹).

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7 278 **Data analysis**

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9 279 We described how sample characteristics vary by disability group using cross-tabulations with Chi-
10 280 Square tests and ANOVAs for categorical and continuous variables, respectively.

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14 282 We employed the 'compensating variation' (CV) approach to calculate the cost of child disability,
15 283 which has been previously used in studies of disability in adults²⁴ and children.⁶ The CV can be
16 284 defined as the additional income that a family with a disabled child needs to be able to achieve the
17 285 same living standards of a family that is similar in all other respects but without a disabled child.
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19 286 More details on the theoretical approach can be found in the supplementary material and in Figure
20 287 S1. We used Propensity Score Matching (PSM)^{26,27} to match families according to comparisons A – F
21 288 and calculate the CV (i.e. the mean income difference). It has been suggested that this approach, by
22 289 simulating a randomised controlled trial setting, can provide a more unbiased estimate of the
23 290 income difference than parametric models in observational studies²⁴.

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27 292 We calculated propensity scores (i.e. predicted probabilities) from probit regression models with
28 293 each of our group allocations in the comparisons defined above (Comparisons A to H) as the
29 294 outcome (e.g., for Comparison A, participation in Group 1 is coded 1 and Group 6 is coded 0, all
30 295 other groups are coded as missing). In all models the independent variables were child age and
31 296 gender, number of children and disabled adults in the family, years of schooling of the main
32 297 respondent, marital status, family savings, government region and survey year. Additionally, for
33 298 comparisons F, G, and H we also controlled for areas of disability (other than those defining the
34 299 Group) as covariates. For all models we calculated areas under the receiver operating characteristic
35 300 (ROC) to estimate goodness of fit of the model and tested whether the distribution of the covariates
36 301 was balanced between disabled and non-disabled children. More details on the PSM theoretical
37 302 approach are in the supplementary material.

38
39 303 For each matching pair obtained with this matching approach we calculated the CV and its 95% CI²⁸.
40 304 As sensitivity analyses we estimated the compensating variation matching disabled children using
41 305 3:1 matching (i.e. matching a disabled child to the three closest matches) and using radius matching

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¹ Rest of England includes: North East, North West & Merseyside, Yorkshire & Humberside, East Midlands, West Midlands, and South West.

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3 306 (defining the radius as a quarter of a the propensity score standard deviation). All our analyses were
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5 307 run using Stata13.²⁹
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308 RESULTS

309 Sample characteristics

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11 310 From an initial sample of 99,142 children (61,952 families), we excluded families with a disabled
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13 311 child whose disability could not be described in terms of one of the 9 main disability areas (N=3,461,
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15 312 3.4%), those with more than one disabled child (n= 2,651 children, 2.7%), and siblings of disabled
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17 313 children (n = 4,636 children, 4.7%). After excluding children with any missing data on the variables of
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19 314 interest (n = 3,182, 3.2%) the final sample consisted of 85,212 children nested in 52,639 families
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21 315 (with minimum of 1 and maximum of 8 children).
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24 317 The majority of children included in our sample were male (51.05%), lived in a two-parent family
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26 318 (74.75%), did not live with an adult with a disability (84.12%), lived in a family whose total savings
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28 319 were less than £1,500 (58.85%), and lived in the 'rest of England' (50.57%) (Table 1). Mean child age
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30 320 was 7.42 years (standard deviation (SD) = 4.69), mean number of dependent children in the
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32 321 household was 2.19 (SD=0.99), and mean number of years spent in education past the age of 18
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34 322 years by the main respondent was 18.08 (SD=2.15).
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324 Child disability

37 325 In total, 1,782 (2.1%) children had some type of mental health disability, irrespective of the presence
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39 326 of physical disabilities, and 352 children (0.4%) had mental health disability without physical health
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41 327 disability (Table 1). A greater number of children had physical health disability, either with (2,686,
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43 328 3.1%) or without (1,126 1.3%) mental health problems, respectively.
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46 330 Compared to children without any disabilities, and for all definitions of disabilities, more children
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48 331 with disabilities were male, lived in a single parent household and with an adult also affected by
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50 332 disability, had a parent who spent less time in education and had fewer savings, and were older
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52 333 (Table 1).
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55 335 Across low and high living standards, families of children with any type of disability had lower
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57 336 income than those of children without disabilities (Table 2); in every disability group income was
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59 337 higher in families with higher living standards. Among families with low living standards, families of
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338 children with both mental health areas affected by disability had higher income than those without
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340 339 disability, whereas families of children with any mental or physical health only had lower income.

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3 340 Among families with high living standards, families of children affected in any of the physical or
4 341 mental health disability areas or in both the mental health areas, regardless of other areas affected,
5 342 had lower income compared to families of children without disabilities.
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9 344 **Benefits**

10 345 As seen in Table 3, across all LS groups combined families of children with both mental health
11 346 disabilities (Group (4)) received the highest amount of weekly benefits (mean value £45.95),
12 347 followed by those with any mental health disabilities (Group (3); £34.48), and those with any
13 348 physical health disabilities (Group (5); £26.22) (Table 3). Note these groups included children with
14 349 both mental and physical disabilities. Children only affected in either or both mental health areas
15 350 received on average £17.40 per week (Group (1)) whilst those affected in any or all physical health
16 351 domains only received £10.63 (Group (2)). The amount of benefits received did not vary by LS,
17 352 reflecting the absence of means testing for disability benefits. None of the children in the non-
18 353 disabled group were receiving any disability benefits.
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29 356 **Compensating variation**

30 357 Over and above their net income (including benefits received) families of children with any (Group 3)
31 358 or both mental health disabilities (Group 4) needed an additional £49.31 (95% confidence interval
32 359 (CI): 21.95; 76.67) and £57.56 (95% CI: 17.69; 97.44), respectively, a week in order to achieve the
33 360 same living standards of similar families without a disabled child (Group 6; Comparisons C and D,
34 361 respectively), across both levels of LS (Table 4). We also found evidence that families of children
35 362 with any physical health disability (Group 2) needed an additional £35.86 (95%CI: 13.77; 57.96) per
36 363 week to meet the living standards of families without disabled children (Group 6; Comparison E).
37 364 When pooling across living standards, we did not find any other differences in any of the other
38 365 disability groups.
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47 367 When we split the sample by low and high levels of living standards, we found that in some cases
48 368 families with low LS with a disabled child needed a higher net income to meet the same LS of
49 369 families without a disabled child. Specifically, we found that families of a child with any mental
50 370 health disability or both mental health disabilities (with or without physical disabilities) required an
51 371 extra £59.28 (95%CI: 41.38; 77.18), Group 3, Comparison C) and £81.37 (95%CI: 53.35; 109.38,
52 372 Group 4, Comparison D) a week more than a family without a disabled child. We also found an
53 373 income difference, albeit smaller, for families of children with disability affecting physical health
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3 374 compared to families of non-disabled children, with the former needing an extra £42.18 (95%CI:
4 375 26.38; 57.97, Group 5, Comparison E) more a week to achieve the same LS.
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8 377 When we compared children affected by disability in any, or both mental health areas and in any
9 378 physical health areas, regardless of the presence of other disabilities, against children without
10 379 disabilities and other with physical and mental health disabilities respectively (i.e., in comparisons F -
11 380 H), we found weak evidence that families of children with both mental health areas affected by
12 381 disabilities needed an extra £47.45 (95% CI: -0.41; 95.30) more per week to achieve the same LS if in
13 382 the low LS category (Table 4). Although, we did not find any evidence of differences for the other
14 383 groups, in particular those with high living standards, there was an indication that children in group 1
15 384 (any mental health disability with no physical health disability), and group 4 (both mental health
16 385 disabilities regardless of physical health disabilities) were adequately compensated, although the
17 386 latter case only among children with greater LS. We did not find evidence of any other group
18 387 differences.
19 388

20 389 *Sensitivity analyses and model checks*

21 390 The sensitivity analysis using 3:1 matching yielded virtually identical results to those in the main
22 391 analysis (results not shown). The sensitivity analysis using radius matching also yielded similar
23 392 results, with some small differences in the size and significance of the compensating variation for
24 393 some comparisons (Supplemental material and Table S3).
25 394

26 395 In our main analysis, for comparisons A to E the distribution of covariates was balanced between
27 396 treatment groups (i.e. disabled and non-disabled children) with the exception of years of schooling,
28 397 which in some models was unbalanced. In models F to H, the distribution of covariates was less well
29 398 balanced in our main analyses. However, in sensitivity analyses all models were balanced, and since
30 399 the results in the sensitivity analysis we similar to those of the main analysis, this suggests that this is
31 400 unlikely to have biased our estimates.
32 401

33 402 **DISCUSSION**

34 403 Little evidence exists on the costs borne by families of children affected by mental health disability in
35 404 the UK. To the best of our knowledge, this is the first UK study aiming to quantify these costs using
36 405 propensity score matching and a compensating variation approach to estimate cost of mental health
37 406 disability.
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3 408 We found no difference in income between families of children with a disability affecting any or all
4 409 areas associated with mental health problems only and families of non-disabled children. When we
5 410 allowed for existence of physical health comorbidities, we found that these families needed an
6 411 additional £49.31 per week over and above existing net incomes (including disability benefits)
7 412 compared to families of non-disabled children to achieve the same living standards, with an even
8 413 greater amount needed if children's disability affected both mental health domains (£57.56). These
9 414 difference were, again, even greater for families with low living standards (£59.28 and £81.37,
10 415 respectively). In comparison, families with children affected by physical health had a positive, but
11 416 smaller in magnitude, CV (£35.86), which was, similarly to what was observed for mental health
12 417 disability, was higher among families with low LS (£42.18). When we tested the relative impact of
13 418 mental and physical health on the CV, by allowing our comparator group to have disabilities in the
14 419 opposite domains of the one under investigation, we found a positive, though weak, CV for children
15 420 affected in both mental health disabilities who live in families with low LS (£47.45). These findings
16 421 suggest that all these groups are undercompensated by the benefits system.
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27 423 These results suggest that mental health disabilities in childhood are associated with substantial
28 424 costs which need to be borne by their families. In other words, families of children with mental
29 425 health disabilities need to have higher income in order to achieve the same living standards of a
30 426 family without a disabled child. These costs appear to be higher when there are co-occurring mental
31 427 and physical disabilities, possibly an indicator of severity of the condition, and for more economically
32 428 deprived families. As benefits were already included in our income measure, the compensating
33 429 variation represents the amount by which families appear to be undercompensated under current
34 430 benefit arrangements.
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42 432 Our findings on the cost of child disability are lower from those found by Dobson and colleagues
43 433 estimating the cost of child disability to the family at £100 per week^{4,5}. Compared to these studies,
44 434 we also found that under-compensation occurred to a lower extent, in the range of £8-£15 and only
45 435 for deprived families with children with mental health disabilities, as opposed to £30-£80⁴ and £24⁵.
46 436 One reason for this difference could be that these studies employed convenience sampling (i.e.
47 437 selecting children with more severe disabilities and living in more deprived settings) and different
48 438 definitions of disability, which did not clearly distinguish between mental and physical health.
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54 440 This study had several strengths. It employed a large and rich dataset representative of the UK
55 441 population. The FRS also makes use of the disability domains employed in the DDA to define areas
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3 442 affected by disability, which makes it consistent with definitions applicable to policy settings. We
4 443 also employed a novel approach which allowed us to match families not only based on their
5 444 propensity scores distribution, but also on the values of living standards with exact matching to the
6 445 first decimal digit. Nevertheless, several limitations should be accounted for. First, we could only
7 446 give an approximate definition of mental and physical health disability, knowing that areas which we
8 447 have considered as physical health could be affected as a result of mental health disability only.
9 448 Nevertheless, our approach represents a first attempt at both costing the impact of mental health
10 449 disabilities on families and disentangling the relative effect of mental and physical health disability.
11 450 We were also unable to explore the effect of severity of disability or of different types of disabilities
12 451 given the nature of the available variables. Future studies should attempt to include specific
13 452 diagnoses, perhaps including sub-clinical presentations as separate categories in order to account for
14 453 varying degrees of severity. A total of 10% had missing data on LS measures; although we calculated
15 454 our index re-scaling the latter to the number of questions each family had answered, it is not
16 455 possible to rule out the possibility that under/over-estimation of the LSI value for these families
17 456 could have occurred. Moreover, our living standards measure provides an indication of what goods
18 457 the family can afford, but not of their quality. However, values of mean income by low/high LSI
19 458 seemed to suggest that the latter adequately describes the intended groups. The sample size for
20 459 some of our disability definitions was small meaning that we could have incurred in type II error and
21 460 failed to observe an income difference when indeed there was one. Due to the cross-sectional
22 461 nature of the study, it was not possible to estimate the CV in the absence of benefits, as the latter
23 462 contribute, when received, to the LS achieved by the family. This approach would have given a
24 463 clearer indication of the income difference between families with and without a disabled child. In
25 464 fact, based on our estimates, we are not able to tell, if we do not observe a difference in income,
26 465 whether an actual difference would have occurred in the absence of the benefits system. By
27 466 comparing the CV to the amount of benefits received, we however attempted to estimate whether
28 467 the family was currently over or undercompensated. Our propensity score model could have been
29 468 improved by including more precise indications of family structure and parental education, as well as
30 469 a greater number of family and child characteristics, such as a clearer specification of parental
31 470 physical or mental health disability. Future studies should endeavor to be more inclusive in order to
32 471 improve model prediction. We used data covering the financial years 2004/05 to 2011/12, which are
33 472 not the most current available. This choice was motivated by a change in the definition of disability
34 473 in 2012/13 to include a separate mental health domain. Although using post-2012/13 data would
35 474 have resulted in a clearer definition of mental health and more recent estimates, we would not have
36 475 had enough statistical power for our analyses. Nevertheless, we found that the amount of DLA

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3 476 received across disability groups in our sample was consistent with 2011/12 and current DLA figures,
4 477 suggesting that our findings bear relevance for current policy. Finally, some of our families,
5 478 especially in adjacent years, could have been recruited in more than one wave of FRS data collection,
6 479 meaning that our samples might have not been totally independent.³⁰ However, given the large size
7 480 of our sample we believe that it is unlikely that this could have biased our results.
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13 482 In conclusion, we found that mental health in childhood and adolescence is associated with high
14 483 costs, which need to be borne by the family. Our findings indicate that families of children from
15 484 more disadvantaged backgrounds are currently undercompensated by the disability benefits system.
16 485 Based on these findings we suggest that mental health should be better defined as a criterion for
17 486 receiving benefits and that the amount of disability benefits that a family is entitled to receive are
18 487 subject to means testing, so that families from more deprived socio-economic backgrounds could be
19 488 entitled to higher benefits amounts.
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25 489 **Acknowledgments**

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27
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30 492 Helen Roberts, Cathy Street, Russell Viner and Miranda Wolpert.
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36 494 **Data Sharing:** The dataset used in these analyses is publicly available on
37 495 <https://www.ukdataservice.ac.uk/>
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563 **TABLES and FIGURES**
564 **Figure 1. Distribution of living standard index**
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For peer review only

Table 1: sample characteristics

Group (comparator)	All, N (%)	Child disability					
		No disability N (%)	Any Mental Health only N (%); P (χ^2)	Any Physical Health only N (%); P (χ^2)	Any Mental Health N (%); P (χ^2)	Both Mental Health N (%); P (χ^2)	Any Physical Health N (%); P (χ^2)
		6	1 (vs. 6)	2 (vs. 6)	3 (vs. 6)	4 (vs. 6)	5 (vs. 6)
Total	85,212(100%)	80,920(94.93%)	352(0.43%)	1,126(1.37%)	1,782(2.1%)	977(1.19%)	2,686(3.10%)
Gender of child			$p < 0.0001$	$p < 0.0001$	$p < 0.0001$	$p < 0.0001$	$p < 0.0001$
Male	43,500(51.05%)	40,772(50.38%)	272(77.27%)	636(56.48%)	1,302(73.06%)	722(73.90%)	1,732(64.48%)
Female	41,712 (48.95%)	40,148(49.62%)	80(22.73%)	490(43.52%)	480(26.94%)	255(26.10%)	954(35.52%)
Government Region			$p=0.09$	$p=0.37$	$p=0.02$	$p=0.01$	$p=0.043$
London	8,700(10.21%)	8,322(10.28%)	26(7.39%)	101(8.97%)	164(9.20%)	85(8.70%)	252(9.38%)
South East	9,952(11.68%)	9,458(11.69%)	52(14.77%)	142(12.61%)	217(12.18%)	134(13.72%)	327(12.17%)
Wales, Scotland, Northern Ireland	23,476(27.55%)	22,334(27.60%)	91(25.85%)	303(26.91%)	449(25.20%)	239(24.46%)	693(25.80%)
Rest of England	43,084(50.57%)	40,806(50.43%)	183(51.99%)	580(51.51%)	952(53.42%)	519(53.12%)	1,414(52.64%)
Marital status			$p < 0.0001$	$p < 0.0001$	$p < 0.0001$	$p < 0.0001$	$p < 0.0001$
Single	21,516(25.25%)	19,876(24.56%)	156(44.32%)	430(38.19%)	678(38.05%)	364(37.26%)	1,004(37.38%)
Couple	63,696(74.75%)	61,044(75.44%)	196(55.68%)	696(61.81%)	1,104(61.95%)	613(62.74%)	1,682(62.62%)
Adult with disability in family			$p < 0.0001$	$p < 0.0001$	$p < 0.0001$	$p < 0.0001$	$p < 0.0001$
No	71,679(84.12%)	68,889(85.13%)	249(70.74%)	740(65.72%)	1,212(68.01%)	649(66.43%)	1,783(66.38%)
Yes (at least one parent)	13,533(15.88%)	12,031(14.87%)	103(29.26%)	386(34.28%)	570(31.99%)	328(33.57%)	903(33.62%)
Year			$p=0.051$	$p=0.53$	$p=0.35$	$p=0.23$	$p=0.76$
2004/05	12,822(15.05%)	12,232(15.12%)	64(18.18%)	166(14.74%)	262(14.70%)	130(13.31%)	385(14.33%)
2005/06	11,639(13.66%)	11,043(13.65%)	46(13.07%)	167(14.83%)	241(13.52%)	119(12.18%)	379(14.11%)
2006/07	11,147(13.08%)	10,600(13.10%)	34(9.66%)	160(14.21%)	208(11.67%)	120(12.28%)	357(13.29%)
2007/08	10,410(12.22%)	9,856(12.18%)	51(14.49%)	125(11.10%)	247(13.86%)	135(13.82%)	346(12.88%)
2008/09	10,303(12.09%)	9,785(12.09%)	53(15.06%)	125(11.10%)	222(12.46%)	116(11.87%)	306(11.39%)
2009/10	10,188(11.96%)	9,658(11.94%)	45(12.78%)	132(11.72%)	222(11.67%)	121(12.38%)	320(11.91%)
2010/11	10,246 (12.02%)	9,728(12.02%)	33(9.38%)	148(13.14%)	208(11.67%)	135(13.82%)	334(12.43%)
2011/12	8,457(9.92%)	8,018(9.91%)	26(7.39%)	103(9.15%)	172(9.65%)	101(10.34%)	259(9.64%)

Table 1 (continued)

Group	All, N (%)	No disability N (%)	Child disability				
			Any Mental Health only N(%);P (χ^2)	Any Physical Health only N (%);P (χ^2)	Any Mental Health N (%); P (χ^2)	Both Mental Health N (%); P (χ^2)	Any Physical Health N (%); P (χ^2)
		6	1 (vs. 6)	2 (vs. 6)	3 (vs. 6)	4 (vs. 6)	5 (vs. 6)
Total savings			<i>p</i> <0.0001	<i>p</i> <0.0001	<i>p</i> <0.0001	<i>p</i> <0.0001	<i>p</i> <0.0001
No savings	4,100(4.81%)	3,842(4.75%)	24(6.82%)	63(5.60%)	94(5.27%)	47(4.81%)	145(5.40%)
Savings less than £1,500	46,052(54.04%)	43,255(53.45%)	221(62.78%)	723(64.21%)	1,157(64.93%)	629(64.38%)	1,745(64.97%)
Savings over £1,500 and up to £20,000	21,863(25.66%)	21,065(26.03%)	68(19.32%)	216(19.18%)	350(19.64%)	209(21.39%)	513(19.10%)
Savings over £20,000	10,553(12.38%)	10,189(12.59%)	34(9.66%)	99(8.79%)	134(8.59%)	78(7.98%)	233(8.67%)
Did not want to say	2,644(3.10%)	2,569(3.17%)	5(1.42%)	25(2.22%)	28(1.57%)	14(1.43%)	50(1.86%)
Employment status			<i>p</i> <0.0001	<i>p</i> <0.0001	<i>p</i> <0.0001	<i>p</i> <0.0001	<i>p</i> <0.0001
Employed	60,510(71.01%)	58,119(71.82%)	192(54.21%)	649(57.64%)	931(52.24%)	508(51.52%)	1,456(54.21%)
Unemployed	3,025(3.55%)	2,838(3.51%)	15(4.49%)	55(4.88%)	77(4.32%)	41(4.16%)	119(4.43%)
Inactive	21,677(25.44%)	19,964(24.67%)	145(41.29%)	422(37.48%)	774(43.43%)	437(44.32%)	1,111(41.36%)
	Mean (SD)	Mean(SD)	Mean(SD) P(F)	Mean(SD) P(F)	Mean(SD) P(F)	Mean(SD) P(F)	Mean(SD) P(F)
Child's age	7.42(4.68)	7.34(4.69)	10.96(3.32) <i>p</i> <0.0001	8.48(4.30) <i>p</i> <0.0001	9.71(3.69) <i>p</i> <0.0001	9.42(3.64) <i>p</i> <0.0001	8.88(4.03) <i>p</i> <0.0001
Age main respondent left full time education	18.08(2.15)	18.10(2.17)	18.53(1.74) <i>p</i> <0.0001	18.71(1.73) <i>p</i> <0.0001	18.64(1.77) <i>p</i> <0.0001	18.71(1.96) <i>p</i> <0.0001	18.70(1.78) <i>p</i> <0.0001
Number of dependent children in household	2.19(1.00)	2.19(0.99)	2.15(1.07) <i>p</i> =0.41	2.12(0.99) <i>p</i> =0.034	2.14(1.01) <i>p</i> =0.035	2.13(1.01) <i>p</i> =0.05	2.11(0.98) <i>P</i> =0.0001

The P values refer to a comparison of sample characteristics between each definition of child disability and the no disability group. Abbreviations: SD = standard deviation

Table 2: Mean (standard deviation) net income by definition of disability and living standards group

Groups	Mean net income (SD), Median (IQR) [N]		
	All LS	Low Living Standards (LS <1)	High Living Standards (LS 1)
No disability (Group 6)	715.06 (672.92) 586.87 (403.77 – 855.92) [80,920]	531.30 (329.45) 475.78 (349.20 – 647.54) [48,632]	991.83 (918.10) 831.72 (605.55 – 1,153.74) [32,288]
(Group 1) Any mental health disability (no physical health disability)	522.93 (361.08)* 522.92 (375.77 – 677.32) [352]	482.80 (194.72)* 459.33 (346.39 – 593.10) [258]	886.05 (516.55) 736.44 (583.70 – 1,113.45) [94]
(Group 2) Any physical health disability (no mental health disability)	612.34 (618.68)* 515.91 (356.36 – 709.71) [1,126]	489.57 (246.44)* 449.75 (324.23 – 598.64) [820]	941.77 (1048.50) 752.52 (570.25 – 1,014.72) [306]
(group 3) Any mental health disability (+/- physical health disability)	631.23 (465.20)* 550.74 (415.83 – 736.81) [1,782]	534.39 (264.37) 497.57 (387.50 – 624.21) [1,293]	887.27 (717.07)* 771.28 (576.90 – 1,011.46) [489]
(Group 4) Both mental health disability (+/- physical health disability)	641.53 (462.56)* 564.41 (435.26 – 742.62) [977]	559.75 (286.78)* 515.11 (415.83 – 651.79) [707]	855.66 (704.87)* 765.66 (570.21 – 947.93) [270]
(Group 5) Any physical health disability (+/- mental health disability)	624.73 (540.95)* 533.17 (394.67 – 729.66) [2,686]	520.50 (264.02) 483.18 (360.12 – 621.76) [1,958]	905.08 (886.08)* 759.69 (567.79 – 1,002.67) [728]

Abbreviations: IQR = inter-quartile range; LS = living standards, SD = standard deviation. Numbers in squared brackets are sample sizes.

* indicates a p-value ≤ 0.05 for the mean income comparisons between each disability group (1 -5) with reference group no disability (6)

Table 3: Mean value of benefits received by disability and living standards group

Groups	Mean benefit received (SD)		
	Median (IQR)		
	[N]		
	All LS	Low Living Standards (LS <1)	High Living Standards (LS 1)
(1) Any mental disability (no physical disability)	17.40 (31.78) 0.00 (0.00 – 0.00) [316]	16.78 (30.81) 0.00 (0.00 – 0.00) [227]	18.98 (34.27) 0.00 (0.00 – 39.63) [89]
(2) Any physical disability (no mental disability)	10.63 (28.10) 0.00 (0.00 – 0.00) [1035]	11.01 (28.58) 0.00 (0.00 – 0.00) [737]	9.71 (26.89) 0.00 (0.00 – 0.00) [298]
(3) Any mental disability (+/- physical disability)	34.48 (43.30) 0.00 (0.00 – 70.68) [1569]	34.36 (42.86) 0.00 (0.00 – 70.68) [1115]	34.80 (44.43) 0.00 (0.00 – 70.52) [454]
(4) Both mental disability (+/- physical disability)	45.95 (45.63) 50.42 (0.00 – 75.36) [848]	46.27 (45.18) 50.42 (0.00 – 75.36) [604]	45.16 (46.80) 50.15 (0.00 – 75.51) [244]
(5) Any physical disability (+/- mental disability)	26.22 (40.85) 0.00 (0.00 – 51.95) [2405]	26.12 (40.49) 0.00 (0.00 – 51.95) [1714]	26.48 (41.74) 0.00 (0.00 – 50.62) [691]

Abbreviations: IQR = inter-quartile range; LS = living standards, SD = standard deviation. Numbers in squared brackets are sample size

Table 4: Compensating variation (£ per week)

Comparisons	Mean income difference (95%CI) [N]		
	All LS [cases on common support/ total no. of cases] ^a	Low Living Standards (LS <1) [cases on common support/ total no. of cases] ^a	High Living Standards (LS=1) [cases on common support/ total no. of cases] ^a
(A) Any mental health disability (no physical disability)	3.65 (-40.91; 48.22) [352/352]	17.43 (- 19.59; 54.46) [258/258]	-34.16 (-167.94; 99.62) [94/94]
(B) Any physical health disability (no mental disability)	9.77 (-28.60; 48.15) [1126/1126]	3.51 (-17.43; 24.45) [820/820]	26.65 (-103.43; 156.54) [306/306]
(C) Any mental health disability (+/- physical disability)	49.31 (21.95; 76.67)** [1772/1782]	59.28 (41.38; 77.18)** [1286/1293]	22.93 (-65.03; 110.89) [486/489]
(D) Both mental health disability (+/- physical disability)	57.56 (17.69; 97.44)** [971/977]	81.37 (53.35; 109.38)** [703/707]	-4.88 (-125.28; 115.51) [268/270]
(E) Any physical health disability (+/- mental disability)	35.86 (13.77; 57.96)** [2680/2686]	42.18 (26.38; 57.97)** [1956/1958]	18.81 (-51.06; 88.68) [724/ 728]
(F) Any mental health disability (+/- physical disability)	34.12 (-20.95; 89.19) [1642/1782]	39.23 (-15.67; 94.12) [1199/1293]	15.77 (-126.88; 158.41) [434/893]
(G) Both mental health disability (+/- physical disability)	33.89 (-36.05; 103.83) [862/977]	47.45 (-0.41; 95.30)* [599/707]	-7.45 (-212.29; 197.39) [259/270]
(H) Any physical health disability (+/- mental health disability)	24.14 (-6.99; 55.28) [2618/ 2686]	5.18 (-22.45; 32.82) [1895/ 1958]	73.83 (-11.32; 158.97) [720/ 728]

^a Total sample size for each model is twice that of cases on common support, due to 1:1 matching.

** $p \leq 0.05$ * $0.1 > p > 0.05$

Abbreviations: LS = living standards. Numbers in squared brackets are sample sizes .

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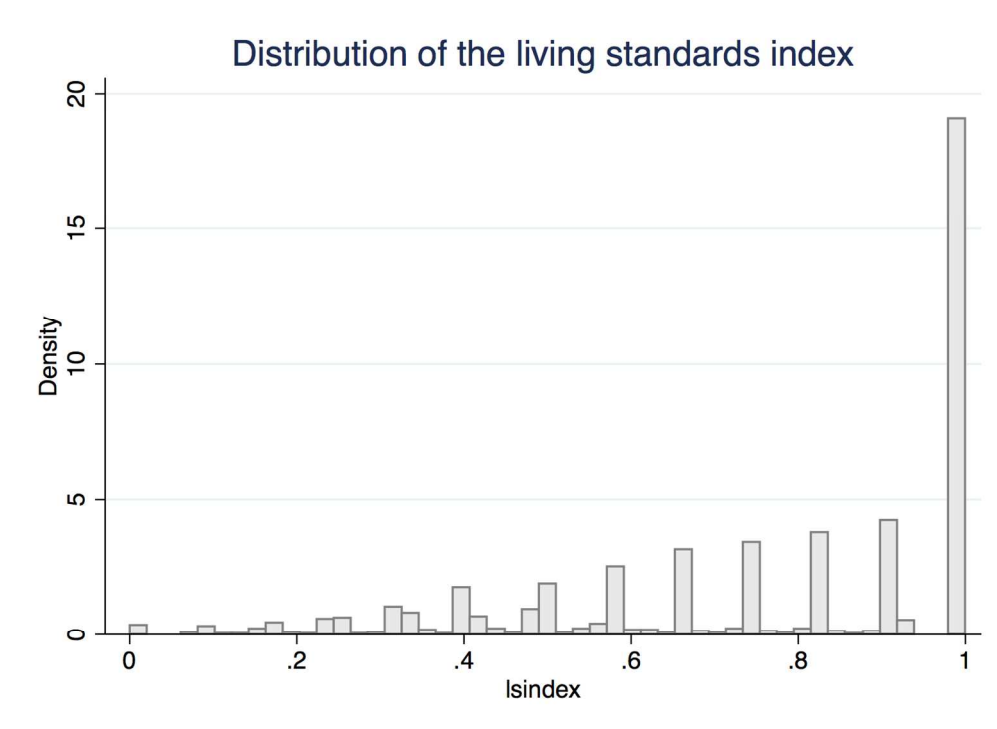


Figure 1. Distribution of living standard index

139x101mm (300 x 300 DPI)

Review only

1
2 **Table S1: Definitions of disability groups**
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Disability Domain	Group 1	Group 2	Group 3	Group 4	Group 5	Group 6
<i>Physical health</i>						
Mobility	No	Yes*	Yes or no	Yes or no	Yes*	No**
Lifting carrying or moving objects	No	Yes*	Yes or no	Yes or no	Yes*	No**
Manual dexterity	No	Yes*	Yes or no	Yes or no	Yes*	No**
Continence	No	Yes*	Yes or no	Yes or no	Yes*	No**
Communication	No	Yes*	Yes or no	Yes or no	Yes*	No**
Physical co-ordination	No	Yes*	Yes or no	Yes or no	Yes*	No**
<i>Mental health</i>						
Memory of ability to concentrate learning or understand	Yes*	No	Yes*	Yes **	Yes or no	No**
Recognizing when in physical danger	Yes*	No	Yes*	Yes **	Yes or no	No**

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5 * = can or cannot be present, as long as another domain from the broader disability area (i.e. mental or
6 physical health) is present

7 **= necessarily present for definition

8 Yellow cells indicate primary domains for group definition

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- Group 1: Any (either or both domains) mental disability (no physical disability);
 - Group 2: Any physical disability (no mental disability) (group 1 & 2 are mutually exclusive);
 - Group 3: Any mental disability (either domains, with or without physical disability);
 - Group 4: Both mental disabilities (both domains, with or without physical disability);
 - Group 5: Any physical disability (with or without mental disability);
 - Group 6: No disability.

1
2 16 **Table S2: Living standard questions in the Family Resources Survey**
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4 17

Question	Included	Rationale
Do you (and your family) have a holiday away from home for at least one week a year, whilst not staying with relatives at their home?	YES	
Do you have friends or family around for a drink or meal at least once a month?	NO	Not directly relevant to children's living standards
Do you have two pairs of all-weather shoes for (all members of family)	NO	Depending on disability, might not be applicable to all children
Do you have enough money to keep your home in a decent state of decoration?	YES	
Do you have household contents insurance?	YES	
Do you make regular savings of £10 a month or more for rainy days or retirement?	YES	
Do you replace any worn out furniture?	YES	
Do you replace or repair major electrical goods such as a refrigerator or a washing machine, when broken?	YES	
Do you have a small amount of money to spend each week on yourself (not on your family)	YES	
do you have a hobby or leisure activity	NO	Not directly relevant to children's living standards
In winter, are you able to keep this accommodation warm enough	NO	Not coded as the other variables (yes/no)
Does your child/do your children have a family holiday away from home for at least one week a year?	YES	
And are there enough bedrooms for every child of 10 or over of a different sex to have their own bedroom?	NO	Not applicable to all families
Does your child/do your children have leisure equipment such as sports equipment or a bicycle?	YES	
Does your child/do your children have celebrations on special occasions such as birthdays, Christmas or other religious festivals?	YES	
Does your child/do your children go swimming at least once a month?	NO	Potentially not applicable to children with disabilities affecting mobility
Does your child/do your children do a hobby or leisure activity?	YES	
Does your child/do your children have friends around for tea or a snack once a fortnight?	YES	
Does your child/do your children (if <6 yrs old) go to toddler group / nursery / playgroup at least once a week?	NO	Not applicable to all families (child < 6yo)
Does your child/do your children go on school trips?	NO	Not applicable to all families (child <6yo)
Does your child/do your children have an outdoor space or facilities nearby where they can play safely	NO	Potentially, not applicable/relevant to families with severely disabled children

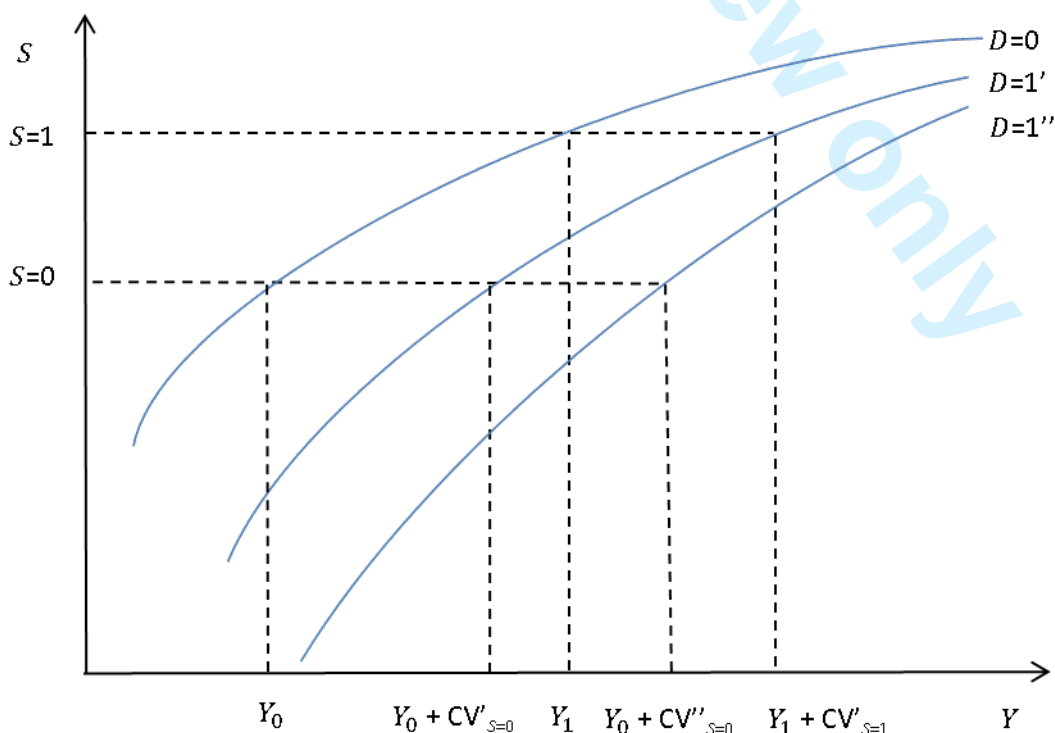
19 Theoretical approach: Compensating Variation

20 In Figure S1 we illustrate the concept of CV by plotting curves relating the income (Y , on the horizontal axis) and the living standards (S , on the vertical axis) of families without a disabled child ($D = 0$) and with a disabled child ($D = 1'$). We assume that: (i) the curves are upward sloping from left to right and convex, due to diminishing returns to S as Y increases; and, (ii) $D = 1'$ lies below $D = 0$ though they tend towards one another at higher levels of Y . At a given level of living standards such as $S = 0$ the CV is the difference between the income that a family with a disabled child ($D = 1'$) needs to have ($= Y_0 + CV'_{S=0}$) compared to the income of a family without a disabled child ($D = 0$) ($= Y_0$) to achieve the same living standard ($S = 0$). Based on our assumptions this difference will decrease at higher levels of living standards. For instance, the CV between $D = 1'$ and $D = 0$ for $S = 1$ (where $S = 1 > S = 0$) will correspond to $Y_1 + CV'_{S=1}$, which is smaller than $Y_0 + CV'_{S=0}$.

31 We hypothesize that families of children with more severe disabilities incur higher costs to achieve the same living standards as families with less severely disabled children. Suppose $D = 1''$ denotes more severe disabilities than $D = 1'$; this is shown in Figure 1 as curve $D = 1''$ lying below curve $D = 1'$. In this case the CV for $S = 0$, corresponds to $Y_0 + CV''_{S=0}$, which is greater than $Y_0 + CV'_{S=0}$.

36 In order to employ this approach to investigate our aims, three measures are needed: 1) a definition of child mental and physical health disability; 2) a measure of living standards (LS); and 3) a measure of income.

39 **Figure S1: Compensating variation**



40

Theoretical Approach: Propensity Score Matching

If we assume that the probability of having a disabled child is adequately explained by the set of observed characteristics X , we can select from the sample of families with non-disabled children a control (i.e. non-treated) group, which is similar to the treated group with respect to X , but different with respect to disability D ²⁷. We therefore calculated the CV as the average treatment effect on the treated (ATT), as follows:

$$ATT = E[Y_1 - Y_0 | D=1] = E[Y_1 - Y_0 | D=1, p(X)] = E[Y_1 | D=1, p(X)] - E[Y_0 | D=0, p(X)] \quad (1)$$

We matched families using nearest neighbor 1:1 matching within a caliper, defined to be one quarter of the standard deviation of the propensity score²⁵. Families are matched based on similar distributions of propensity scores, which might not arise from identical values of X . Since one of our aims is to estimate the income difference for families with and without a disabled child for the same value of living standards (S), we included values of our LSI rounded to the first decimal point as external to X and matched on both, so that the CV is given by:

$$ATT = E[Y_1 - Y_0 | D=1] = E[Y_1 - Y_0 | D=1, L, p(X)] = E[Y_1 | D=1, L, p(X)] - E[Y_0 | D=0, L, p(X)] \quad (2)$$

In other words, our procedure was as follows: first, the propensity score was calculated as the predicted probability from the probit model. Then, for each family with a disabled child we selected a match from the pool of families without a disabled child with the same value of living standards (based on the first four digits of the index) and the closest propensity score within the common support area.

67 **Sensitivity analyses**

68 Our results remain largely consistent in sensitivity analyses using 3:1 matching, where we did not
69 observe any substantial differences compared with the results in Table 3 (results not shown).

70
71 Results were also similar when we used radius matching, although the magnitude of the CV in
72 analyses not stratified by LS generally decreased. As shown in table S3, we observed that children
73 with any mental health disabilities (Group 3, Comparison C), those both mental health disabilities
74 (Group 4, comparison D), and those with any physical disabilities (Group 5, comparison S) needed
75 an extra £34.20 (95%CI: 23.42; 44.98), £39.21 (95%CI: 14.22; 64.08) and £25.20 (95%CI: 12.71;
76 37.78), respectively, to achieve the same LS of families with non-disabled children. We also
77 observed that CV for families of disabled children in these three groups and low LS was even
78 greater: children with any mental health disabilities (Group 3, Comparison C), those both mental
79 health disabilities (Group 4, comparison D), and those with any physical disabilities (Group 5,
80 comparison S) needed an extra £60.35 (95CI: 57.38; 63.32), £81.47 (95%CI: 60.15; 102.80) and
81 £42.47 (95%CI: 33.64; 51.29) to meet the same LS of families without a disabled child. These
82 figures were comparable to those presented in our main analyses.

83
84 We also found that families in low LS with a child with any mental health disability (Group 3,
85 Comparison F) needed an extra £29.74 (95%CI: 15.92; 43.56) per week to meet the same LS of
86 families with no disabled children or children with any physical health disabilities. In our main
87 analyses we found a figure similar in magnitude (£39.23 (95%CI: -15.67; 94.12)), but for which
88 there was no evidence of a difference.

89
90 The only inconsistent findings we observed was that, when we used radius matching, we found
91 that families with high LS and children with any mental health disability (Group 3, comparison F)
92 were over compensated by £77.41 (95%CI: -138.31; -16.50).

93
94 All models were balanced.

95

96
97 Table S3: Compensating variation using radius matching

Comparisons	Mean income difference (95%CI) [N]		
	All LS [cases on common support/ total no. of cases] ^a	Low Living Standards (LS <1) [cases on common support/ total no. of cases] ^a	High Living Standards (LS=1) [cases on common support/ total no. of cases] ^a
(A) Any mental disability (no physical disability)	-1.42 (-32.27; 35.10) [352/352]	13.65 (-7.43; 34.74) [258/258]	-32.16 (-145.43; 81.05) [94/94]
(B) Any physical disability (no mental disability)	5.55 (2.56; 8.53) [1126/1126]	4.93 (2.19; 7.68) [820/820]	7.19 (-2.86; 17.27) [306/306]
(C) Any mental disability (+/- physical disability)	34.20 (23.42; 44.98)** [1772/1782]	60.35 (57.38; 63.32)** [1286/1293]	-34.98 (-80.18; 11.04) [486/489]
(D) Both mental disability (+/- physical disability)	39.21 (14.22; 64.08)** [971/977]	81.47 (60.15; 102.80)** [703/707]	-71.66 (-142.58; -0.74) [268/270]

98

(E) Any physical disability (+/- mental disability)	25.20 (12.71; 37.78)** [2681/2686]	42.47 (33.64; 51.29)** [1956/1958]	-21.41 (-61.02; 18.21) [725/728]
(F) Any mental disability (+/- physical disability)	-1.05 (-21.10; 19.01) [1695/1782]	29.74 (15.92; 43.56)** [1208/1293]	-77.41 (-138.31; -16.50)** [487/489]
(G) Both mental disability (+/- physical disability)	0.09 (-47.17; 47.36) [871/977]	47.06 (17.21; 76.91)** [603/707]	70.40 (-244.19; 33.03) [268/270]
(H) Any physical disability (+/- mental disability)	11.72 (-7.11; 30.55) [2626/ 2686]	3.58 (-12.05; 19.22) [1898/ 1958]	32.94 (-21.45; 87.32) [728/728]

99 a Total sample size for each model is twice that of cases on common support, due to 1:1 matching.

100 ** p<=0.05 *0.1>p>0.05

101 Abbreviations: LS = living standards. Numbers in squared brackets are sample sizes.

102 Highlighted in bold are results whose magnitude and significance differed from those found in the main
 103 analyses (Table 3 of the main text), but whose direction of association was unchanged; highlighted in **bold**
 104 **and italics** are those whose magnitude, direction, and significance of association changed.

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STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No	Recommendation	PAGE
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract (b) Provide in the abstract an informative and balanced summary of what was done and what was found	1-2 2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	4-5
Objectives	3	State specific objectives, including any prespecified hypotheses	5
Methods			
Study design	4	Present key elements of study design early in the paper	1, 5-6
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	2, 5-6
Participants	6	(a) <i>Cohort study</i> —Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up <i>Case-control study</i> —Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls <i>Cross-sectional study</i> —Give the eligibility criteria, and the sources and methods of selection of participants (b) <i>Cohort study</i> —For matched studies, give matching criteria and number of exposed and unexposed <i>Case-control study</i> —For matched studies, give matching criteria and the number of controls per case	5-6
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6-9
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	6-9
Bias	9	Describe any efforts to address potential sources of bias	13
Study size	10	Explain how the study size was arrived at	5-6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	6-9
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding (b) Describe any methods used to examine subgroups and interactions (c) Explain how missing data were addressed (d) <i>Cohort study</i> —If applicable, explain how loss to follow-up was addressed <i>Case-control study</i> —If applicable, explain how matching of cases and controls was addressed <i>Cross-sectional study</i> —If applicable, describe analytical methods taking account of sampling strategy (e) Describe any sensitivity analyses	12-13 N/A 10-11 10, 13

Continued on next page

Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	5-6
		(b) Give reasons for non-participation at each stage	5-6
		(c) Consider use of a flow diagram	N-A
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	11
		(b) Indicate number of participants with missing data for each variable of interest	11
		(c) <i>Cohort study</i> —Summarise follow-up time (eg, average and total amount)	11
Outcome data	15*	<i>Cohort study</i> —Report numbers of outcome events or summary measures over time	
		<i>Case-control study</i> —Report numbers in each exposure category, or summary measures of exposure	
		<i>Cross-sectional study</i> —Report numbers of outcome events or summary measures	11-12
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	11-13
		(b) Report category boundaries when continuous variables were categorized	
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	
Discussion			
Key results	18	Summarise key results with reference to study objectives	13-14
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	15
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	13-15
Generalisability	21	Discuss the generalisability (external validity) of the study results	15
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	1

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.

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The cost of mental and physical health disability in childhood and adolescence to families in the United Kingdom: findings from a repeated cross-sectional survey using propensity score matching

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3 1 **The cost of mental and physical health disability in childhood and adolescence to families in the**
4 2 **United Kingdom: findings from a repeated cross-sectional survey using propensity score matching**

5
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27 18 **Keywords:** Child disability; living standards; disability benefits; compensating variation; propensity
28 19 score matching.
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33 21 **Competing interests:**

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35 22 The authors declare no competing interests.
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ABSTRACT

Objective: UK families of disabled children are entitled to receive disability benefits to help meet costs associated with caring for their child. Evidence of actual costs incurred is scant, especially for mental health disability. In this study we aimed to quantify the cost of mental and physical health disability in childhood and adolescence to families in the UK using the concept of compensating variation (CV).

Design: Repeated cross-sectional survey.

Setting: UK general population

Participants: 85,212 children drawn from eight waves of the Family Resources Survey.

Outcomes: Using propensity score matching we matched families with a disabled child to similar families without a disabled child and calculated the extra income the former require to achieve the same living standards as the latter, i.e. their CV. We calculated the additional costs specifically associated with several definitions of mental health and physical health disability.

Results Families of a child with any mental health disability, regardless of the presence of physical health comorbidity, needed an additional £49.31 (95% confidence interval (CI): 21.95; 76.67) and, for more severe disabilities, an additional £57.56 (95%CI: 17.69; 97.44) per week to achieve the same living standards of families without a disabled child. This difference was greater for more deprived families, who needed between £59.28 (95%CI: 41.38; 77.18) and £81.26 (95%CI: 53.35; 109.38) more per week depending on the extent of mental health disability. Families of children with physical health disabilities, with or without mental health disabilities, required an additional £35.86 (95%CI: 13.77; 57.96) per week, with economically deprived families requiring an extra £42.18 (95%CI: 26.38; 57.97) per week.

Conclusions Mental and physical health disabilities among children and adolescents were associated with high additional costs for the family, especially for those from deprived economic backgrounds. Means testing could help achieve a more equitable redistribution of disability benefit.

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3 64 **Strengths and Limitations**
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- 5 65 • Strengths of this study are the use of: (i) a large and rich dataset representative of the UK
6 66 population; (ii) disability domains employed in the Disability Discrimination Act (DDA) consistent
7 67 with definitions applicable to policy settings; and, (iii) novel analytical approach based on
8 68 propensity score matching.
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11 69 • Limitations of this study are: (i) its cross-sectional design; (ii) difficulties in disentangling physical
12 70 and mental health disabilities (which are often co-occurring); and, (iii) data limitations making it
13 71 problematic to account for severity of disability and to measure living standards, and only
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15 72 covering the period 2004/05 up to 2011/12.
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INTRODUCTION

Families of children suffering from chronic conditions and physical and mental health disabilities incur significantly higher costs than those of their healthy counterparts.¹⁻⁵ These costs are primarily accounted for by more frequent visits to inpatient and outpatient departments and by greater use of prescribed drugs,¹⁻³ although evidence also suggests that the need to provide or secure informal care adds to the financial burden of child disability for these families.^{4,5} Previously, UK studies have estimated the cost of having a disabled child at about £79-£100 per week⁴ and that under the benefits arrangements at the time (1997) families of disabled children were undercompensated by £30-£80 per week⁴ and by £28 in 2001.⁵ More recent evidence has estimated that in the UK families of severely disabled children require up to an additional £79 per week to be able to meet the same living standards of those without disabled children.⁶

Mental health conditions account for a great portion of the burden of disease among children and adolescents below the age of 16 years.⁷ Onset of most mental health conditions occurs at different stages of childhood and adolescence: developmental and hyperkinetic disorders become manifest in early childhood, whilst depressive (including suicide and self-harm), psychotic, anxiety, conduct, and eating disorders most commonly arise in adolescence and young adulthood.⁸ Evidence suggests that in the UK there has been a trend towards increasing rates of children and young people suffering from mental health conditions since the 1980s.⁹ The 2004 British Child and Adolescent Mental Health Survey (B-CAMHS) conducted by the Office of National Statistics (ONS) reported that 10% of children aged 5 – 16 years met diagnostic criteria for a mental health disorder.¹⁰

A socio-economic gradient exists in the distribution of child mental health disorders¹¹⁻¹³. In the 2004 B-CAMHS, prevalence of diagnosable child mental health conditions was higher among single-parent (15.6%) compared to married or co-habiting (7.7%) households; among families with low (16.1%) compared to high (5.3%) income; and among families whose parents had no academic qualifications (17.0%) compared to those with university degrees (4.4%)¹⁴. Evidence exists that life adversities are a risk factor for the onset of mental health conditions as well as that mental health problems of the child can lead to family breakdown and unemployment¹⁴.

Both mental health problems and socio-economic disadvantage in childhood and adolescence can have enduring effects and significantly impact on a young person's future. Children and adolescents suffering from mental health problems more often report low levels of academic achievement, and engage in risky behaviours such as alcohol and drug use with detrimental effects on employment

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3 107 prospects¹⁵. Similarly, childhood experience of economic hardship can result in long-term adverse
4 108 health outcomes via the persistence of lower socio-economic status¹⁵.

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8 110 Since 1992, in the UK, families of children affected by disability have been eligible to receive a non-
9 111 means-tested weekly Disability Living Allowance (DLA).¹⁶ The rationale for these benefits is that
10 112 they “*may help with the extra costs of looking after a child who: is under 16; has difficulties walking*
11 113 *or needs more looking after than a child of the same age who doesn’t have a disability*”.¹⁶ The
12 114 amount of benefits that the family is entitled to receive largely depends on the severity of the child’s
13 115 condition, which is determined by the disability service centre often in conjunction with external
14 116 assessments. In 2017, under the care component of DLA, children could receive either £22 (if they
15 117 needed a little help during the day or night), £55.65 (if they needed frequent supervision), or £83.10
16 118 (if they needed constant help day and night, or were terminally ill) per week. Under the mobility
17 119 component of DLA, children were entitled to receive between £22 (if they could walk but needed
18 120 supervision outdoors) and £58 (if they could not walk, if walking represented a health risk, or if they
19 121 were blind) per week.

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22 123 Previous UK studies have shown that families of disabled children incur high costs, but were
23 124 however unable to attribute these extra expenditures to either physical or mental health disability,
24 125 which has been shown to inflict a substantial economic burden in other settings.^{2,3} In the absence of
25 126 literature exploring the cost of child mental health disability to families, and the rising prevalence of
26 127 these problems, the aims of this study are to: (1) investigate the cost to families of having a child
27 128 with a mental health disability; (2) compare the costs of mental health versus physical health
28 129 disability to assess whether such stratification is needed when considering disability benefits; and,
29 130 (3) examine how these costs vary by economic deprivation in order to assess whether means testing
30 131 of DLA should be considered.

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MATERIALS AND METHODS

Sample

37 135
38 136 We employed data from eight consecutive rounds of data collection from the Family Resources
39 137 Survey (FRS) covering the financial years 2004/05 to 2011/12. The FRS is a repeated cross-sectional
40 138 survey undertaken by the Department of Work and Pensions (DWP) whose aim is to collect data on
41 139 the financial and social circumstances of individuals living within private UK households. Although
42 140 representativeness of the older age groups within the population might be limited in FRS due to the

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3 141 focus on private households (nursing and retirement homes are not included), the overall sample,
4 142 used in this study, is representative of the UK population¹⁷, and our focus on families with children
5 143 under 16 years of age means this is unlikely to introduce a bias.
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9 145 In the FRS households are defined as 'a single person or group of people living at the same address
10 146 who either share one meal a day or share the living accommodation, i.e. a living room'. Each
11 147 household may include one or more benefit unit, 'a single adult or couple living as married and any
12 148 dependent children'. A dependent child is a 'child younger than 16 years or an unmarried 16 to 19-
13 149 year-old in full time non-advanced education'.¹⁸ In this study, for simplicity we refer to benefit units
14 150 as 'families' and consider children as our main unit of analyses, as matching was done at child-level.
15 151 Our sample includes children aged 0-15 years and their families who had complete data on all
16 152 variables included in the model covariates and necessary to estimate the CV (i.e. income and living
17 153 standards). We excluded all the children from families with more than one disabled child because of
18 154 difficulties separating the effects of multiple disabled children in the same family (2.7% of total
19 155 children). In families with only one disabled child who had siblings we excluded the siblings to avoid
20 156 within-family matching.
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32 159 **Child mental and physical health disability**

33 160 In line with the definition of disability included in the Disability Discrimination Act (DDA) 1995 and
34 161 2005, the FRS defines a child as having a disability if they have a longstanding illness lasting longer
35 162 than 6 months and affecting their ability to undertake daily activities. Families were asked if their
36 163 child had any longstanding illness, disability or infirmity. Families responding 'yes' were directed to a
37 164 set of follow up questions asking which area of the child's life was affected by their disability.
38 165 Possible answers were: mobility; lifting; manual dexterity; continence (i.e. bladder control);
39 166 communication (i.e. speech, hearing, or eyesight); memory and learning; recognition of physical
40 167 danger; physical coordination; other; or, none of these areas. As we were not able to define their
41 168 disability either as affecting physical or mental health, we excluded children whose family claimed
42 169 had a disability but subsequently said that none of these areas were affected by disability (3.4% of
43 170 total children).
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53 172 Of these eight disability domains, we assume that memory and learning, and recognition of physical
54 173 danger can be attributable solely to mental health problems, as they are related to cognitive
55 174 impairment. We assume all other areas primarily reflect physical health problems¹⁹, but
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175 acknowledge these domains could also be affected by, or affect, mental health status. For ease of
176 explanation, we will hereafter refer to memory and learning, and recognition of physical danger as
177 'mental health' disability areas, and mobility, lifting, manual dexterity, continence, communication,
178 and physical coordination as 'physical health' disability areas.

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180 Using this distinction we defined disability accounting for: 1) presence of comorbidity between
181 mental and physical disability; 2) number and type of areas affected by disability. Therefore we
182 created 6 disability groups defined as follows:

- 183 • Group 1: Any mental disability (either or both domains), no physical disability;
- 184 • Group 2: Any physical disability, no mental disability (group 1 & 2 are mutually exclusive);
- 185 • Group 3: Any mental disability (either or both domains), with or without physical disability;
- 186 • Group 4: Both mental disabilities (both domains), with or without physical disability;
- 187 • Group 5: Any physical disability, with or without mental disability;
- 188 • Group 6: No disability.

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190 **Supplemental table 1** provides a summary of our groups. We did not create a separate group for
191 children with both mental health domains affected by disabilities, but no physical disability as the
192 numbers were too low. Under the same rationale we did not include a group with children affected
193 by disability in all of the physical health domains due to low numbers. We compared these groups as
194 follows:

- 195 • Comparison A: Group 1 versus Group 6;
- 196 • Comparison B: Group 2 versus Group 6;
- 197 • Comparison C: Group 3 versus Group 6;
- 198 • Comparison D: Group 4 versus Group 6;
- 199 • Comparison E: Group 5 versus Group 6.

200

201 By allowing for comorbidity between mental and physical health disability in groups 3, 4, and 5, we
202 attempt to explore whether these disability groups could represent more severe conditions
203 compared to groups 1 and 2. Physical health impairments are more common in children with mental
204 health problems¹⁴ similarly, physical health disability can adversely affect mental health²⁰. We
205 hypothesise that if the cost of mental health disability is greater than that of physical health
206 disability we should see a positive CV for groups 1, 3, and 4 and this will be greater in magnitude
207 than that observed in groups 2 and 5.

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209 It is possible, however, that both physical and mental health have a positive and significant impact
 210 and, although the magnitude of the CV across the previously defined groups can give an indication of
 211 the overall impact of mental and physical health disability on the costs borne by the family, it is
 212 important to attempt to quantify their relative impact. Therefore, in order to investigate our second
 213 aim we ran three additional models comparing the exposed group against both children without
 214 disabilities and children who had a disability 'other' than that employed to define the main
 215 exposure. For example, children with any or both (all) 'mental (physical) health disabilities' plus
 216 other physical (mental) health comorbidities were compared with children with no disabilities and
 217 children with only physical (mental) health comorbidities. We defined these models as:

- 218 • Comparison F: Group 3 versus Group 6 and Group 2;
- 219 • Comparison G: Group 4 versus Group 6 and Group 2;
- 220 • Comparison H: Group 5 versus Group 6 and Group 1

222 **Living standards**

223 Material deprivation is measured in the FRS through a set of 21 questions asking whether the family:
 224 (i) can afford and has; (ii) would like to have, but cannot afford; or (iii) can afford, but does not want
 225 a number of goods previously identified as necessities by families. Ten of the 21 questions were
 226 relevant for families without children; all 21 were relevant for families with children.²¹ We employed
 227 a sub-set of 12 questions asked to the whole sample at each survey wave included in our study.
 228 These questions were selected on the basis of their relevance for families with children, irrespective
 229 of whether or not the child was disabled. For instance, a question about taking children to swim at
 230 least monthly was not included as this might not have been a relevant domain for families with
 231 children with disabilities affecting mobility, irrespective of whether or not it was affordable. In
 232 **Supplemental Table 2** we provide a list of all questions we did and did not include with a rationale
 233 for the latter.

234
 235 From these questions we developed a living standards index (*LSI*) using prevalence weighting²² with
 236 weights representing the proportion of families considering the item a necessity. We calculated the
 237 *LSI* as follows:

$$238 \quad LSI = \frac{\sum_{i=1}^M x_i w_i}{\sum_{i=1}^M w_i} \quad (1)$$

240 In Eq.(1), x_i is a binary variable indicating whether the family can afford each item (1='yes, can afford
 241 and has it'; or 'yes, can afford, but does not want', 0='would like to have, but cannot afford), w_i is the

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3 242 proportion (i.e. weight) of respondents who consider the item desirable, as defined above²² and M
4 243 is the number of items.

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7 244 A total of 10% of families in our sample had missing data for one or more of these questions. In
8 245 order to derive a LSI value for these families, we scaled the score they obtained from the questions
9 246 they answered on the total score they could have obtained if they had could afford each of the items
10 247 they were asked about ($\sum_{i=1}^M w_i$).

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14 248 Finally, from the continuous *LSI* ranging from 0 to 1 (distribution in Figure 1) we defined families with
15 249 a *LSI*=1 as having 'high living standards', since they could afford each item included, and families with
16 250 *LSI*<1 as having 'low living standards' as they could not afford one or more of the items. We
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18 251 employed continuous values of the *LSI* to match families using propensity scores and the derived
19 252 binary variable to conduct stratified analyses (see Data Analysis section).

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24 254 **Income**

25 255 We derived a measure of income accounting for all available resources affecting living standards^{23,24},
26 256 including net income from all sources (i.e. earnings, self-employment, investments, and pensions) as
27 257 well as from any benefits, including disability benefits, received by the family. Disability and other
28 258 benefits were included because these affect living standards. We inflated incomes to 2011/12 prices.
29 259 We did not employ an equivalised measure of income for ease of interpretation of the results (i.e.,
30 260 our unit of analysis is the family and equivalised income is a measure of income per person);
31 261 however, in order to account for family composition we included variables indicating number of
32 262 adults and ages of children in the matching stage of the analyses (see below), in line with previous
33 263 literature^{23,25}. Values of net income are reported 'per week' in the FRS.

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41 265 **Other variables**

42 266 In our analyses we match families with and without a disabled child on a number of socio-
43 267 demographic and socio-economic characteristics of the families and their children. We included
44 268 indicators of the child's age (linear term) and gender (male/female); two linear terms for number of
45 269 dependent children in the family (range 1-8) and number of years of schooling after the age of 18
46 270 years (i.e. the age at which compulsory education ends in the UK) of the head of the household and
47 271 their marital status (single/couple); presence of a disabled adult (yes/no), and to account for family
48 272 wealth, a categorical variable indicating family savings banded in five categories and an indicator of
49 273 parental (i.e. main respondent's) employment (employed/unemployed/inactive).

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3 275 We also included a categorical indicator for survey year and UK Government Office Region (London;
4 276 South East; Rest of England; Northern Ireland, Wales and Scotland¹).

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7 278 **Data analysis**

8 279 We described how sample characteristics vary by disability group using cross-tabulations with Chi-
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10 280 Square tests and ANOVAs for categorical and continuous variables, respectively.

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14 282 We employed the 'compensating variation' (CV) approach to calculate the cost of child disability,
15 283 which has been previously used in studies of disability in adults²⁴ and children.⁶ The CV can be
16 284 defined as the additional income that a family with a disabled child needs to be able to achieve the
17 285 same living standards of a family that is similar in all other respects but without a disabled child.
18
19 286 More details on the theoretical approach can be found in the supplementary material and in Figure
20 287 S1. We used Propensity Score Matching (PSM)^{26,27} to match families according to comparisons A – H
21 288 and calculate the CV (i.e. the mean income difference). It has been suggested that this approach, by
22 289 simulating a randomised controlled trial setting, can provide a more unbiased estimate of the
23 290 income difference than parametric models in observational studies²⁴.

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27 292 We calculated propensity scores (i.e. predicted probabilities) from probit regression models with
28 293 each of our group allocations in the comparisons defined above (Comparisons A to H) as the
29 294 outcome (e.g., for Comparison A, participation in Group 1 is coded 1 and Group 6 is coded 0, all
30 295 other groups are coded as missing). In all models the independent variables were child age and
31 296 gender, number of children and disabled adults in the family, years of schooling of the main
32 297 respondent, marital status, family savings, government region and survey year. Additionally, for
33 298 comparisons F, G, and H we also controlled for areas of disability (other than those defining the
34 299 Group) as covariates. For all models we calculated areas under the receiver operating characteristic
35 300 (ROC) to estimate goodness of fit of the model and tested whether the distribution of the covariates
36 301 was balanced between disabled and non-disabled children. More details on the PSM theoretical
37 302 approach are in the supplementary material.

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39 303 For each matching pair obtained with this matching approach we calculated the CV and its 95% CI²⁸.
40 304 As sensitivity analyses we estimated the compensating variation matching disabled children using
41 305 3:1 matching (i.e. matching a disabled child to the three closest matches) and using radius matching

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¹ Rest of England includes: North East, North West & Merseyside, Yorkshire & Humberside, East Midlands, West Midlands, and South West.

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3 306 (defining the radius as a quarter of a the propensity score standard deviation). All our analyses were
4 307 run using Stata13.²⁹
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308 RESULTS

309 Sample characteristics

310 From an initial sample of 99,142 children (61,952 families), we excluded families with a disabled
311 child whose disability could not be described in terms of one of the 9 main disability areas (N=3,461,
312 3.4%), those with more than one disabled child (n= 2,651 children, 2.7%), and siblings of disabled
313 children (n = 4,636 children, 4.7%). After excluding children with any missing data on the variables of
314 interest (n = 3,182, 3.2%) the final sample consisted of 85,212 children nested in 52,639 families
315 (with minimum of 1 and maximum of 8 children).
316

317 The majority of children included in our sample were male (51.05%), lived in a two-parent family
318 (74.75%), did not live with an adult with a disability (84.12%), lived in a family whose total savings
319 were less than £1,500 (58.85%), and lived in the 'rest of England' (50.57%) (Table 1). Mean child age
320 was 7.42 years (standard deviation (SD) = 4.69), mean number of dependent children in the
321 household was 2.19 (SD=0.99), and mean number of years spent in education past the age of 18
322 years by the main respondent was 18.08 (SD=2.15).
323

324 Child disability

325 In total, 1,782 (2.1%) children had some type of mental health disability, irrespective of the presence
326 of physical disabilities, and 352 children (0.4%) had mental health disability without physical health
327 disability (Table 1). A greater number of children had physical health disability, either with (2,686,
328 3.1%) or without (1,126 1.3%) mental health problems, respectively.
329

330 Compared to children without any disabilities, and for all definitions of disabilities, more children
331 with disabilities were male, lived in a single parent household and with an adult also affected by
332 disability, had a parent who spent less time in education and had fewer savings, and were older
333 (Table 1).
334

335 Across low and high living standards, families of children with any type of disability had lower
336 income than those of children without disabilities (Table 2); in every disability group income was
337 higher in families with higher living standards. Among families with low living standards, families of
338 children with both mental health areas affected by disability had higher income than those without
339 disability, whereas families of children with any mental or physical health only had lower income.

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3 340 Among families with high living standards, families of children affected in any of the physical or
4 341 mental health disability areas or in both the mental health areas, regardless of other areas affected,
5 342 had lower income compared to families of children without disabilities.
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344 **Benefits**

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10 345 As seen in Table 3, across all LS groups combined families of children with both mental health
11 346 disabilities (Group (4)) received the highest amount of weekly benefits (mean value £45.95),
12 347 followed by those with any mental health disabilities (Group (3); £34.48), and those with any
13 348 physical health disabilities (Group (5); £26.22) (Table 3). Note these groups included children with
14 349 both mental and physical disabilities. Children only affected in either or both mental health areas
15 350 received on average £17.40 per week (Group (1)) whilst those affected in any or all physical health
16 351 domains only received £10.63 (Group (2)). The amount of benefits received did not vary by LS,
17 352 reflecting the absence of means testing for disability benefits. None of the children in the non-
18 353 disabled group were receiving any disability benefits.
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356 **Compensating variation**

30 357 Over and above their net income (including benefits received) families of children with any (Group 3)
31 358 or both mental health disabilities (Group 4) needed an additional £49.31 (95% confidence interval
32 359 (CI): 21.95; 76.67) and £57.56 (95% CI: 17.69; 97.44), respectively, a week in order to achieve the
33 360 same living standards of similar families without a disabled child (Group 6; Comparisons C and D,
34 361 respectively), across both levels of LS (Table 4). We also found evidence that families of children
35 362 with any physical health disability (Group 2) needed an additional £35.86 (95%CI: 13.77; 57.96) per
36 363 week to meet the living standards of families without disabled children (Group 6; Comparison E).
37 364 When pooling across living standards, we did not find any other differences in any of the other
38 365 disability groups.
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47 367 When we split the sample by low and high levels of living standards, we found that in some cases
48 368 families with low LS with a disabled child needed a higher net income to meet the same LS of
49 369 families without a disabled child. Specifically, we found that families of a child with any mental
50 370 health disability or both mental health disabilities (with or without physical disabilities) required an
51 371 extra £59.28 (95%CI: 41.38; 77.18), Group 3, Comparison C) and £81.37 (95%CI: 53.35; 109.38,
52 372 Group 4, Comparison D) a week more than a family without a disabled child. We also found an
53 373 income difference, albeit smaller, for families of children with disability affecting physical health
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3 374 compared to families of non-disabled children, with the former needing an extra £42.18 (95%CI:
4 375 26.38; 57.97, Group 5, Comparison E) more a week to achieve the same LS.
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8 377 When we compared children affected by disability in any, or both mental health areas and in any
9 378 physical health areas, regardless of the presence of other disabilities, against children without
10 379 disabilities and other with physical and mental health disabilities respectively (i.e., in comparisons F -
11 380 H), we found weak evidence that families of children with both mental health areas affected by
12 381 disabilities needed an extra £47.45 (95% CI: -0.41; 95.30) more per week to achieve the same LS if in
13 382 the low LS category (Table 4). Although, we did not find any evidence of differences for the other
14 383 groups, in particular those with high living standards, there was an indication that children in group 1
15 384 (any mental health disability with no physical health disability), and group 4 (both mental health
16 385 disabilities regardless of physical health disabilities) were adequately compensated, although the
17 386 latter case only among children with greater LS. We did not find evidence of any other group
18 387 differences.
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27 389 *Sensitivity analyses and model checks*

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29 390 The sensitivity analysis using 3:1 matching yielded virtually identical results to those in the main
30 391 analysis (results not shown). The sensitivity analysis using radius matching also yielded similar
31 392 results, with some small differences in the size and significance of the compensating variation for
32 393 some comparisons (Supplemental material and Table S3).
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37 395 In our main analysis, for comparisons A to E the distribution of covariates was balanced between
38 396 treatment groups (i.e. disabled and non-disabled children) with the exception of years of schooling,
39 397 which in some models was unbalanced. In models F to H, the distribution of covariates was less well
40 398 balanced in our main analyses. However, in sensitivity analyses all models were balanced, and since
41 399 the results in the sensitivity analysis were similar to those of the main analysis, this suggests that this
42 400 is unlikely to have biased our estimates.
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48 **DISCUSSION**

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50 403 Little evidence exists on the costs borne by families of children affected by mental health disability in
51 404 the UK. To the best of our knowledge, this is the first UK study aiming to quantify these costs using
52 405 propensity score matching and a compensating variation approach to estimate cost of mental health
53 406 disability.
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3 408 We found no difference in income between families of children with a disability affecting any or all
4 409 areas associated with mental health problems only and families of non-disabled children. When we
5 410 allowed for existence of physical health comorbidities, we found that these families needed an
6 411 additional £49.31 per week over and above existing net incomes (including disability benefits)
7 412 compared to families of non-disabled children to achieve the same living standards, with an even
8 413 greater amount needed if children's disability affected both mental health domains (£57.56). These
9 414 difference were, again, even greater for families with low living standards (£59.28 and £81.37,
10 415 respectively). In comparison, families with children affected by physical health had a positive, but
11 416 smaller in magnitude, CV (£35.86), which was, similarly to what was observed for mental health
12 417 disability, higher among families with low LS (£42.18). When we tested the relative impact of mental
13 418 and physical health on the CV, by allowing our comparator group to have disabilities in the opposite
14 419 domains of the one under investigation, we found a positive, though weak, CV for children affected
15 420 in both mental health disabilities who live in families with low LS (£47.45). These findings suggest
16 421 that all these groups are undercompensated by the benefits system.
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27 423 These results suggest that mental health disabilities in childhood are associated with substantial
28 424 costs which need to be borne by their families. In other words, families of children with mental
29 425 health disabilities need to have higher income in order to achieve the same living standards of a
30 426 family without a disabled child. These costs appear to be higher when there are co-occurring mental
31 427 and physical disabilities, possibly an indicator of severity of the condition, and for more economically
32 428 deprived families. As benefits were already included in our income measure, the compensating
33 429 variation represents the amount by which families appear to be undercompensated under current
34 430 benefit arrangements.
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41 432 Our findings on the cost of child disability are lower from those found by Dobson and colleagues
42 433 estimating the cost of child disability to the family at £100 per week^{4,5}. Compared to these studies,
43 434 we also found that under-compensation occurred to a lower extent, in the range of £8-£15 and only
44 435 for deprived families with children with mental health disabilities, as opposed to £30-£80⁴ and £24⁵.
45 436 One reason for this difference could be that these studies employed convenience sampling (i.e.
46 437 selecting children with more severe disabilities and living in more deprived settings) and different
47 438 definitions of disability, which did not clearly distinguish between mental and physical health.
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54 440 This study had several strengths. It employed a large and rich dataset representative of the UK
55 441 population. The FRS also makes use of the disability domains employed in the DDA to define areas
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3 442 affected by disability, which makes it consistent with definitions applicable to policy settings. We
4 443 also employed a novel approach which allowed us to match families not only based on their
5 444 propensity scores distribution, but also on the values of living standards with exact matching to the
6 445 first decimal digit. Nevertheless, several limitations should be accounted for. First, we could only
7 446 give an approximate definition of mental and physical health disability, knowing that areas which we
8 447 have considered as physical health could be affected as a result of mental health disability only.
9 448 Nevertheless, our approach represents a first attempt at both costing the impact of mental health
10 449 disabilities on families and disentangling the relative effect of mental and physical health disability.
11 450 We were also unable to explore the effect of severity of disability or of different types of disabilities
12 451 given the nature of the available variables. Future studies should attempt to include specific
13 452 diagnoses, perhaps including sub-clinical presentations as separate categories in order to account for
14 453 varying degrees of severity. A total of 10% had missing data on LS measures; although we calculated
15 454 our index re-scaling the latter to the number of questions each family had answered, it is not
16 455 possible to rule out the possibility that under/over-estimation of the LSI value for these families
17 456 could have occurred. Moreover, our living standards measure provides an indication of what goods
18 457 the family can afford, but not of their quality. However, values of mean income by low/high LSI
19 458 seemed to suggest that the latter adequately describes the intended groups. The sample size for
20 459 some of our disability definitions was small meaning that we could have incurred in type II error and
21 460 failed to observe an income difference when indeed there was one. Due to the cross-sectional
22 461 nature of the study, it was not possible to estimate the CV in the absence of benefits, as the latter
23 462 contribute, when received, to the LS achieved by the family. This approach would have given a
24 463 clearer indication of the income difference between families with and without a disabled child. In
25 464 fact, based on our estimates, we are not able to tell, if we do not observe a difference in income,
26 465 whether an actual difference would have occurred in the absence of the benefits system. By
27 466 comparing the CV to the amount of benefits received, we however attempted to estimate whether
28 467 the family was currently over or undercompensated. Our propensity score model could have been
29 468 improved by including more precise indications of family structure and parental education, as well as
30 469 a greater number of family and child characteristics, such as a clearer specification of parental
31 470 physical or mental health disability. Future studies should endeavor to be more inclusive in order to
32 471 improve model prediction. We used data covering the financial years 2004/05 to 2011/12, which are
33 472 not the most current available. This choice was motivated by a change in the definition of disability
34 473 in 2012/13 to include a separate mental health domain. Although using post-2012/13 data would
35 474 have resulted in a clearer definition of mental health and more recent estimates, we would not have
36 475 had enough statistical power for our analyses. Nevertheless, we found that the amount of DLA

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3 476 received across disability groups in our sample was consistent with 2011/12 and current DLA figures,
4 477 suggesting that our findings bear relevance for current policy. Finally, some of our families,
5 478 especially in adjacent years, could have been recruited in more than one wave of FRS data collection,
6 479 meaning that our samples might have not been totally independent.³⁰ However, given the large size
7 480 of our sample we believe that it is unlikely that this could have biased our results.
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13 482 In conclusion, we found that mental health in childhood and adolescence is associated with high
14 483 costs, which need to be borne by the family. Our findings indicate that families of children from
15 484 more disadvantaged backgrounds are currently undercompensated by the disability benefits system.
16 485 Based on these findings we suggest that mental health should be better defined as a criterion for
17 486 receiving benefits and that the amount of disability benefits that a family is entitled to receive are
18 487 subject to means testing, so that families from more deprived socio-economic backgrounds could be
19 488 entitled to higher benefits amounts.
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27
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36 494 **Data Sharing:** The dataset used in these analyses is publicly available on
37 495 <https://www.ukdataservice.ac.uk/>
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42 497 **Contributors:** Francesca Solmi: Developed research question and study design, analyzed data, and
43 498 wrote manuscript. Maria Melnychuk: Developed research question and study design, analyzed data,
44 499 and contributed to manuscript revision. Steve Morris: Developed research question and study
45 500 design, contributed to manuscript revision, and supervised data analyses and the overall project.
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566 **TABLES and FIGURES**
567 **Figure 1. Distribution of living standard index**
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For peer review only

Table 1: sample characteristics

Group (comparator)	All, N (%)	Child disability					
		No disability N (%)	Any Mental Health only N (%); P (χ^2)	Any Physical Health only N (%); P (χ^2)	Any Mental Health N (%); P (χ^2)	Both Mental Health N (%); P (χ^2)	Any Physical Health N (%); P (χ^2)
		6	1 (vs. 6)	2 (vs. 6)	3 (vs. 6)	4 (vs. 6)	5 (vs. 6)
Total	85,212(100%)	80,920(94.93%)	352(0.43%)	1,126(1.37%)	1,782(2.1%)	977(1.19%)	2,686(3.10%)
Gender of child			$p < 0.0001$	$p < 0.0001$	$p < 0.0001$	$p < 0.0001$	$p < 0.0001$
Male	43,500(51.05%)	40,772(50.38%)	272(77.27%)	636(56.48%)	1,302(73.06%)	722(73.90%)	1,732(64.48%)
Female	41,712 (48.95%)	40,148(49.62%)	80(22.73%)	490(43.52%)	480(26.94%)	255(26.10%)	954(35.52%)
Government Region			$p=0.09$	$p=0.37$	$p=0.02$	$p=0.01$	$p=0.043$
London	8,700(10.21%)	8,322(10.28%)	26(7.39%)	101(8.97%)	164(9.20%)	85(8.70%)	252(9.38%)
South East	9,952(11.68%)	9,458(11.69%)	52(14.77%)	142(12.61%)	217(12.18%)	134(13.72%)	327(12.17%)
Wales, Scotland, Northern Ireland	23,476(27.55%)	22,334(27.60%)	91(25.85%)	303(26.91%)	449(25.20%)	239(24.46%)	693(25.80%)
Rest of England	43,084(50.57%)	40,806(50.43%)	183(51.99%)	580(51.51%)	952(53.42%)	519(53.12%)	1,414(52.64%)
Marital status			$p < 0.0001$	$p < 0.0001$	$p < 0.0001$	$p < 0.0001$	$p < 0.0001$
Single	21,516(25.25%)	19,876(24.56%)	156(44.32%)	430(38.19%)	678(38.05%)	364(37.26%)	1,004(37.38%)
Couple	63,696(74.75%)	61,044(75.44%)	196(55.68%)	696(61.81%)	1,104(61.95%)	613(62.74%)	1,682(62.62%)
Adult with disability in family			$p < 0.0001$	$p < 0.0001$	$p < 0.0001$	$p < 0.0001$	$p < 0.0001$
No	71,679(84.12%)	68,889(85.13%)	249(70.74%)	740(65.72%)	1,212(68.01%)	649(66.43%)	1,783(66.38%)
Yes (at least one parent)	13,533(15.88%)	12,031(14.87%)	103(29.26%)	386(34.28%)	570(31.99%)	328(33.57%)	903(33.62%)
Year			$p=0.051$	$p=0.53$	$p=0.35$	$p=0.23$	$p=0.76$
2004/05	12,822(15.05%)	12,232(15.12%)	64(18.18%)	166(14.74%)	262(14.70%)	130(13.31%)	385(14.33%)
2005/06	11,639(13.66%)	11,043(13.65%)	46(13.07%)	167(14.83%)	241(13.52%)	119(12.18%)	379(14.11%)
2006/07	11,147(13.08%)	10,600(13.10%)	34(9.66%)	160(14.21%)	208(11.67%)	120(12.28%)	357(13.29%)
2007/08	10,410(12.22%)	9,856(12.18%)	51(14.49%)	125(11.10%)	247(13.86%)	135(13.82%)	346(12.88%)
2008/09	10,303(12.09%)	9,785(12.09%)	53(15.06%)	125(11.10%)	222(12.46%)	116(11.87%)	306(11.39%)
2009/10	10,188(11.96%)	9,658(11.94%)	45(12.78%)	132(11.72%)	222(11.67%)	121(12.38%)	320(11.91%)
2010/11	10,246 (12.02%)	9,728(12.02%)	33(9.38%)	148(13.14%)	208(11.67%)	135(13.82%)	334(12.43%)
2011/12	8,457(9.92%)	8,018(9.91%)	26(7.39%)	103(9.15%)	172(9.65%)	101(10.34%)	259(9.64%)

Table 1 (continued)

Group	All, N (%)	Child disability					
		No disability N (%)	Any Mental Health only N(%);P (χ^2)	Any Physical Health only N (%);P (χ^2)	Any Mental Health N (%); P (χ^2)	Both Mental Health N (%); P (χ^2)	Any Physical Health N (%); P (χ^2)
		6	1 (vs. 6)	2 (vs. 6)	3 (vs. 6)	4 (vs. 6)	5 (vs. 6)
Total savings			<i>p</i> <0.0001	<i>p</i> <0.0001	<i>p</i> <0.0001	<i>p</i> <0.0001	<i>p</i> <0.0001
No savings	4,100(4.81%)	3,842(4.75%)	24(6.82%)	63(5.60%)	94(5.27%)	47(4.81%)	145(5.40%)
Savings less than £1,500	46,052(54.04%)	43,255(53.45%)	221(62.78%)	723(64.21%)	1,157(64.93%)	629(64.38%)	1,745(64.97%)
Savings over £1,500 and up to £20,000	21,863(25.66%)	21,065(26.03%)	68(19.32%)	216(19.18%)	350(19.64%)	209(21.39%)	513(19.10%)
Savings over £20,000	10,553(12.38%)	10,189(12.59%)	34(9.66%)	99(8.79%)	134(8.59%)	78(7.98%)	233(8.67%)
Did not want to say	2,644(3.10%)	2,569(3.17%)	5(1.42%)	25(2.22%)	28(1.57%)	14(1.43%)	50(1.86%)
Employment status			<i>p</i> <0.0001	<i>p</i> <0.0001	<i>p</i> <0.0001	<i>p</i> <0.0001	<i>p</i> <0.0001
Employed	60,510(71.01%)	58,119(71.82%)	192(54.21%)	649(57.64%)	931(52.24%)	508(51.52%)	1,456(54.21%)
Unemployed	3,025(3.55%)	2,838(3.51%)	15(4.49%)	55(4.88%)	77(4.32%)	41(4.16%)	119(4.43%)
Inactive	21,677(25.44%)	19,964(24.67%)	145(41.29%)	422(37.48%)	774(43.43%)	437(44.32%)	1,111(41.36%)
	Mean (SD)	Mean(SD)	Mean(SD) P(F)	Mean(SD) P(F)	Mean(SD) P(F)	Mean(SD) P(F)	Mean(SD) P(F)
Child's age	7.42(4.68)	7.34(4.69)	10.96(3.32) <i>p</i> <0.0001	8.48(4.30) <i>p</i> <0.0001	9.71(3.69) <i>p</i> <0.0001	9.42(3.64) <i>p</i> <0.0001	8.88(4.03) <i>p</i> <0.0001
Age main respondent left full time education	18.08(2.15)	18.10(2.17)	18.53(1.74) <i>p</i> <0.0001	18.71(1.73) <i>p</i> <0.0001	18.64(1.77) <i>p</i> <0.0001	18.71(1.96) <i>p</i> <0.0001	18.70(1.78) <i>p</i> <0.0001
Number of dependent children in household	2.19(1.00)	2.19(0.99)	2.15(1.07) <i>p</i> =0.41	2.12(0.99) <i>p</i> =0.034	2.14(1.01) <i>p</i> =0.035	2.13(1.01) <i>p</i> =0.05	2.11(0.98) <i>P</i> =0.0001

The P values refer to a comparison of sample characteristics between each definition of child disability and the no disability group. Abbreviations: SD = standard deviation

Table 2: Mean (standard deviation) net income by definition of disability and living standards group

Groups	Mean net income (SD), Median (IQR) [N]		
	All LS	Low Living Standards (LS <1)	High Living Standards (LS 1)
No disability (Group 6)	715.06 (672.92) 586.87 (403.77 – 855.92) [80,920]	531.30 (329.45) 475.78 (349.20 – 647.54) [48,632]	991.83 (918.10) 831.72 (605.55 – 1,153.74) [32,288]
(Group 1) Any mental health disability (no physical health disability)	522.93 (361.08)* 522.92 (375.77 – 677.32) [352]	482.80 (194.72)* 459.33 (346.39 – 593.10) [258]	886.05 (516.55) 736.44 (583.70 – 1,113.45) [94]
(Group 2) Any physical health disability (no mental health disability)	612.34 (618.68)* 515.91 (356.36 – 709.71) [1,126]	489.57 (246.44)* 449.75 (324.23 – 598.64) [820]	941.77 (1048.50) 752.52 (570.25 – 1,014.72) [306]
(group 3) Any mental health disability (+/- physical health disability)	631.23 (465.20)* 550.74 (415.83 – 736.81) [1,782]	534.39 (264.37) 497.57 (387.50 – 624.21) [1,293]	887.27 (717.07)* 771.28 (576.90 – 1,011.46) [489]
(Group 4) Both mental health disability (+/- physical health disability)	641.53 (462.56)* 564.41 (435.26 – 742.62) [977]	559.75 (286.78)* 515.11 (415.83 – 651.79) [707]	855.66 (704.87)* 765.66 (570.21 – 947.93) [270]
(Group 5) Any physical health disability (+/- mental health disability)	624.73 (540.95)* 533.17 (394.67 – 729.66) [2,686]	520.50 (264.02) 483.18 (360.12 – 621.76) [1,958]	905.08 (886.08)* 759.69 (567.79 – 1,002.67) [728]

Abbreviations: IQR = inter-quartile range; LS = living standards, SD = standard deviation. Numbers in squared brackets are sample sizes.

* indicates a p-value ≤ 0.05 for the mean income comparisons between each disability group (1 -5) with reference group no disability (6)

Table 3: Mean value of benefits received by disability and living standards group

Groups	Mean benefit received (SD)		
	Median (IQR)		
	[N]		
	All LS	Low Living Standards (LS <1)	High Living Standards (LS 1)
(1) Any mental disability (no physical disability)	17.40 (31.78) 0.00 (0.00 – 0.00) [316]	16.78 (30.81) 0.00 (0.00 – 0.00) [227]	18.98 (34.27) 0.00 (0.00 – 39.63) [89]
(2) Any physical disability (no mental disability)	10.63 (28.10) 0.00 (0.00 – 0.00) [1035]	11.01 (28.58) 0.00 (0.00 – 0.00) [737]	9.71 (26.89) 0.00 (0.00 – 0.00) [298]
(3) Any mental disability (+/- physical disability)	34.48 (43.30) 0.00 (0.00 – 70.68) [1569]	34.36 (42.86) 0.00 (0.00 – 70.68) [1115]	34.80 (44.43) 0.00 (0.00 – 70.52) [454]
(4) Both mental disability (+/- physical disability)	45.95 (45.63) 50.42 (0.00 – 75.36) [848]	46.27 (45.18) 50.42 (0.00 – 75.36) [604]	45.16 (46.80) 50.15 (0.00 – 75.51) [244]
(5) Any physical disability (+/- mental disability)	26.22 (40.85) 0.00 (0.00 – 51.95) [2405]	26.12 (40.49) 0.00 (0.00 – 51.95) [1714]	26.48 (41.74) 0.00 (0.00 – 50.62) [691]

Abbreviations: IQR = inter-quartile range; LS = living standards, SD = standard deviation. Numbers in squared brackets are sample size

Table 4: Compensating variation (£ per week)

Comparisons	Mean income difference (95%CI) [N]		
	All LS [cases on common support/ total no. of cases] ^a	Low Living Standards (LS <1) [cases on common support/ total no. of cases] ^a	High Living Standards (LS=1) [cases on common support/ total no. of cases] ^a
(A) Any mental health disability (no physical disability)	3.65 (-40.91; 48.22) [352/352]	17.43 (- 19.59; 54.46) [258/258]	-34.16 (-167.94; 99.62) [94/94]
(B) Any physical health disability (no mental disability)	9.77 (-28.60; 48.15) [1126/1126]	3.51 (-17.43; 24.45) [820/820]	26.65 (-103.43; 156.54) [306/306]
(C) Any mental health disability (+/- physical disability)	49.31 (21.95; 76.67)** [1772/1782]	59.28 (41.38; 77.18)** [1286/1293]	22.93 (-65.03; 110.89) [486/489]
(D) Both mental health disability (+/- physical disability)	57.56 (17.69; 97.44)** [971/977]	81.37 (53.35; 109.38)** [703/707]	-4.88 (-125.28; 115.51) [268/270]
(E) Any physical health disability (+/- mental disability)	35.86 (13.77; 57.96)** [2680/2686]	42.18 (26.38; 57.97)** [1956/1958]	18.81 (-51.06; 88.68) [724/ 728]
(F) Any mental health disability (+/- physical disability)	34.12 (-20.95; 89.19) [1642/1782]	39.23 (-15.67; 94.12) [1199/1293]	15.77 (-126.88; 158.41) [434/893]
(G) Both mental health disability (+/- physical disability)	33.89 (-36.05; 103.83) [862/977]	47.45 (-0.41; 95.30)* [599/707]	-7.45 (-212.29; 197.39) [259/270]
(H) Any physical health disability (+/- mental health disability)	24.14 (-6.99; 55.28) [2618/ 2686]	5.18 (-22.45; 32.82) [1895/ 1958]	73.83 (-11.32; 158.97) [720/ 728]

^a Total sample size for each model is twice that of cases on common support, due to 1:1 matching.

** $p \leq 0.05$ * $0.1 > p > 0.05$

Abbreviations: LS = living standards. Numbers in squared brackets are sample sizes .

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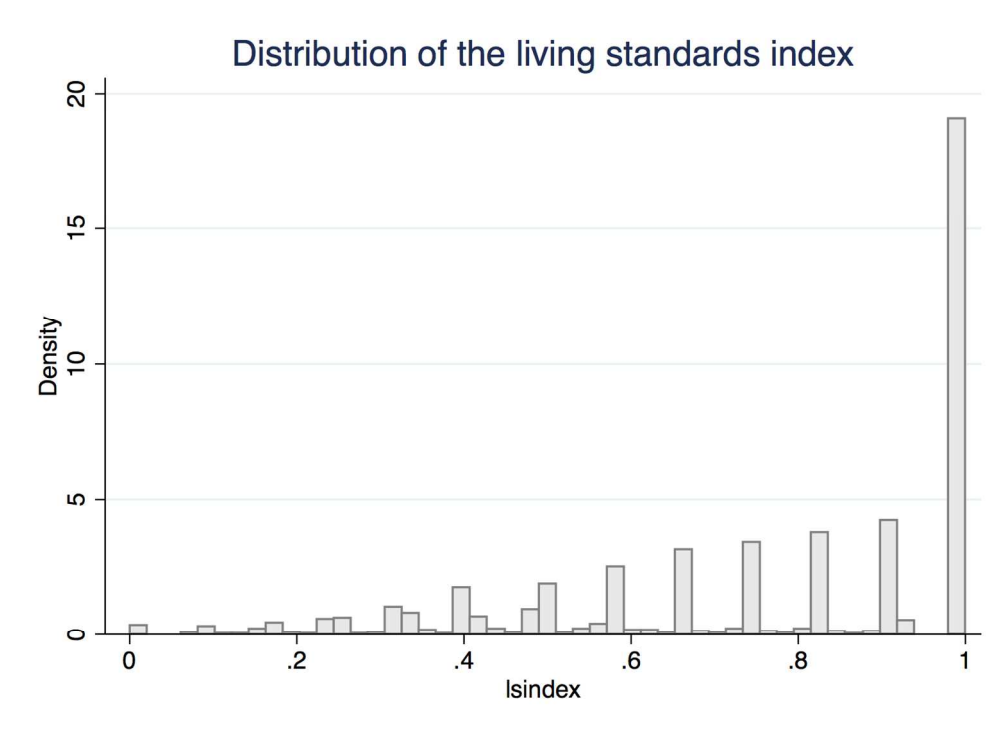


Figure 1. Distribution of living standard index

139x101mm (300 x 300 DPI)

Review only

1
2 **Table S1: Definitions of disability groups**
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Disability Domain	Group 1	Group 2	Group 3	Group 4	Group 5	Group 6
<i>Physical health</i>						
Mobility	No	Yes*	Yes or no	Yes or no	Yes*	No**
Lifting carrying or moving objects	No	Yes*	Yes or no	Yes or no	Yes*	No**
Manual dexterity	No	Yes*	Yes or no	Yes or no	Yes*	No**
Continence	No	Yes*	Yes or no	Yes or no	Yes*	No**
Communication	No	Yes*	Yes or no	Yes or no	Yes*	No**
Physical co-ordination	No	Yes*	Yes or no	Yes or no	Yes*	No**
<i>Mental health</i>						
Memory of ability to concentrate learning or understand	Yes*	No	Yes*	Yes **	Yes or no	No**
Recognizing when in physical danger	Yes*	No	Yes*	Yes **	Yes or no	No**

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5 * = can or cannot be present, as long as another domain from the broader disability area (i.e. mental or
6 physical health) is present

7 **= necessarily present for definition

8 Yellow cells indicate primary domains for group definition

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- Group 1: Any (either or both domains) mental disability (no physical disability);
 - Group 2: Any physical disability (no mental disability) (group 1 & 2 are mutually exclusive);
 - Group 3: Any mental disability (either domains, with or without physical disability);
 - Group 4: Both mental disabilities (both domains, with or without physical disability);
 - Group 5: Any physical disability (with or without mental disability);
 - Group 6: No disability.

1
2 16 **Table S2: Living standard questions in the Family Resources Survey**
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4 17

Question	Included	Rationale
Do you (and your family) have a holiday away from home for at least one week a year, whilst not staying with relatives at their home?	YES	
Do you have friends or family around for a drink or meal at least once a month?	NO	Not directly relevant to children's living standards
Do you have two pairs of all-weather shoes for (all members of family)	NO	Depending on disability, might not be applicable to all children
Do you have enough money to keep your home in a decent state of decoration?	YES	
Do you have household contents insurance?	YES	
Do you make regular savings of £10 a month or more for rainy days or retirement?	YES	
Do you replace any worn out furniture?	YES	
Do you replace or repair major electrical goods such as a refrigerator or a washing machine, when broken?	YES	
Do you have a small amount of money to spend each week on yourself (not on your family)	YES	
do you have a hobby or leisure activity	NO	Not directly relevant to children's living standards
In winter, are you able to keep this accommodation warm enough	NO	Not coded as the other variables (yes/no)
Does your child/do your children have a family holiday away from home for at least one week a year?	YES	
And are there enough bedrooms for every child of 10 or over of a different sex to have their own bedroom?	NO	Not applicable to all families
Does your child/do your children have leisure equipment such as sports equipment or a bicycle?	YES	
Does your child/do your children have celebrations on special occasions such as birthdays, Christmas or other religious festivals?	YES	
Does your child/do your children go swimming at least once a month?	NO	Potentially not applicable to children with disabilities affecting mobility
Does your child/do your children do a hobby or leisure activity?	YES	
Does your child/do your children have friends around for tea or a snack once a fortnight?	YES	
Does your child/do your children (if <6 yrs old) go to toddler group / nursery / playgroup at least once a week?	NO	Not applicable to all families (child < 6yo)
Does your child/do your children go on school trips?	NO	Not applicable to all families (child <6yo)
Does your child/do your children have an outdoor space or facilities nearby where they can play safely	NO	Potentially, not applicable/relevant to families with severely disabled children

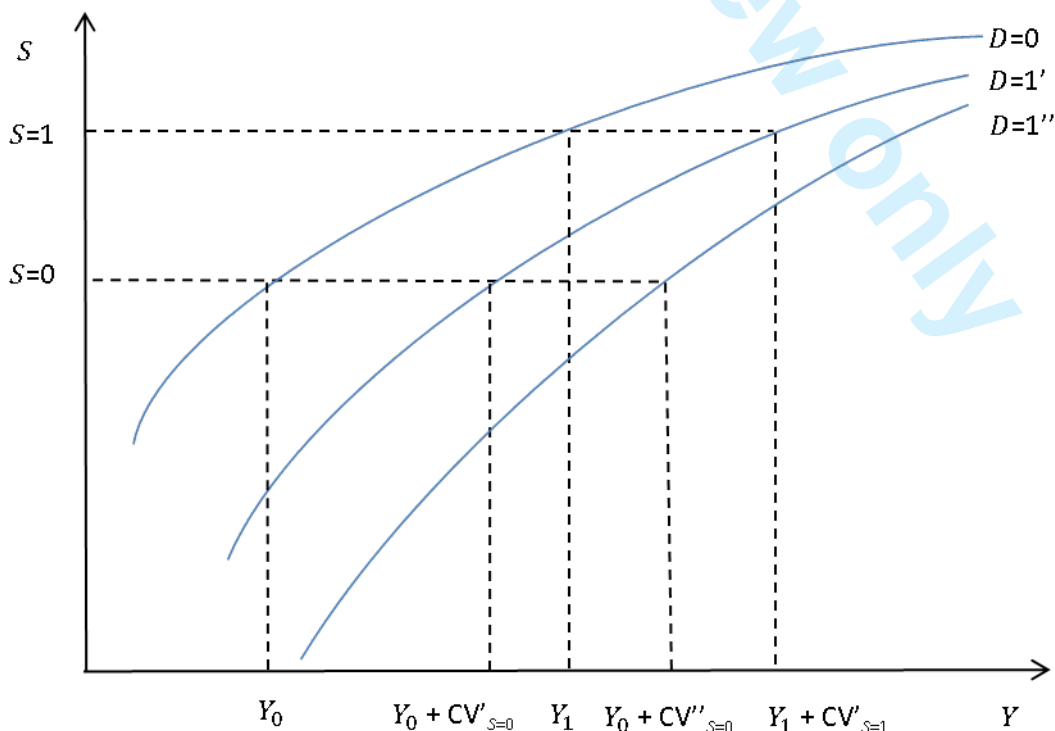
19 Theoretical approach: Compensating Variation

20 In Figure S1 we illustrate the concept of CV by plotting curves relating the income (Y , on the horizontal axis) and the living standards (S , on the vertical axis) of families without a disabled child ($D = 0$) and with a disabled child ($D = 1'$). We assume that: (i) the curves are upward sloping from left to right and convex, due to diminishing returns to S as Y increases; and, (ii) $D = 1'$ lies below $D = 0$ though they tend towards one another at higher levels of Y . At a given level of living standards such as $S = 0$ the CV is the difference between the income that a family with a disabled child ($D = 1'$) needs to have ($= Y_0 + CV'_{S=0}$) compared to the income of a family without a disabled child ($D = 0$) ($= Y_0$) to achieve the same living standard ($S = 0$). Based on our assumptions this difference will decrease at higher levels of living standards. For instance, the CV between $D = 1'$ and $D = 0$ for $S = 1$ (where $S = 1 > S = 0$) will correspond to $Y_1 + CV'_{S=1}$, which is smaller than $Y_0 + CV'_{S=0}$.

31 We hypothesize that families of children with more severe disabilities incur higher costs to achieve the same living standards as families with less severely disabled children. Suppose $D = 1''$ denotes more severe disabilities than $D = 1'$; this is shown in Figure 1 as curve $D = 1''$ lying below curve $D = 1'$. In this case the CV for $S = 0$, corresponds to $Y_0 + CV''_{S=0}$, which is greater than $Y_0 + CV'_{S=0}$.

36 In order to employ this approach to investigate our aims, three measures are needed: 1) a definition of child mental and physical health disability; 2) a measure of living standards (LS); and 3) a measure of income.

39 **Figure S1: Compensating variation**



40

Theoretical Approach: Propensity Score Matching

If we assume that the probability of having a disabled child is adequately explained by the set of observed characteristics X , we can select from the sample of families with non-disabled children a control (i.e. non-treated) group, which is similar to the treated group with respect to X , but different with respect to disability D ²⁷. We therefore calculated the CV as the average treatment effect on the treated (ATT), as follows:

$$ATT = E[Y_1 - Y_0 | D=1] = E[Y_1 - Y_0 | D=1, p(X)] = E[Y_1 | D=1, p(X)] - E[Y_0 | D=0, p(X)] \quad (1)$$

We matched families using nearest neighbor 1:1 matching within a caliper, defined to be one quarter of the standard deviation of the propensity score²⁵. Families are matched based on similar distributions of propensity scores, which might not arise from identical values of X . Since one of our aims is to estimate the income difference for families with and without a disabled child for the same value of living standards (S), we included values of our LSI rounded to the first decimal point as external to X and matched on both, so that the CV is given by:

$$ATT = E[Y_1 - Y_0 | D=1] = E[Y_1 - Y_0 | D=1, L, p(X)] = E[Y_1 | D=1, L, p(X)] - E[Y_0 | D=0, L, p(X)] \quad (2)$$

In other words, our procedure was as follows: first, the propensity score was calculated as the predicted probability from the probit model. Then, for each family with a disabled child we selected a match from the pool of families without a disabled child with the same value of living standards (based on the first four digits of the index) and the closest propensity score within the common support area.

67 **Sensitivity analyses**

68 Our results remain largely consistent in sensitivity analyses using 3:1 matching, where we did not
69 observe any substantial differences compared with the results in Table 3 (results not shown).

70
71 Results were also similar when we used radius matching, although the magnitude of the CV in
72 analyses not stratified by LS generally decreased. As shown in table S3, we observed that children
73 with any mental health disabilities (Group 3, Comparison C), those both mental health disabilities
74 (Group 4, comparison D), and those with any physical disabilities (Group 5, comparison S) needed
75 an extra £34.20 (95%CI: 23.42; 44.98), £39.21 (95%CI: 14.22; 64.08) and £25.20 (95%CI: 12.71;
76 37.78), respectively, to achieve the same LS of families with non-disabled children. We also
77 observed that CV for families of disabled children in these three groups and low LS was even
78 greater: children with any mental health disabilities (Group 3, Comparison C), those both mental
79 health disabilities (Group 4, comparison D), and those with any physical disabilities (Group 5,
80 comparison S) needed an extra £60.35 (95CI: 57.38; 63.32), £81.47 (95%CI: 60.15; 102.80) and
81 £42.47 (95%CI: 33.64; 51.29) to meet the same LS of families without a disabled child. These
82 figures were comparable to those presented in our main analyses.

83
84 We also found that families in low LS with a child with any mental health disability (Group 3,
85 Comparison F) needed an extra £29.74 (95%CI: 15.92; 43.56) per week to meet the same LS of
86 families with no disabled children or children with any physical health disabilities. In our main
87 analyses we found a figure similar in magnitude (£39.23 (95%CI: -15.67; 94.12)), but for which
88 there was no evidence of a difference.

89
90 The only inconsistent findings we observed was that, when we used radius matching, we found
91 that families with high LS and children with any mental health disability (Group 3, comparison F)
92 were over compensated by £77.41 (95%CI: -138.31; -16.50).

93
94 All models were balanced.

95

96
97 Table S3: Compensating variation using radius matching

Comparisons	Mean income difference (95%CI) [N]		
	All LS [cases on common support/ total no. of cases] ^a	Low Living Standards (LS <1) [cases on common support/ total no. of cases] ^a	High Living Standards (LS=1) [cases on common support/ total no. of cases] ^a
(A) Any mental disability (no physical disability)	-1.42 (-32.27; 35.10) [352/352]	13.65 (-7.43; 34.74) [258/258]	-32.16 (-145.43; 81.05) [94/94]
(B) Any physical disability (no mental disability)	5.55 (2.56; 8.53) [1126/1126]	4.93 (2.19; 7.68) [820/820]	7.19 (-2.86; 17.27) [306/306]
(C) Any mental disability (+/- physical disability)	34.20 (23.42; 44.98)** [1772/1782]	60.35 (57.38; 63.32)** [1286/1293]	-34.98 (-80.18; 11.04) [486/489]
(D) Both mental disability (+/- physical disability)	39.21 (14.22; 64.08)** [971/977]	81.47 (60.15; 102.80)** [703/707]	-71.66 (-142.58; -0.74) [268/270]

98

(E) Any physical disability (+/- mental disability)	25.20 (12.71; 37.78)** [2681/2686]	42.47 (33.64; 51.29)** [1956/1958]	-21.41 (-61.02; 18.21) [725/728]
(F) Any mental disability (+/- physical disability)	-1.05 (-21.10; 19.01) [1695/1782]	29.74 (15.92; 43.56)** [1208/1293]	-77.41 (-138.31; -16.50)** [487/489]
(G) Both mental disability (+/- physical disability)	0.09 (-47.17; 47.36) [871/977]	47.06 (17.21; 76.91)** [603/707]	70.40 (-244.19; 33.03) [268/270]
(H) Any physical disability (+/- mental disability)	11.72 (-7.11; 30.55) [2626/ 2686]	3.58 (-12.05; 19.22) [1898/ 1958]	32.94 (-21.45; 87.32) [728/728]

99 a Total sample size for each model is twice that of cases on common support, due to 1:1 matching.

100 ** p<=0.05 *0.1>p>0.05

101 Abbreviations: LS = living standards. Numbers in squared brackets are sample sizes.

102 Highlighted in bold are results whose magnitude and significance differed from those found in the main
 103 analyses (Table 3 of the main text), but whose direction of association was unchanged; highlighted in **bold**
 104 **and italics** are those whose magnitude, direction, and significance of association changed.

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STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No	Recommendation	PAGE
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract (b) Provide in the abstract an informative and balanced summary of what was done and what was found	1-2 2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	4-5
Objectives	3	State specific objectives, including any prespecified hypotheses	5
Methods			
Study design	4	Present key elements of study design early in the paper	1, 5-6
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	2, 5-6
Participants	6	(a) <i>Cohort study</i> —Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up <i>Case-control study</i> —Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls <i>Cross-sectional study</i> —Give the eligibility criteria, and the sources and methods of selection of participants (b) <i>Cohort study</i> —For matched studies, give matching criteria and number of exposed and unexposed <i>Case-control study</i> —For matched studies, give matching criteria and the number of controls per case	5-6
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6-9
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	6-9
Bias	9	Describe any efforts to address potential sources of bias	13
Study size	10	Explain how the study size was arrived at	5-6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	6-9
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding (b) Describe any methods used to examine subgroups and interactions (c) Explain how missing data were addressed (d) <i>Cohort study</i> —If applicable, explain how loss to follow-up was addressed <i>Case-control study</i> —If applicable, explain how matching of cases and controls was addressed <i>Cross-sectional study</i> —If applicable, describe analytical methods taking account of sampling strategy (e) Describe any sensitivity analyses	12-13 N/A 10-11 10, 13

Continued on next page

Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	5-6
		(b) Give reasons for non-participation at each stage	5-6
		(c) Consider use of a flow diagram	N-A
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	11
		(b) Indicate number of participants with missing data for each variable of interest	11
		(c) <i>Cohort study</i> —Summarise follow-up time (eg, average and total amount)	11
Outcome data	15*	<i>Cohort study</i> —Report numbers of outcome events or summary measures over time	
		<i>Case-control study</i> —Report numbers in each exposure category, or summary measures of exposure	
		<i>Cross-sectional study</i> —Report numbers of outcome events or summary measures	11-12
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	11-13
		(b) Report category boundaries when continuous variables were categorized	
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	
Discussion			
Key results	18	Summarise key results with reference to study objectives	13-14
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	15
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	13-15
Generalisability	21	Discuss the generalisability (external validity) of the study results	15
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	1

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.