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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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1 **The cost of mental health disability to families in childhood and adolescence in the United**

2 **Kingdom: findings from a repeated cross-sectional survey using propensity score matching**

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18 **Keywords:** Child disability; living standards; disability benefits; compensating variation; propensity

19 score matching.

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1

31 **ABSTRACT**

32 **Objective:** Since 1992, UK families of disabled children have been entitled to receive disability

33 benefits to help meet costs associated with caring for their disabled child. Evidence of actual costs

34 incurred is scant, especially for mental health disability. The aim of this study was to quantify the

35 cost of mental health disability in childhood and adolescence to families in the UK using the concept

36 of compensating variation (CV).

37

38 **Design:** Repeated cross-sectional survey.

39

40 **Setting**: UK general population

41

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

43

44 **Outcomes:** We used propensity score matching to match families with a disabled child to similar

45 families without a disabled child and calculated the extra income the former require to achieve the

46 same living standards as the latter, i.e. their CV. We calculated the costs specifically associated with

47 mental health and physical health disability, using several definitions of each.

48

49 **Results** Families of a child with any mental health disability, regardless of the presence of physical

50 health comorbidity, needed an additional £33 per week to achieve the same living standards as

51 matched families without a disabled child. This difference was greater for more deprived families,

52 who needed £42 to £61 more per week depending on the extent of mental health disability.

53 Economically deprived families of a child with a physical health disability required an additional £25

54 per week to meet the same living standards of a family without a disabled child. More deprived

55 families with a child with mental health disabilities were undercompensated by £8-£15 per week

56 under the current benefits system.

57

58 **Conclusions** Mental health disability among children and adolescents was associated with relatively

59 high costs for the family compared with physical health disability, especially for those from deprived

60 economic backgrounds. Means testing could help achieving a more equitable redistribution of

61 disability benefit.

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2
3 **Strengths and Limitations**
4
5 • Strengths of this study are the use of: (i) large and rich dataset representative of the UK
6
7   population; (ii) disability domains employed in the Disability Discrimination Act (DDA) consistent
8
9   with definitions applicable to policy settings; and, (iii) novel analytical approach based on
10
11   propensity score matching.
12
13 • Limitations of this study are: (i) its cross-sectional design; (ii) difficulties in disentangling physical
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15   and mental health disabilities (which are often co-occurring); and, (iii) data limitations making it
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68   and mental health disabilities (which are often co-occurring); and, (iii) data limitations making it

69   problematic to account for severity of disability and to measure living standards.

3

INTRODUCTION

70

71 Families of children suffering from chronic conditions and physical and mental health disabilities

72 incur significantly higher costs than those of their healthy counterparts.[1–5] These costs are primarily

73 accounted for by more frequent visits to inpatient and outpatient departments and by greater use of

74 prescribed drugs,[1–3] although evidence also suggests that the need to provide or secure informal

75 care adds to the financial burden of child disability for these families.[4,5] Previously, UK studies have

76 estimated the cost of having a disabled child at about £79-£100 per week[4] and that under the

77 benefits arrangements at the time (1997) families of disabled children were undercompensated by

78 £30-£80 per week [4] and by £28 in 2001.[5] More recent evidence has estimated that in the UK families

79 of severely disabled children require up to an additional £79 per week to be able to meet the same

80 living standards of those without disabled children, a figure that does not find correspondence in

81 disability benefits that these families receive (i.e., up to £71 per week).[6]

82

83 Mental health conditions account for a great portion of the burden of disease among children and

84 adolescents below the age of 16 years.[7] Onset of most mental health conditions occurs at different

85 stages of childhood and adolescence: developmental and hyperkinetic disorders become manifest in

86 early childhood, whilst depressive (including suicide and self-harm), psychotic, anxiety, conduct, and

87 eating disorders most commonly arise in adolescence and young adulthood.[8] Evidence suggests that

88 in the UK there has been a trend towards increasing rates of children and young people suffering

89 from mental health conditions since the 1980s.[9] The 2004 British Child and Adolescent Mental

90 Health Survey (B-CAMHS) conducted by the Office of National Statistics (ONS) reported that 10% of

91 children aged 5 – 16 years met diagnostic criteria for a mental health disorder. [10]

92

93 A socio-economic gradient exists in the distribution of child mental health disorders [11–13]. In the 2004

94 B-CAMHS, prevalence of diagnosable child mental health conditions was higher among single-parent

95 (15.6%) compared to married or co-habiting (7.7%) households; among families with low (16.1%)

96 compared to high (5.3%) income; and among families whose parents had no academic qualifications

97 (17.0%) compared to those with university degrees (4.4%) [14]. Evidence exists that life adversities are

98 a risk factor for the onset of mental health conditions as well as that mental health problems of the

99 child can lead to family breakdown and unemployment [14].

100

101 Both mental health problems and socio-economic disadvantage in childhood and adolescence can

102 have enduring effects and significantly impact on a young person's future. Children and adolescents

103 suffering from mental health problems more often report low levels of academic achievement, and

4

104   engage in risk-behaviours such as alcohol and drug use with detrimental effects on employment

105   prospects [15]. Similarly, childhood experience of economic hardship can result in long-term adverse

106   health outcomes via the persistence of lower socio-economic status [15].

107

108   Since 1992, in the UK, families of children affected by disability have been eligible to receive a non-

109   means-tested weekly Disability Living Allowance (DLA).[16] The rationale for these benefits is that

110   they "*may help with the extra costs of looking after a child who: is under 16; has difficulties walking*

111   *or needs more looking after than a child of the same age who doesn't have a disability*".[16] The

112   amount of benefits that the family is entitled to receive largely depends on the severity of the child's

113   condition, which is determined by the disability service centre often in conjunction with external

114   assessments. In 2014, under the care component of DLA, children could receive either £21.80 (if

115   they needed a little help during the day or night), £55.10 (if they needed frequent supervision), or

116   £82.30 (if they needed constant help day and night, or were terminally ill) per week. Under the

117   mobility component of DLA, children were entitled to receive between £21.80 (if they could walk but

118   needed supervision outdoors) and £57.45 (if they could not walk, if walking represented a health

119   risk, or if they were blind) per week.

120

121   Previous UK studies have shown that families of disabled children incur high costs, but were

122   however unable to attribute these extra expenditures to either physical or mental health disability,

123   which has been shown to inflict a substantial economic burden in other settings.[2,3] In the absence of

124   literature exploring the cost of child mental health disability to families, and the rising prevalence of

125   these problems, the aims of this study are to: (1) investigate the cost to families of having a child

126   with a mental health disability; (2) compare the costs of mental health versus physical health

127   disability; and, (3) examine how these costs vary by economic deprivation. We use repeated cross-

128   sectional data from the Family Resources Survey (2004/05 – 2011/12).

129

130

131   **MATERIALS AND METHODS**

132   **Sample**

133   We employed data from eight consecutive rounds of data collection from the Family Resources

134   Survey (FRS) covering the financial years 2004/05 to 2011/12. The FRS is a repeated cross-sectional

135   survey of private households in the UK undertaken by the Department of Work and Pensions (DWP)

136   with the aim of collecting data on the financial and social circumstances of private households.

137   Although representativeness of the older age groups within the population might be limited in FRS

5

138   due to the focus on private households (nursing and retirement homes are not included), the overall

139   sample, used in this study, is representative of the UK population [18], and our focus on families with

140   children under 16 years of age means this is unlikely to introduce a bias.

141

142   Our sample includes all children aged 0-15 years and their families with complete data on all

143   variables included in the model covariates and necessary to estimate the CV (i.e. income and living

144   standards). We excluded families with more than one disabled child because of difficulties

145   separating the effects of multiple disabled children in the same family (2.7% of total children).

146

147   **Child mental and physical health disability**

148   In line with the definition of disability included in the Disability Discrimination Act (DDA) 1995 and

149   2005, the FRS defines a child as having a disability if they have a longstanding illness lasting longer

150   than 6 months and affecting their ability to undertake daily activities. Families were asked if their

151   child had any longstanding illness, disability or infirmity. Families responding 'yes' were directed to a

152   set of follow up questions asking which area of the child's life was affected by their disability.

153   Possible answers were: mobility; lifting; manual dexterity; continence (i.e. bladder control);

154   communication (i.e. speech, hearing, or eyesight); memory and learning; recognition of physical

155   danger; physical coordination; other; or, none of these areas. As we were not able to define their

156   disability either as affecting physical or mental health, we excluded children whose family claimed

157   had a disability but subsequently said that none of these areas where affected by disability (3.4% of

158   total children).

159

160   Of these eight disability domains, we assume that memory and learning, and recognition of physical

161   danger can be attributable solely to mental health problems, as they are related to cognitive

162   impairment. We assume all other areas primarily reflect physical health problems [19], but

163   acknowledge these domains could also be affected by, or affect, mental health status. For ease of

164   explanation, we will hereafter refer to memory and learning, and recognition of physical danger as

165   'mental health' disability areas, and mobility, lifting, manual dexterity, continence, communication,

166   and physical coordination as 'physical health' disability areas.

167

168   Using this distinction we defined disability accounting for: 1) presence of comorbidity between

169   mental and physical disability; 2) number and type of areas affected by disability. Therefore we

170   created 6 disability groups defined as follows:

171   • Group 1: Any (either or both domains) mental disability (no physical disability);

6

172 • Group 2: Any physical disability (no mental disability) (group 1 & 2 are mutually exclusive);

173 • Group 3: Any mental disability (either domains, with or without physical disability);

174 • Group 4: Both mental disability (both domains, with or without physical disability);

175 • Group 5: Any physical disability (with or without mental disability);

176 • Group 6: No disability.

177

178 We did not create a separate group for children with both mental health domains affected by

179 disabilities, but no physical disability as the numbers were too low. Under the same rationale we did

180 not include a group with children affected by disability in all of the physical health domains due to

181 low numbers. We compared these groups as follows:

182 • Comparison A: Group 1 versus Group 6;

183 • Comparison B: Group 2 versus Group 6;

184 • Comparison C: Group 3 versus Group 6;

185 • Comparison D: Group 4 versus Group 6;

186 • Comparison E: Group 5 versus Group 6.

187

188 By allowing for comorbidity between mental and physical health disability in groups 3, 4, and 5, we

189 attempt to explore whether these disability groups could represent more severe conditions

190 compared to groups 1 and 2. Physical health impairments are more common in children with mental

191 health problems [14] similarly, physical health disability can adversely affect mental health [20]. We

192 hypothesise that if the cost of mental health disability is greater than that of physical health

193 disability we should see a positive CV for groups 1, 3, and 4 and this will be greater in magnitude

194 than that observed in groups 2 and 5.

195

196 It is possible, however, that both physical and mental health have a positive and significant impact

197 and, although the magnitude of the CV across the previously defined groups can give an indication of

198 the overall impact of mental and physical health disability on the costs borne by the family, it is

199 important to attempt to quantify their relative impact. Therefore, in order to investigate our second

200 aim we ran three additional models comparing the exposed group against both children without

201 disabilities and children who had a disability 'other' than that employed to define the main

202 exposure. For example, children with any or both (all) 'mental (physical) health disabilities' plus

203 other physical (mental) health comorbidities were compared with children with no disabilities and

204 children with only physical (mental) health comorbidities. We defined these models as:

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

7

206 • Comparison G: Group 4 versus Group 6 and Group 2;

207 • Comparison H: Group 5 versus Group 6 and Group 1

208

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) children [21]. 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 weighting [22] with weights representing the proportion of families considering the item a

216 necessity. We calculated the *LSI* as follows:

217 $$LSI = \frac{\sum_{i=1}^{M} x_i w_i}{\sum_{i=1}^{M} w_i} \tag{1}$$

218

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 above [22] 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.

232

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

8

238   standards is dependent upon their receipt. We inflated incomes to 2011/12 prices. We did not

239   employ an equivalised measure of income for ease of interpretation of the results (i.e., our unit of

240   analysis is the benefit unit and equivalised income is a measure of income per person); however, in

241   order to account for family composition we included variables indicating number of adults and ages

242   of children in the matching stage of the analyses (see below), in line with previous literature [23,24].

243   Values of net income are reported 'per week' in the FRS.

244

245   **Other variables**

246   In our analyses we match families with and without a disabled child on a number of socio-

247   demographic and socio-economic characteristics of the families and their children. We included

248   indicators of the child's age (linear term) and gender (male/female); two linear terms for number of

249   dependent children in the family (range 1-8) and number of years of schooling after the age of 18

250   years (i.e. the age at which compulsory education ends in the UK) of the head of the household and

251   their marital status (single/couple); presence of a disabled adult (yes/no), and to account for family

252   wealth, a categorical variable indicating family savings banded in five categories.

253

254   We also included a categorical indicator for survey year and UK Government Office Region (London;

255   South East; Rest of England; Northern Ireland, Wales and Scotland[1]).

256

257   **Data analysis**

258   We described how sample characteristics vary by disability group using cross-tabulations with Chi-

259   Square tests and ANOVAs for categorical and continuous variables, respectively.

260

261   We employed the 'compensating variation' (CV) approach to calculate the cost of child disability,

262   which has been previously used in studies of disability in adults [17]. The CV can be defined as the

263   additional income that a family with a disabled child needs to be able to achieve the same living

264   standards of a family that is similar in all other respects but without a disabled child. More details on

265   the theoretical approach can be found in the supplementary material. We used Propensity Score

266   Matching (PSM) [25,26] to match families according to comparisons A – F and calculate the CV (i.e. the

267   mean income difference). It has been suggested that this approach, by simulating a randomised

268   controlled trial setting, can provide a more unbiased estimate of the income difference than

269   parametric models in observational studies [17].

270

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

9

271 We calculated propensity scores (i.e. predicted probabilities) from multivariate probit regression

272 models with each of our group allocations in the comparisons defined above (Comparisons A to H) as

273 the outcome (e.g., for Comparison A, participation in Group 1 is coded 1 and Group 6 is coded 0, all

274 other groups are coded as missing). In all models the independent variables were child age and

275 gender, number of children and disabled adults in the family, years of schooling of the main

276 respondent, marital status, family savings, government region and survey year. Additionally, for

277 comparisons F, G, and H we also controlled for areas of disability (other than those defining the

278 Group) as covariates. For all models we calculated areas under the receiver operating characteristic

279 (ROC) to estimate goodness of fit of the model. More details on the PSM theoretical approach are in

280 the supplementary material.

281 For each matching pair obtained with this matching approach we calculated the CV and 95% CI [28].

282 Finally, we compared the CV with the mean (SD) amount of disability benefits received by each

283 group. All our analyses were run using Stata13.[29]

284

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.

291

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).

298

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.

10

304

305 Compared to children without any disabilities, and for all definitions of disabilities, more children

306 with disabilities were male, lived in a single parent household and with an adult also affected by

307 disability, had a parent who spent less time in education and had fewer savings, and were older

308 (Table 1).

309

310 Across low and high living standards, families of children with any type of disability had lower

311 income than those of children without disabilities (Table 2); in every disability group income was

312 higher in families with higher living standards. Among families with low living standards, families of

313 children with both mental health areas affected by disability had higher income than those without

314 disability, whereas families of children with any mental or physical health only had lower income.

315 Among families with high living standards, families of children affected in any of the physical or

316 mental health disability areas or in both the mental health areas, regardless of other areas affected,

317 had lower income compared to families of children without disabilities.

318

319 **Compensating variation**

320 Families of children with any or both mental health disabilities (Group 3) needed an additional

321 £33.20 in order to achieve the same living standards of similar families without a disabled child

322 (Group 6; Comparison C), across both levels of LS (Table 3). When pooling across living standards, we

323 did not find any other differences in any of the other disability groups.

324

325 When we split the sample by low and high levels of living standards, we found that in some cases

326 families of a disabled child needed a higher net income to meet the same LS of families without a

327 disabled child. Specifically, we found that families of a child with any mental health disability or both

328 mental health disabilities (with or without physical disabilities) required £42.03 (Group 3,

329 Comparison C) and £60.62 (Group 4, Comparison D) more than a family without a disabled child

330 (Table 3). We also found an income difference, albeit smaller, for families of children with disability

331 affecting physical health areas compared to families of non-disabled children, with the former

332 needing £25.31 (Group 5, Comparison E) more to achieve the same LS.

333

334 When we compared children affected by disability in any, or both mental health areas and in any

335 physical health areas, regardless of the presence of other disabilities, against children without

336 disabilities and other with physical and mental health disabilities respectively (i.e., in groups 6-8), we

337 found that families of children with both mental health areas affected by disabilities needed £52.38

11

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.

348

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.

368

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

372　additional £33 per week compared to families of non-disabled children to achieve the same living

373　standards. This difference was even greater for families with low living standards (£42). When we

374　compared children with both mental health areas affected by disability as well as possible comorbid

375　conditions related to physical health we did not find an overall difference in income, however we

376　found a high and positive CV of approximately £61 for children of families with low LS. In

377　comparison, families in the same LS group, with children affected by physical health had a positive,

378　but smaller in magnitude, CV (£25). When we tested the relative impact of mental and physical

379　health on the CV, by allowing our comparator group to have disabilities in the opposite domains of

380　the one under investigation, we found a positive and significant CV for children affected in both

381　mental health disabilities who live in families with low LS (£53).

382

383　We compared these amounts against benefits received, in order to investigate if these families were

384　adequately compensated for the costs associated with their child's disability. We found that overall

385　children with any mental health disabilities were adequately compensated (CV=£33, mean

386　benefits=£34) and so were families of children with physical health disabilities with low LS (CV=£25,

387　mean benefits= £26). We also found, however, that families of children with any or both mental

388　health disabilities with low LS were undercompensated under the current benefit scheme (any

389　mental health: CV=£42, mean benefit=£34; both mental health: CV=£61, mean benefits=£46).

390

391　These results suggest that mental health disabilities in childhood are associated with substantial

392　costs, which need to be borne by their families. In other words, families of children with mental

393　health disabilities need to have higher income in order to achieve the same living standards of a

394　family without a disabled child. These costs appear to be higher when there are co-occurring mental

395　and physical disabilities, possibly an indicator of severity of the condition, and for more economically

396　deprived families. These families also appear to be undercompensated under current benefit

397　arrangements.

398

399　Our findings on the cost of child disability are lower from those found by Dobson and colleagues

400　estimating the cost of child disability to the family at £100 per week [4,5]. Compared to these studies,

401　we also found that undercompensation occurred to a lower extent, in the range of £8-£15 and only

402　for deprived families with children with mental health disabilities, as opposed to £30-£80 [4] and £24 [5].

403　One reason for this difference could be that these studies employed convenience sampling (i.e.

404　selecting children with more severe disabilities and living in more deprived settings) and different

405　definitions of disability, which did not clearly distinguish between mental and physical health.

13

406

407   This study had several strengths. It employed a large and rich dataset representative of the UK
408   population. The FRS also makes use of the disability domains employed in the DDA to define areas
409   affected by disability, which makes it consistent with definitions applicable to policy settings. We
410   also employed a novel approach which allowed us to match families not only based on their
411   propensity scores distribution, but also on the values of living standards with exact matching to the
412   first decimal digit. Nevertheless, several limitations should be accounted for. First, we could only
413   give an approximate definition of mental and physical health disability, knowing that areas which we
414   have considered as physical health could be affected as a result of mental health disability only.
415   Nevertheless, our approach represents a first attempt at both costing the impact of mental health
416   disabilities on families and disentangling the relative effect of mental and physical health disability.
417   We were also unable to explore the effect of severity of disability or of different types of disabilities
418   given the nature of the available variables. Future studies should attempt to include specific
419   diagnoses, perhaps including sub-clinical presentations as separate categories in order to account for
420   varying degrees of severity. A total of 10% had missing data on LS measures; although we calculated
421   our index re-scaling the latter to the number of questions each family had answered, it is not
422   possible to rule out the possibility that under/over-estimation of the LSI value for these families
423   could have occurred. Moreover, our living standards measure provides an indication of what goods
424   the family can afford, but not of their quality. However, values of mean income by low/high LSI
425   seemed to suggest that the latter adequately describes the intended groups. The sample size for
426   some of our disability definitions was small meaning that we could have incurred in type II error and
427   failed to observe an income difference when indeed there was one. Due to the cross-sectional
428   nature of the study, it was not possible to estimate the CV in the absence of benefits, as the latter
429   contribute, when received, to the LS achieved by the family. This approach would have given a
430   clearer indication of the income difference between families with and without a disabled child. In
431   fact, based on our estimates, we are not able to tell, if we do not observe a difference in income,
432   whether an actual difference would have occurred in the absence of the benefits system. By
433   comparing the CV to the amount of benefits received, we however attempted to estimate whether
434   the family was currently over or undercompensated. Finally, our propensity score model could have
435   been improved by including more precise indications of family structure and parental education, as
436   well as a greater number of family and child characteristics, such as parental employment, child
437   emotional problems or school attainment. Future studies should endeavor to be more inclusive in
438   order to improve model prediction.

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440   In conclusion, we found that mental health in childhood and adolescence is associated with high

441   costs, which need to be borne by the family. Our findings indicate that families of children from

442   more disadvantaged backgrounds are currently undercompensated by the disability benefits system.

443   Based on these findings we suggest that mental health should be better defined as a criterion for

444   receiving benefits and that the amount of disability benefits that a family is entitled to receive are

445   subject to means testing, so that families from more deprived socio-economic backgrounds could be

446   entitled to higher benefits amounts.

447

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452

453   **Authors' contributions**

454   Francesca Solmi: Contributed to designing research question and study designed, analyzed data,

455   wrote manuscript.

456   Maria Melnychuk: Contributed to designing research question and study designed, analyzed data,

457   contributed to manuscript revision.

458   Steve Morris: Contributed to designing research question and study designed, contributed to

459   manuscript revision, supervised data analyses and the overall project.

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527   **TABLES and FIGURES**

528   **Figure 1. Distribution of LSI**

Distribution of the living standards index 1

529

Table 1: sample characteristics

	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)
				Child disability			
Group		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
Male	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%)
Female	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
London	8,743(10.21%)	8,365(10.29%)	26(7.30%)	101(8.90%)	164(9.14%)	85(8.62%)	252(9.32%)
South East	9,996(11.67%)	9,498(11.68%)	52(14.61%)	145(1.78%)	217(12.10%)	134(13.59%)	330(12.21%)
Wales, Scotland, Northern Ireland	23,566(27.52%)	22,420(27.57%)	91.25.56%)	303(26.70%)	451(25.14%)	240(24.34%)	695(25.71%)
Rest of England	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
Single	21,586(25.21%)	19,934(24.52%)	159(44.66%)	434(38.24%)	685(38.18%)	368(37.32%)	1,012(37.44%)
Couple	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
No	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%)
Yes (at least one parent)	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%)

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Table 1 (continued)

	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)
				Child disability			
Group		6	1	2	3	4	5
Total savings			*p<0.0001*	*p<0.0001*	*p<0.0001*	*p<0.0001*	*p<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) *p<0.0001*	8.48(4.30) *p<0.0001*	9.71(3.69) *p<0.0001*	9.42(3.64) *p<0.0001*	8.88(4.03) *p<0.0001*
Age main respondent left full time education *(years above 18)*	1.08(2.15)	1.10(2.17)	0.53(1.74) *p<0.0001*	0.71(1.73) *p<0.0001*	0.64(1.77) *p<0.0001*	0.71(1.96) *p<0.0001*	0.70(1.78) *p<0.0001*
Number of dependent children in household	2.19(0.99)	2.19(0.99)	2.15(1.07) *p=0.41*	2.12(0.99) *p=0.034*	2.14(1.01) *p=0.035*	2.13(1.01) *p=0.05*	2.11(0.98) *P=0.0001*

Abbreviations: SD = standard deviation

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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 .

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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

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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
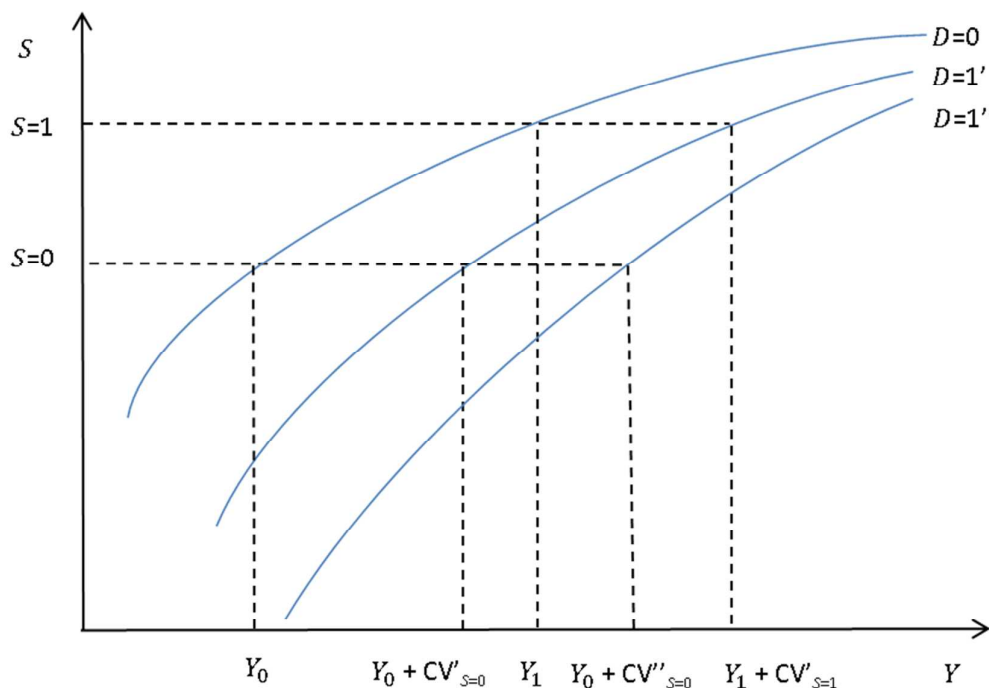
Theoretical Approach: Propensity Score Matching

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:

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

We matched families using nearest neighbor matching within a caliper, defined to be one quarter of the standard deviation of the propensity score [25]. 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:

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

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

	Item No	Recommendation
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
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported
Objectives	3	State specific objectives, including any prespecified hypotheses
Methods		
Study design	4	Present key elements of study design early in the paper
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—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 *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—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
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
Bias	9	Describe any efforts to address potential sources of bias
Study size	10	Explain how the study size was arrived at
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why
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*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed *Cross-sectional study*—If applicable, describe analytical methods taking account of sampling strategy
		(*e*) Describe any sensitivity analyses

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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) *Cohort study*—Summarise follow-up time (eg, average and total amount)	.
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time	
		Case-control study—Report numbers in each exposure category, or summary measures of exposure	
		Cross-sectional study—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	12-14
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	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.

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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   **The cost of mental and physical health disability in childhood and adolescence to families in the**

4   **United Kingdom: findings from a repeated cross-sectional survey using propensity score matching**

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18   **Keywords:** Child disability; living standards; disability benefits; compensating variation; propensity

19   score matching.

20

21   **Competing interests:**

22   The authors declare no competing interests.

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31   **ABSTRACT**

32 **Objective:** UK families of disabled children are entitled to receive disability benefits to help meet

33 costs associated with caring for their child. Evidence of actual costs incurred is scant, especially for

34 mental health disability. In this study we aimed to quantify the cost of mental and physical health

35 disability in childhood and adolescence to families in the UK using the concept of compensating

36 variation (CV).

37

38 **Design:** Repeated cross-sectional survey.

39

40 **Setting**: UK general population

41

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

43

44 **Outcomes:** Using propensity score matching we matched families with a disabled child to similar

45 families without a disabled child and calculated the extra income the former require to achieve the

46 same living standards as the latter, i.e. their CV. We calculated the additional costs specifically

47 associated with several definitions of mental health and physical health disability.

48

49 **Results** Families of a child with any mental health disability, regardless of the presence of physical

50 health comorbidity, needed an additional £49.31 (either mental health disability, 95% confidence

51 interval (CI): 21.95; 76.67) or £57.56 (both mental health disabilities, 95%CI: 17.69; 97.44) per week

52 to achieve the same living standards of families without a disabled child. This difference was greater

53 for more deprived families, who needed between £59.28 (95%CI: 41.38; 77.18) and £81.26 (95%CI:

54 53.35; 109.38) more per week depending on the extent of mental health disability. Families of

55 children with physical health disabilities, with or without mental health disabilities, required an

56 additional £35.86 (95%CI: 13.77; 57.96) per week, with economically deprived families requiring an

57 extra £42.18 (95%CI: 26.38; 57.97) per week.

58

59 **Conclusions** Mental and physical health disabilities among children and adolescents were associated

60 with high additional costs for the family, especially for those from deprived economic backgrounds.

61 Means testing could help achieve a more equitable redistribution of disability benefit.

62

63

2

64   **Strengths and Limitations**

65   • Strengths of this study are the use of: (i) a large and rich dataset representative of the UK

66   population; (ii) disability domains employed in the Disability Discrimination Act (DDA) consistent

67   with definitions applicable to policy settings; and, (iii) novel analytical approach based on

68   propensity score matching.

69   • Limitations of this study are: (i) its cross-sectional design; (ii) difficulties in disentangling physical

70   and mental health disabilities (which are often co-occurring); and, (iii) data limitations making it

71   problematic to account for severity of disability and to measure living standards, and only

72   covering the period 2004/05 up to 2011/12.

3

INTRODUCTION

73

74   Families of children suffering from chronic conditions and physical and mental health disabilities

75   incur significantly higher costs than those of their healthy counterparts.[1–5] These costs are primarily

76   accounted for by more frequent visits to inpatient and outpatient departments and by greater use of

77   prescribed drugs,[1–3] although evidence also suggests that the need to provide or secure informal

78   care adds to the financial burden of child disability for these families.[4,5] Previously, UK studies have

79   estimated the cost of having a disabled child at about £79-£100 per week[4] and that under the

80   benefits arrangements at the time (1997) families of disabled children were undercompensated by

81   £30-£80 per week [4] and by £28 in 2001.[5] More recent evidence has estimated that in the UK families

82   of severely disabled children require up to an additional £79 per week to be able to meet the same

83   living standards of those without disabled children.[6]

84

85   Mental health conditions account for a great portion of the burden of disease among children and

86   adolescents below the age of 16 years.[7] Onset of most mental health conditions occurs at different

87   stages of childhood and adolescence: developmental and hyperkinetic disorders become manifest in

88   early childhood, whilst depressive (including suicide and self-harm), psychotic, anxiety, conduct, and

89   eating disorders most commonly arise in adolescence and young adulthood.[8] Evidence suggests that

90   in the UK there has been a trend towards increasing rates of children and young people suffering

91   from mental health conditions since the 1980s.[9] The 2004 British Child and Adolescent Mental

92   Health Survey (B-CAMHS) conducted by the Office of National Statistics (ONS) reported that 10% of

93   children aged 5 – 16 years met diagnostic criteria for a mental health disorder. [10]

94

95   A socio-economic gradient exists in the distribution of child mental health disorders [11–13]. In the 2004

96   B-CAMHS, prevalence of diagnosable child mental health conditions was higher among single-parent

97   (15.6%) compared to married or co-habiting (7.7%) households; among families with low (16.1%)

98   compared to high (5.3%) income; and among families whose parents had no academic qualifications

99   (17.0%) compared to those with university degrees (4.4%) [14]. Evidence exists that life adversities are

100   a risk factor for the onset of mental health conditions as well as that mental health problems of the

101   child can lead to family breakdown and unemployment [14].

102

103   Both mental health problems and socio-economic disadvantage in childhood and adolescence can

104   have enduring effects and significantly impact on a young person's future. Children and adolescents

105   suffering from mental health problems more often report low levels of academic achievement, and

106   engage in risky behaviours such as alcohol and drug use with detrimental effects on employment

4

107 prospects [15]. Similarly, childhood experience of economic hardship can result in long-term adverse

108 health outcomes via the persistence of lower socio-economic status [15].

109

110 Since 1992, in the UK, families of children affected by disability have been eligible to receive a non-

111 means-tested weekly Disability Living Allowance (DLA).[16] The rationale for these benefits is that

112 they "*may help with the extra costs of looking after a child who: is under 16; has difficulties walking*

113 *or needs more looking after than a child of the same age who doesn't have a disability*".[16] The

114 amount of benefits that the family is entitled to receive largely depends on the severity of the child's

115 condition, which is determined by the disability service centre often in conjunction with external

116 assessments. In 2017, under the care component of DLA, children could receive either £22 (if they

117 needed a little help during the day or night), £55.65 (if they needed frequent supervision), or £83.10

118 (if they needed constant help day and night, or were terminally ill) per week. Under the mobility

119 component of DLA, children were entitled to receive between £22 (if they could walk but needed

120 supervision outdoors) and £58 (if they could not walk, if walking represented a health risk, or if they

121 were blind) per week.

122

123 Previous UK studies have shown that families of disabled children incur high costs, but were

124 however unable to attribute these extra expenditures to either physical or mental health disability,

125 which has been shown to inflict a substantial economic burden in other settings.[2,3] In the absence of

126 literature exploring the cost of child mental health disability to families, and the rising prevalence of

127 these problems, the aims of this study are to: (1) investigate the cost to families of having a child

128 with a mental health disability; (2) compare the costs of mental health versus physical health

129 disability to assess whether such stratification is needed when considering disability benefits; and,

130 (3) examine how these costs vary by economic deprivation in order to assess whether means testing

131 of DLA should be considered.

132

133

MATERIALS AND METHODS

134

135 **Sample**

136 We employed data from eight consecutive rounds of data collection from the Family Resources

137 Survey (FRS) covering the financial years 2004/05 to 2011/12. The FRS is a repeated cross-sectional

138 survey undertaken by the Department of Work and Pensions (DWP) whose aim is to collect data on

139 the financial and social circumstances of individuals living within private UK households. Although

140 representativeness of the older age groups within the population might be limited in FRS due to the

5

141   focus on private households (nursing and retirement homes are not included), the overall sample,

142   used in this study, is representative of the UK population [17], and our focus on families with children

143   under 16 years of age means this is unlikely to introduce a bias.

144

145   In the FRS households are defined as 'a single person or group of people living at the same address

146   who either share one meal a day or share the living accommodation, i.e. a living room'. Each

147   household may include one or more benefit unit, 'a single adult or couple living as married and any

148   dependent children'. A dependent child is a 'child younger than 16 years or an unmarried 16 to 19-

149   year-old in full time non-advanced education'.[18] In this study, for simplicity we refer to benefit units

150   as 'families' and consider children as our main unit of analyses, as matching was done at child-level.

151   Our sample includes children aged 0-15 years and their families who had complete data on all

152   variables included in the model covariates and necessary to estimate the CV (i.e. income and living

153   standards). We excluded all the children from families with more than one disabled child because of

154   difficulties separating the effects of multiple disabled children in the same family (2.7% of total

155   children). In families with only one disabled child who had siblings we excluded the siblings to avoid

156   within-family matching.

157

158

159   **Child mental and physical health disability**

160   In line with the definition of disability included in the Disability Discrimination Act (DDA) 1995 and

161   2005, the FRS defines a child as having a disability if they have a longstanding illness lasting longer

162   than 6 months and affecting their ability to undertake daily activities. Families were asked if their

163   child had any longstanding illness, disability or infirmity. Families responding 'yes' were directed to a

164   set of follow up questions asking which area of the child's life was affected by their disability.

165   Possible answers were: mobility; lifting; manual dexterity; continence (i.e. bladder control);

166   communication (i.e. speech, hearing, or eyesight); memory and learning; recognition of physical

167   danger; physical coordination; other; or, none of these areas. As we were not able to define their

168   disability either as affecting physical or mental health, we excluded children whose family claimed

169   had a disability but subsequently said that none of these areas where affected by disability (3.4% of

170   total children).

171

172   Of these eight disability domains, we assume that memory and learning, and recognition of physical

173   danger can be attributable solely to mental health problems, as they are related to cognitive

174   impairment. We assume all other areas primarily reflect physical health problems [19], but

6

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.

179

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.

189

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 problems [14] similarly, physical health disability can adversely affect mental health [20]. 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.

208

7

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

221

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 weighting [22] with

236 weights representing the proportion of families considering the item a necessity. We calculated the

237 *LSI* as follows:

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

239

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

8

242   proportion (i.e. weight) of respondents who consider the item desirable, as defined above [22] and *M*

243   is the number of items.

244   A total of 10% of families in our sample had missing data for one or more of these questions. In

245   order to derive a LSI value for these families, we scaled the score they obtained from the questions

246   they answered on the total score they could have obtained if they had could afford each of the items

247   they were asked about ($\sum_{i=1}^{M} w_i$).

248   Finally, from the continuous *LSI* ranging from 0 to 1 (distribution in Figure 1) we defined families with

249   a *LSI*=1 as having 'high living standards', since they could afford each item included, and families with

250   *LSI*<1 as having 'low living standards' as they could not afford one or more of the items.   We

251   employed continuous values of the *LSI* to match families using propensity scores and the derived

252   binary variable to conduct stratified analyses (see Data Analysis section).

253

254   **Income**

255   We derived a measure of income accounting for all available resources affecting living standards [23,24],

256   including net income from all sources (i.e. earnings, self-employment, investments, and pensions) as

257   well as from any benefits, including disability benefits, received by the family. Disability and other

258   benefits were included because these affect living standards. We inflated incomes to 2011/12 prices.

259   We did not employ an equivalised measure of income for ease of interpretation of the results (i.e.,

260   our unit of analysis is the family and equivalised income is a measure of income per person);

261   however, in order to account for family composition we included variables indicating number of

262   adults and ages of children in the matching stage of the analyses (see below), in line with previous

263   literature [23,25]. Values of net income are reported 'per week' in the FRS.

264

265   **Other variables**

266   In our analyses we match families with and without a disabled child on a number of socio-

267   demographic and socio-economic characteristics of the families and their children. We included

268   indicators of the child's age (linear term) and gender (male/female); two linear terms for number of

269   dependent children in the family (range 1-8) and number of years of schooling after the age of 18

270   years (i.e. the age at which compulsory education ends in the UK) of the head of the household and

271   their marital status (single/couple); presence of a disabled adult (yes/no), and to account for family

272   wealth, a categorical variable indicating family savings banded in five categories and an indicator of

273   parental (i.e. main respondent's) employment (employed/unemployed/inactive).

274

9

275 We also included a categorical indicator for survey year and UK Government Office Region (London;

276 South East; Rest of England; Northern Ireland, Wales and Scotland[1]).

277

278 **Data analysis**

279 We described how sample characteristics vary by disability group using cross-tabulations with Chi-

280 Square tests and ANOVAs for categorical and continuous variables, respectively.

281

282 We employed the 'compensating variation' (CV) approach to calculate the cost of child disability,

283 which has been previously used in studies of disability in adults[24] and children.[6] The CV can be

284 defined as the additional income that a family with a disabled child needs to be able to achieve the

285 same living standards of a family that is similar in all other respects but without a disabled child.

286 More details on the theoretical approach can be found in the supplementary material and in Figure

287 S1. We used Propensity Score Matching (PSM) [26,27] to match families according to comparisons A – F

288 and calculate the CV (i.e. the mean income difference). It has been suggested that this approach, by

289 simulating a randomised controlled trial setting, can provide a more unbiased estimate of the

290 income difference than parametric models in observational studies [24].

291

292 We calculated propensity scores (i.e. predicted probabilities) from probit regression models with

293 each of our group allocations in the comparisons defined above (Comparisons A to H) as the

294 outcome (e.g., for Comparison A, participation in Group 1 is coded 1 and Group 6 is coded 0, all

295 other groups are coded as missing). In all models the independent variables were child age and

296 gender, number of children and disabled adults in the family, years of schooling of the main

297 respondent, marital status, family savings, government region and survey year. Additionally, for

298 comparisons F, G, and H we also controlled for areas of disability (other than those defining the

299 Group) as covariates. For all models we calculated areas under the receiver operating characteristic

300 (ROC) to estimate goodness of fit of the model and tested whether the distribution of the covariates

301 was balanced between disabled and non-disabled children. More details on the PSM theoretical

302 approach are in the supplementary material.

303 For each matching pair obtained with this matching approach we calculated the CV and its 95% CI [28].

304 As sensitivity analyses we estimated the compensating variation matching disabled children using

305 3:1 matching (i.e. matching a disabled child to the three closest matches) and using radius matching

---

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

10

306   (defining the radius as a quarter of a the propensity score standard deviation). All our analyses were

307   run using Stata13.[29]

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.

11

340   Among families with high living standards, families of children affected in any of the physical or

341   mental health disability areas or in both the mental health areas, regardless of other areas affected,

342   had lower income compared to families of children without disabilities.

343

344   **Benefits**

345   As seen in Table 3, across all LS groups combined families of children with both mental health

346   disabilities (Group (4)) received the highest amount of weekly benefits (mean value £45.95),

347   followed by those with any mental health disabilities (Group (3); £34.48), and those with any

348   physical health disabilities (Group (5); £26.22) (Table 3). Note these groups included children with

349   both mental and physical disabilities. Children only affected in either or both mental health areas

350   received on average £17.40 per week (Group (1)) whilst those affected in any or all physical health

351   domains only received £10.63 (Group (2)). The amount of benefits received did not vary by LS,

352   reflecting the absence of means testing for disability benefits. None of the children in the non-

353   disabled group were receiving any disability benefits.

354

355

356   **Compensating variation**

357   Over and above their net income (including benefits received) families of children with any (Group 3)

358   or both mental health disabilities (Group 4) needed an additional £49.31 (95% confidence interval

359   (CI): 21.95; 76.67) and £57.56 (95% CI: 17.69; 97.44), respectively, a week in order to achieve the

360   same living standards of similar families without a disabled child (Group 6; Comparisons C and D,

361   respectively), across both levels of LS (Table 4). We also found evidence that families of children

362   with any physical health disability (Group 2) needed an additional £35.86 (95%CI: 13.77; 57.96) per

363   week to meet the living standards of families without disabled children (Group 6; Comparison E).

364   When pooling across living standards, we did not find any other differences in any of the other

365   disability groups.

366

367   When we split the sample by low and high levels of living standards, we found that in some cases

368   families with low LS with a disabled child needed a higher net income to meet the same LS of

369   families without a disabled child. Specifically, we found that families of a child with any mental

370   health disability or both mental health disabilities (with or without physical disabilities) required an

371   extra £59.28 (95%CI: 41.38; 77.18), Group 3, Comparison C) and £81.37 (95%CI: 53.35; 109.38,

372   Group 4, Comparison D) a week more than a family without a disabled child. We also found an

373   income difference, albeit smaller, for families of children with disability affecting physical health

374 compared to families of non-disabled children, with the former needing an extra £42.18 (95%CI:

375 26.38; 57.97, Group 5, Comparison E) more a week to achieve the same LS.

376

377 When we compared children affected by disability in any, or both mental health areas and in any

378 physical health areas, regardless of the presence of other disabilities, against children without

379 disabilities and other with physical and mental health disabilities respectively (i.e., in comparisons F -

380 H), we found weak evidence that families of children with both mental health areas affected by

381 disabilities needed an extra £47.45 (95% CI: -0.41; 95.30) more per week to achieve the same LS if in

382 the low LS category (Table 4). Although, we did not find any evidence of differences for the other

383 groups, in particular those with high living standards, there was an indication that children in group 1

384 (any mental health disability with no physical health disability), and group 4 (both mental health

385 disabilities regardless of physical health disabilities) were adequately compensated, although the

386 latter case only among children with greater LS. We did not find evidence of any other group

387 differences.

388

389 *Sensitivity analyses and model checks*

390 The sensitivity analysis using 3:1 matching yielded virtually identical results to those in the main

391 analysis (results not shown). The sensitivity analysis using radius matching also yielded similar

392 results, with some small differences in the size and significance of the compensating variation for

393 some comparisons (Supplemental material and Table S3).

394

395 In our main analysis, for comparisons A to E the distribution of covariates was balanced between

396 treatment groups (i.e. disabled and non-disabled children) with the exception of years of schooling,

397 which in some models was unbalanced. In models F to H, the distribution of covariates was less well

398 balanced in our main analyses. However, in sensitivity analyses all models were balanced, and since

399 the results in the sensitivity analysis we similar to those of the main analysis, this suggests that this is

400 unlikely to have biased our estimates.

401

402 **DISCUSSION**

403 Little evidence exists on the costs borne by families of children affected by mental health disability in

404 the UK. To the best of our knowledge, this is the first UK study aiming to quantify these costs using

405 propensity score matching and a compensating variation approach to estimate cost of mental health

406 disability.

407

13

408 We found no difference in income between families of children with a disability affecting any or all

409 areas associated with mental health problems only and families of non-disabled children. When we

410 allowed for existence of physical health comorbidities, we found that these families needed an

411 additional £49.31 per week over and above existing net incomes (including disability benefits)

412 compared to families of non-disabled children to achieve the same living standards, with an even

413 greater amount needed if children's disability affected both mental health domains (£57.56). These

414 difference were, again, even greater for families with low living standards (£59.28 and £81.37,

415 respectively). In comparison, families with children affected by physical health had a positive, but

416 smaller in magnitude, CV (£35.86), which was, similarly to what was observed for mental health

417 disability, was higher among families with low LS (£42.18). When we tested the relative impact of

418 mental and physical health on the CV, by allowing our comparator group to have disabilities in the

419 opposite domains of the one under investigation, we found a positive, though weak, CV for children

420 affected in both mental health disabilities who live in families with low LS (£47.45). These findings

421 suggest that all these groups are undercompensated by the benefits system.

422

423 These results suggest that mental health disabilities in childhood are associated with substantial

424 costs which need to be borne by their families. In other words, families of children with mental

425 health disabilities need to have higher income in order to achieve the same living standards of a

426 family without a disabled child. These costs appear to be higher when there are co-occurring mental

427 and physical disabilities, possibly an indicator of severity of the condition, and for more economically

428 deprived families. As benefits were already included in our income measure, the compensating

429 variation represents the amount by which families appear to be undercompensated under current

430 benefit arrangements.

431

432 Our findings on the cost of child disability are lower from those found by Dobson and colleagues

433 estimating the cost of child disability to the family at £100 per week [4,5]. Compared to these studies,

434 we also found that under-compensation occurred to a lower extent, in the range of £8-£15 and only

435 for deprived families with children with mental health disabilities, as opposed to £30-£80 [4] and £24 [5].

436 One reason for this difference could be that these studies employed convenience sampling (i.e.

437 selecting children with more severe disabilities and living in more deprived settings) and different

438 definitions of disability, which did not clearly distinguish between mental and physical health.

439

440 This study had several strengths. It employed a large and rich dataset representative of the UK

441 population. The FRS also makes use of the disability domains employed in the DDA to define areas

14

442   affected by disability, which makes it consistent with definitions applicable to policy settings. We

443   also employed a novel approach which allowed us to match families not only based on their

444   propensity scores distribution, but also on the values of living standards with exact matching to the

445   first decimal digit. Nevertheless, several limitations should be accounted for. First, we could only

446   give an approximate definition of mental and physical health disability, knowing that areas which we

447   have considered as physical health could be affected as a result of mental health disability only.

448   Nevertheless, our approach represents a first attempt at both costing the impact of mental health

449   disabilities on families and disentangling the relative effect of mental and physical health disability.

450   We were also unable to explore the effect of severity of disability or of different types of disabilities

451   given the nature of the available variables. Future studies should attempt to include specific

452   diagnoses, perhaps including sub-clinical presentations as separate categories in order to account for

453   varying degrees of severity. A total of 10% had missing data on LS measures; although we calculated

454   our index re-scaling the latter to the number of questions each family had answered, it is not

455   possible to rule out the possibility that under/over-estimation of the LSI value for these families

456   could have occurred. Moreover, our living standards measure provides an indication of what goods

457   the family can afford, but not of their quality. However, values of mean income by low/high LSI

458   seemed to suggest that the latter adequately describes the intended groups. The sample size for

459   some of our disability definitions was small meaning that we could have incurred in type II error and

460   failed to observe an income difference when indeed there was one. Due to the cross-sectional

461   nature of the study, it was not possible to estimate the CV in the absence of benefits, as the latter

462   contribute, when received, to the LS achieved by the family. This approach would have given a

463   clearer indication of the income difference between families with and without a disabled child. In

464   fact, based on our estimates, we are not able to tell, if we do not observe a difference in income,

465   whether an actual difference would have occurred in the absence of the benefits system. By

466   comparing the CV to the amount of benefits received, we however attempted to estimate whether

467   the family was currently over or undercompensated. Our propensity score model could have been

468   improved by including more precise indications of family structure and parental education, as well as

469   a greater number of family and child characteristics, such as a clearer specification of parental

470   physical or mental health disability. Future studies should endeavor to be more inclusive in order to

471   improve model prediction. We used data covering the financial years 2004/05 to 2011/12, which are

472   not the most current available. This choice was motivated by a change in the definition of disability

473   in 2012/13 to include a separate mental health domain. Although using post-2012/13 data would

474   have resulted in a clearer definition of mental health and more recent estimates, we would not have

475   had enough statistical power for our analyses. Nevertheless, we found that the amount of DLA

15

476 received across disability groups in our sample was consistent with 2011/12 and current DLA figures,

477 suggesting that our findings bear relevance for current policy. Finally, some of our families,

478 especially in adjacent years, could have been recruited in more than one wave of FRS data collection,

479 meaning that our samples might have not been totally independent.[30] However, given the large size

480 of our sample we believe that it is unlikely that this could have biased our results.

481

482 In conclusion, we found that mental health in childhood and adolescence is associated with high

483 costs, which need to be borne by the family. Our findings indicate that families of children from

484 more disadvantaged backgrounds are currently undercompensated by the disability benefits system.

485 Based on these findings we suggest that mental health should be better defined as a criterion for

486 receiving benefits and that the amount of disability benefits that a family is entitled to receive are

487 subject to means testing, so that families from more deprived socio-economic backgrounds could be

488 entitled to higher benefits amounts.

489 **Acknowledgments**

493

494 **Data Sharing:** The dataset used in these analyses is publicly available on

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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Table 1: sample characteristics

	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)
				Child disability			
Group (comparator)		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%)

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Table 1 (continued)

			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)
Group		6	1 (vs. 6)	2 (vs. 6)	3 (vs. 6)	4 (vs. 6)	5 (vs. 6)
Total savings			p<0.0001	p<0.0001	p<0.0001	p<0.0001	p<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			p<0.0001	p<0.0001	p<0.0001	p<0.0001	p<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) p<0.0001	8.48(4.30) p<0.0001	9.71(3.69) p<0.0001	9.42(3.64) p<0.0001	8.88(4.03) p<0.0001
Age main respondent left full time education	18.08(2.15)	18.10(2.17)	18.53(1.74) p<0.0001	18.71(1.73) p<0.0001	18.64(1.77) p<0.0001	18.71(1.96) p<0.0001	18.70(1.78) p<0.0001
Number of dependent children in household	2.19(1.00)	2.19(0.99)	2.15(1.07) p=0.41	2.12(0.99) p=0.034	2.14(1.01) p=0.035	2.13(1.01) p=0.05	2.11(0.98) P=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

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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)

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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

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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≤0.05 *0.1>p>0.05

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

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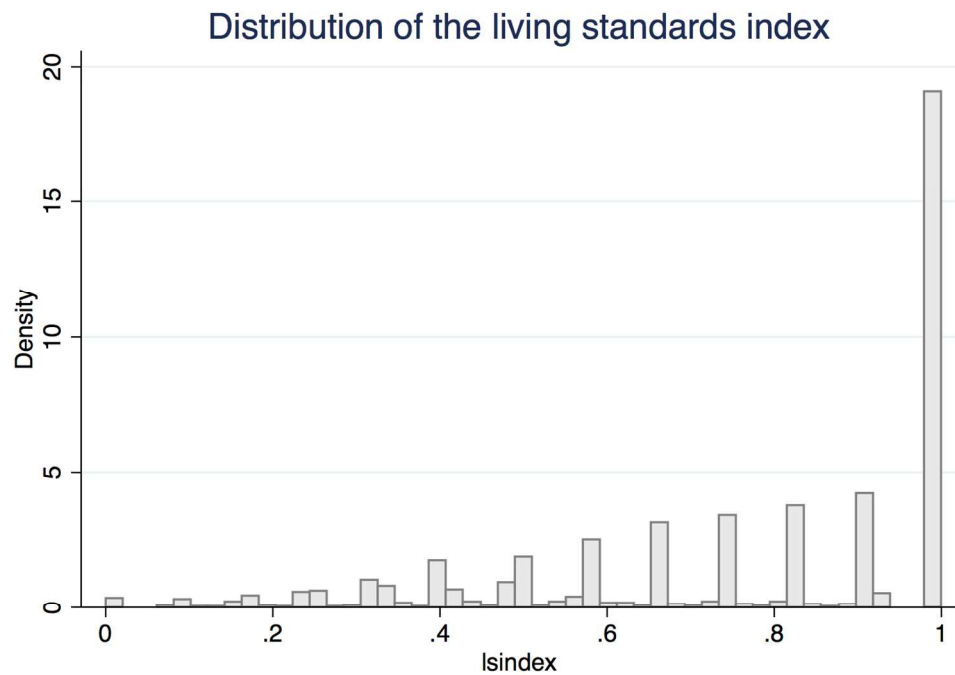## Distribution of the living standards index

Figure 1. Distribution of living standard index

139x101mm (300 x 300 DPI)

1 **Table S1: Definitions of disability groups**

2

3

Disability Domain	Group 1	Group 2	Group 3	Group 4	Group 5	Group 6
Physical health						
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**
Mental health						
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**

4

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

9

10 • Group 1: Any (either or both domains) mental disability (no physical disability);

11 • Group 2: Any physical disability (no mental disability) (group 1 & 2 are mutually exclusive);

12 • Group 3: Any mental disability (either domains, with or without physical disability);

13 • Group 4: Both mental disabilities (both domains, with or without physical disability);

14 • Group 5: Any physical disability (with or without mental disability);

15 • Group 6: No disability.

1

16 **Table S2: Living standard questions in the Family Resources Survey**

17

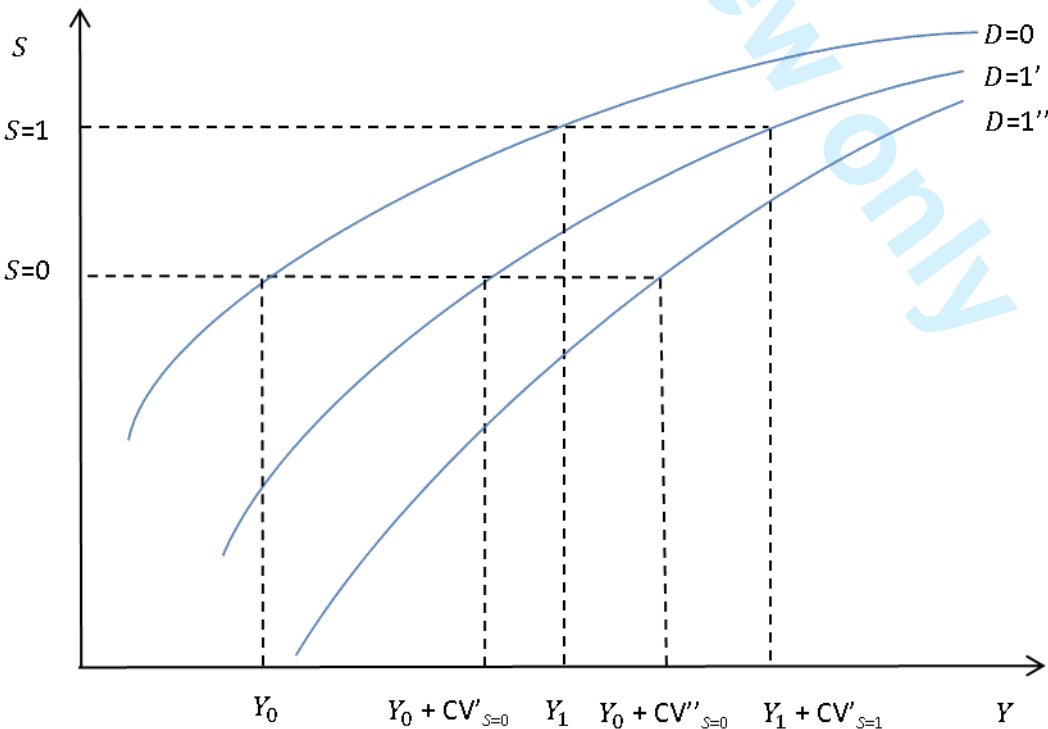| Question	Included	Rationale
Do you (and your family) have a holiday away from home for at least one week a year, whilst not staying with relatives at their home?	YES	
Do you have friends or family around for a drink or meal at least once a month?	NO	Not directly relevant to children's living standards
Do you have two pairs of all-weather shoes for (all members of family)	NO	Depending on disability, might not be applicable to all chidlren
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

18

2

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)

21 and the living standards (S, on the vertical axis) of families without a disabled child (D =0) and with a

22 disabled child (D =1'). We assume that: (i) the curves are upward sloping from left to right and convex, due

23 to diminishing returns to S as Y increases; and, (ii) D =1' lies below D =0 though they tend towards one

24 another at higher levels of Y. At a given level of living standards such as S =0 the CV is the difference

25 between the income that a family with a disabled child (D =1') needs to have (= $Y_0 + CV'_{S=0}$) compared to

26 the income of a family without a disabled child (D =0) (=Y_0) to achieve the same living standard (S =0).

27 Based on our assumptions this difference will decrease at higher levels of living standards. For instance, the

28 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

29 $Y_0 + CV'_{S=0}$.

30

31 We hypothesize that families of children with more severe disabilities incur higher costs to achieve the

32 same living standards as families with less severely disabled children. Suppose D =1'' denotes more severe

33 disabilities than D = 1'; this is shown in Figure 1 as curve D =1'' lying below curve D =1'. In this case the CV

34 for S =0, corresponds to $Y_0 + CV''_{S=0}$, which is greater than $Y_0 + CV'_{S=0}$.

35

36 In order to employ this approach to investigate our aims, three measures are needed: 1) a definition of

37 child mental and physical health disability; 2) a measure of living standards (LS); and 3) a measure of

38 income.

39 **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:

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

We matched families using nearest neighbor 1:1 matching within a caliper, defined to be one quarter of the standard deviation of the propensity score [25]. 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:

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

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.

4

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

5

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.

105

106

7

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

	Item No	Recommendation	
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	1-2
		(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	1, 5
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) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up	
		Case-control study—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	
		Cross-sectional study—Give the eligibility criteria, and the sources and methods of selection of participants	5-6
		(b) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed	
		Case-control study—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
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
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	6-8
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	12
		(b) Describe any methods used to examine subgroups and interactions	N/A
		(c) Explain how missing data were addressed	10
		(d) *Cohort study*—If applicable, explain how loss to follow-up was addressed	
		Case-control study—If applicable, explain how matching of cases and controls was addressed	
		Cross-sectional study—If applicable, describe analytical methods taking account of sampling strategy	
		(e) Describe any sensitivity analyses	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
		(b) Give reasons for non-participation at each stage
		(c) Consider use of a flow diagram
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders
		(b) Indicate number of participants with missing data for each variable of interest
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time
		Case-control study—Report numbers in each exposure category, or summary measures of exposure
		Cross-sectional study—Report numbers of outcome events or summary measures
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
		(*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
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
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence
Generalisability	21	Discuss the generalisability (external validity) of the study results

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

*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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1 **The cost of mental and physical health disability in childhood and adolescence to families in the**

2 **United Kingdom: findings from a repeated cross-sectional survey using propensity score matching**

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20

21 **Competing interests:**

22 The authors declare no competing interests.

23

29

30

1

31 **ABSTRACT**

32 **Objective:** UK families of disabled children are entitled to receive disability benefits to help meet

33 costs associated with caring for their child. Evidence of actual costs incurred is scant, especially for

34 mental health disability. In this study we aimed to quantify the cost of mental and physical health

35 disability in childhood and adolescence to families in the UK using the concept of compensating

36 variation (CV).

37

38 **Design:** Repeated cross-sectional survey.

39

40 **Setting**: UK general population

41

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

43

44 **Outcomes:** Using propensity score matching we matched families with a disabled child to similar

45 families without a disabled child and calculated the extra income the former require to achieve the

46 same living standards as the latter, i.e. their CV. We calculated the additional costs specifically

47 associated with several definitions of mental health and physical health disability.

48

49 **Results** Families of a child with any mental health disability, regardless of the presence of physical

50 health comorbidity, needed an additional £49.31 (95% confidence interval (CI): 21.95; 76.67) and, for

51 more severe disabilities, an additional £57.56 (95%CI: 17.69; 97.44) per week to achieve the same

52 living standards of families without a disabled child. This difference was greater for more deprived

53 families, who needed between £59.28 (95%CI: 41.38; 77.18) and £81.26 (95%CI: 53.35; 109.38) more

54 per week depending on the extent of mental health disability. Families of children with physical

55 health disabilities, with or without mental health disabilities, required an additional £35.86 (95%CI:

56 13.77; 57.96) per week, with economically deprived families requiring an extra £42.18 (95%CI: 26.38;

57 57.97) per week.

58

59 **Conclusions** Mental and physical health disabilities among children and adolescents were associated

60 with high additional costs for the family, especially for those from deprived economic backgrounds.

61 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
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7 66 population; (ii) disability domains employed in the Disability Discrimination Act (DDA) consistent
8
9 67 with definitions applicable to policy settings; and, (iii) novel analytical approach based on
10
11 68 propensity score matching.
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13 69 • Limitations of this study are: (i) its cross-sectional design; (ii) difficulties in disentangling physical
14
15 70 and mental health disabilities (which are often co-occurring); and, (iii) data limitations making it
16
17 71 problematic to account for severity of disability and to measure living standards, and only
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19 72 covering the period 2004/05 up to 2011/12.
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3

73 **INTRODUCTION**

74 Families of children suffering from chronic conditions and physical and mental health disabilities

75 incur significantly higher costs than those of their healthy counterparts.[1–5] These costs are primarily

76 accounted for by more frequent visits to inpatient and outpatient departments and by greater use of

77 prescribed drugs,[1–3] although evidence also suggests that the need to provide or secure informal

78 care adds to the financial burden of child disability for these families.[4,5] Previously, UK studies have

79 estimated the cost of having a disabled child at about £79-£100 per week[4] and that under the

80 benefits arrangements at the time (1997) families of disabled children were undercompensated by

81 £30-£80 per week [4] and by £28 in 2001.[5] More recent evidence has estimated that in the UK families

82 of severely disabled children require up to an additional £79 per week to be able to meet the same

83 living standards of those without disabled children.[6]

84

85 Mental health conditions account for a great portion of the burden of disease among children and

86 adolescents below the age of 16 years.[7] Onset of most mental health conditions occurs at different

87 stages of childhood and adolescence: developmental and hyperkinetic disorders become manifest in

88 early childhood, whilst depressive (including suicide and self-harm), psychotic, anxiety, conduct, and

89 eating disorders most commonly arise in adolescence and young adulthood.[8] Evidence suggests that

90 in the UK there has been a trend towards increasing rates of children and young people suffering

91 from mental health conditions since the 1980s.[9] The 2004 British Child and Adolescent Mental

92 Health Survey (B-CAMHS) conducted by the Office of National Statistics (ONS) reported that 10% of

93 children aged 5 – 16 years met diagnostic criteria for a mental health disorder. [10]

94

95 A socio-economic gradient exists in the distribution of child mental health disorders [11–13]. In the 2004

96 B-CAMHS, prevalence of diagnosable child mental health conditions was higher among single-parent

97 (15.6%) compared to married or co-habiting (7.7%) households; among families with low (16.1%)

98 compared to high (5.3%) income; and among families whose parents had no academic qualifications

99 (17.0%) compared to those with university degrees (4.4%) [14]. Evidence exists that life adversities are

100 a risk factor for the onset of mental health conditions as well as that mental health problems of the

101 child can lead to family breakdown and unemployment [14].

102

103 Both mental health problems and socio-economic disadvantage in childhood and adolescence can

104 have enduring effects and significantly impact on a young person's future. Children and adolescents

105 suffering from mental health problems more often report low levels of academic achievement, and

106 engage in risky behaviours such as alcohol and drug use with detrimental effects on employment

4

107   prospects [15]. Similarly, childhood experience of economic hardship can result in long-term adverse

108   health outcomes via the persistence of lower socio-economic status [15].

109

110   Since 1992, in the UK, families of children affected by disability have been eligible to receive a non-

111   means-tested weekly Disability Living Allowance (DLA).[16] The rationale for these benefits is that

112   they "*may help with the extra costs of looking after a child who: is under 16; has difficulties walking*

113   *or needs more looking after than a child of the same age who doesn't have a disability*".[16] The

114   amount of benefits that the family is entitled to receive largely depends on the severity of the child's

115   condition, which is determined by the disability service centre often in conjunction with external

116   assessments. In 2017, under the care component of DLA, children could receive either £22 (if they

117   needed a little help during the day or night), £55.65 (if they needed frequent supervision), or £83.10

118   (if they needed constant help day and night, or were terminally ill) per week. Under the mobility

119   component of DLA, children were entitled to receive between £22 (if they could walk but needed

120   supervision outdoors) and £58 (if they could not walk, if walking represented a health risk, or if they

121   were blind) per week.

122

123   Previous UK studies have shown that families of disabled children incur high costs, but were

124   however unable to attribute these extra expenditures to either physical or mental health disability,

125   which has been shown to inflict a substantial economic burden in other settings.[2,3] In the absence of

126   literature exploring the cost of child mental health disability to families, and the rising prevalence of

127   these problems, the aims of this study are to: (1) investigate the cost to families of having a child

128   with a mental health disability; (2) compare the costs of mental health versus physical health

129   disability to assess whether such stratification is needed when considering disability benefits; and,

130   (3) examine how these costs vary by economic deprivation in order to assess whether means testing

131   of DLA should be considered.

132

133

MATERIALS AND METHODS

135   **Sample**

136   We employed data from eight consecutive rounds of data collection from the Family Resources

137   Survey (FRS) covering the financial years 2004/05 to 2011/12. The FRS is a repeated cross-sectional

138   survey undertaken by the Department of Work and Pensions (DWP) whose aim is to collect data on

139   the financial and social circumstances of individuals living within private UK households. Although

140   representativeness of the older age groups within the population might be limited in FRS due to the

5

141 focus on private households (nursing and retirement homes are not included), the overall sample,

142 used in this study, is representative of the UK population [17], and our focus on families with children

143 under 16 years of age means this is unlikely to introduce a bias.

144

145 In the FRS households are defined as 'a single person or group of people living at the same address

146 who either share one meal a day or share the living accommodation, i.e. a living room'. Each

147 household may include one or more benefit unit, 'a single adult or couple living as married and any

148 dependent children'. A dependent child is a 'child younger than 16 years or an unmarried 16 to 19-

149 year-old in full time non-advanced education'.[18] In this study, for simplicity we refer to benefit units

150 as 'families' and consider children as our main unit of analyses, as matching was done at child-level.

151 Our sample includes children aged 0-15 years and their families who had complete data on all

152 variables included in the model covariates and necessary to estimate the CV (i.e. income and living

153 standards). We excluded all the children from families with more than one disabled child because of

154 difficulties separating the effects of multiple disabled children in the same family (2.7% of total

155 children). In families with only one disabled child who had siblings we excluded the siblings to avoid

156 within-family matching.

157

158

159 **Child mental and physical health disability**

160 In line with the definition of disability included in the Disability Discrimination Act (DDA) 1995 and

161 2005, the FRS defines a child as having a disability if they have a longstanding illness lasting longer

162 than 6 months and affecting their ability to undertake daily activities. Families were asked if their

163 child had any longstanding illness, disability or infirmity. Families responding 'yes' were directed to a

164 set of follow up questions asking which area of the child's life was affected by their disability.

165 Possible answers were: mobility; lifting; manual dexterity; continence (i.e. bladder control);

166 communication (i.e. speech, hearing, or eyesight); memory and learning; recognition of physical

167 danger; physical coordination; other; or, none of these areas. As we were not able to define their

168 disability either as affecting physical or mental health, we excluded children whose family claimed

169 had a disability but subsequently said that none of these areas where affected by disability (3.4% of

170 total children).

171

172 Of these eight disability domains, we assume that memory and learning, and recognition of physical

173 danger can be attributable solely to mental health problems, as they are related to cognitive

174 impairment. We assume all other areas primarily reflect physical health problems [19], but

6

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.

179

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.

189

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 problems [14] similarly, physical health disability can adversely affect mental health [20]. 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.

208

7

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

221

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 weighting [22] with

236 weights representing the proportion of families considering the item a necessity. We calculated the

237 *LSI* as follows:

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

239

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

242 proportion (i.e. weight) of respondents who consider the item desirable, as defined above [22] and *M*

243 is the number of items.

244 A total of 10% of families in our sample had missing data for one or more of these questions. In

245 order to derive a LSI value for these families, we scaled the score they obtained from the questions

246 they answered on the total score they could have obtained if they had could afford each of the items

247 they were asked about ($\sum_{i=1}^{M} w_i$).

248 Finally, from the continuous *LSI* ranging from 0 to 1 (distribution in Figure 1) we defined families with

249 a *LSI*=1 as having 'high living standards', since they could afford each item included, and families with

250 *LSI*<1 as having 'low living standards' as they could not afford one or more of the items. We

251 employed continuous values of the *LSI* to match families using propensity scores and the derived

252 binary variable to conduct stratified analyses (see Data Analysis section).

253

254 **Income**

255 We derived a measure of income accounting for all available resources affecting living standards [23,24],

256 including net income from all sources (i.e. earnings, self-employment, investments, and pensions) as

257 well as from any benefits, including disability benefits, received by the family. Disability and other

258 benefits were included because these affect living standards. We inflated incomes to 2011/12 prices.

259 We did not employ an equivalised measure of income for ease of interpretation of the results (i.e.,

260 our unit of analysis is the family and equivalised income is a measure of income per person);

261 however, in order to account for family composition we included variables indicating number of

262 adults and ages of children in the matching stage of the analyses (see below), in line with previous

263 literature [23,25]. Values of net income are reported 'per week' in the FRS.

264

265 **Other variables**

266 In our analyses we match families with and without a disabled child on a number of socio-

267 demographic and socio-economic characteristics of the families and their children. We included

268 indicators of the child's age (linear term) and gender (male/female); two linear terms for number of

269 dependent children in the family (range 1-8) and number of years of schooling after the age of 18

270 years (i.e. the age at which compulsory education ends in the UK) of the head of the household and

271 their marital status (single/couple); presence of a disabled adult (yes/no), and to account for family

272 wealth, a categorical variable indicating family savings banded in five categories and an indicator of

273 parental (i.e. main respondent's) employment (employed/unemployed/inactive).

274

275 We also included a categorical indicator for survey year and UK Government Office Region (London;

276 South East; Rest of England; Northern Ireland, Wales and Scotland[1]).

277

278 **Data analysis**

279 We described how sample characteristics vary by disability group using cross-tabulations with Chi-

280 Square tests and ANOVAs for categorical and continuous variables, respectively.

281

282 We employed the 'compensating variation' (CV) approach to calculate the cost of child disability,

283 which has been previously used in studies of disability in adults[24] and children.[6] The CV can be

284 defined as the additional income that a family with a disabled child needs to be able to achieve the

285 same living standards of a family that is similar in all other respects but without a disabled child.

286 More details on the theoretical approach can be found in the supplementary material and in Figure

287 S1. We used Propensity Score Matching (PSM) [26,27] to match families according to comparisons A – H

288 and calculate the CV (i.e. the mean income difference). It has been suggested that this approach, by

289 simulating a randomised controlled trial setting, can provide a more unbiased estimate of the

290 income difference than parametric models in observational studies [24].

291

292 We calculated propensity scores (i.e. predicted probabilities) from probit regression models with

293 each of our group allocations in the comparisons defined above (Comparisons A to H) as the

294 outcome (e.g., for Comparison A, participation in Group 1 is coded 1 and Group 6 is coded 0, all

295 other groups are coded as missing). In all models the independent variables were child age and

296 gender, number of children and disabled adults in the family, years of schooling of the main

297 respondent, marital status, family savings, government region and survey year. Additionally, for

298 comparisons F, G, and H we also controlled for areas of disability (other than those defining the

299 Group) as covariates. For all models we calculated areas under the receiver operating characteristic

300 (ROC) to estimate goodness of fit of the model and tested whether the distribution of the covariates

301 was balanced between disabled and non-disabled children. More details on the PSM theoretical

302 approach are in the supplementary material.

303 For each matching pair obtained with this matching approach we calculated the CV and its 95% CI [28].

304 As sensitivity analyses we estimated the compensating variation matching disabled children using

305 3:1 matching (i.e. matching a disabled child to the three closest matches) and using radius matching

---

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

10

306   (defining the radius as a quarter of a the propensity score standard deviation). All our analyses were

307   run using Stata13.[29]

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.

11

340 Among families with high living standards, families of children affected in any of the physical or

341 mental health disability areas or in both the mental health areas, regardless of other areas affected,

342 had lower income compared to families of children without disabilities.

343

344 **Benefits**

345 As seen in Table 3, across all LS groups combined families of children with both mental health

346 disabilities (Group (4)) received the highest amount of weekly benefits (mean value £45.95),

347 followed by those with any mental health disabilities (Group (3); £34.48), and those with any

348 physical health disabilities (Group (5); £26.22) (Table 3). Note these groups included children with

349 both mental and physical disabilities. Children only affected in either or both mental health areas

350 received on average £17.40 per week (Group (1)) whilst those affected in any or all physical health

351 domains only received £10.63 (Group (2)). The amount of benefits received did not vary by LS,

352 reflecting the absence of means testing for disability benefits. None of the children in the non-

353 disabled group were receiving any disability benefits.

354

355

356 **Compensating variation**

357 Over and above their net income (including benefits received) families of children with any (Group 3)

358 or both mental health disabilities (Group 4) needed an additional £49.31 (95% confidence interval

359 (CI): 21.95; 76.67) and £57.56 (95% CI: 17.69; 97.44), respectively, a week in order to achieve the

360 same living standards of similar families without a disabled child (Group 6; Comparisons C and D,

361 respectively), across both levels of LS (Table 4). We also found evidence that families of children

362 with any physical health disability (Group 2) needed an additional £35.86 (95%CI: 13.77; 57.96) per

363 week to meet the living standards of families without disabled children (Group 6; Comparison E).

364 When pooling across living standards, we did not find any other differences in any of the other

365 disability groups.

366

367 When we split the sample by low and high levels of living standards, we found that in some cases

368 families with low LS with a disabled child needed a higher net income to meet the same LS of

369 families without a disabled child. Specifically, we found that families of a child with any mental

370 health disability or both mental health disabilities (with or without physical disabilities) required an

371 extra £59.28 (95%CI: 41.38; 77.18), Group 3, Comparison C) and £81.37 (95%CI: 53.35; 109.38,

372 Group 4, Comparison D) a week more than a family without a disabled child. We also found an

373 income difference, albeit smaller, for families of children with disability affecting physical health

12

374 compared to families of non-disabled children, with the former needing an extra £42.18 (95%CI:

375 26.38; 57.97, Group 5, Comparison E) more a week to achieve the same LS.

376

377 When we compared children affected by disability in any, or both mental health areas and in any

378 physical health areas, regardless of the presence of other disabilities, against children without

379 disabilities and other with physical and mental health disabilities respectively (i.e., in comparisons F -

380 H), we found weak evidence that families of children with both mental health areas affected by

381 disabilities needed an extra £47.45 (95% CI: -0.41; 95.30) more per week to achieve the same LS if in

382 the low LS category (Table 4). Although, we did not find any evidence of differences for the other

383 groups, in particular those with high living standards, there was an indication that children in group 1

384 (any mental health disability with no physical health disability), and group 4 (both mental health

385 disabilities regardless of physical health disabilities) were adequately compensated, although the

386 latter case only among children with greater LS. We did not find evidence of any other group

387 differences.

388

389 *Sensitivity analyses and model checks*

390 The sensitivity analysis using 3:1 matching yielded virtually identical results to those in the main

391 analysis (results not shown). The sensitivity analysis using radius matching also yielded similar

392 results, with some small differences in the size and significance of the compensating variation for

393 some comparisons (Supplemental material and Table S3).

394

395 In our main analysis, for comparisons A to E the distribution of covariates was balanced between

396 treatment groups (i.e. disabled and non-disabled children) with the exception of years of schooling,

397 which in some models was unbalanced. In models F to H, the distribution of covariates was less well

398 balanced in our main analyses. However, in sensitivity analyses all models were balanced, and since

399 the results in the sensitivity analysis were similar to those of the main analysis, this suggests that this

400 is unlikely to have biased our estimates.

401

402 **DISCUSSION**

403 Little evidence exists on the costs borne by families of children affected by mental health disability in

404 the UK. To the best of our knowledge, this is the first UK study aiming to quantify these costs using

405 propensity score matching and a compensating variation approach to estimate cost of mental health

406 disability.

407

13

408 We found no difference in income between families of children with a disability affecting any or all

409 areas associated with mental health problems only and families of non-disabled children. When we

410 allowed for existence of physical health comorbidities, we found that these families needed an

411 additional £49.31 per week over and above existing net incomes (including disability benefits)

412 compared to families of non-disabled children to achieve the same living standards, with an even

413 greater amount needed if children's disability affected both mental health domains (£57.56). These

414 difference were, again, even greater for families with low living standards (£59.28 and £81.37,

415 respectively). In comparison, families with children affected by physical health had a positive, but

416 smaller in magnitude, CV (£35.86), which was, similarly to what was observed for mental health

417 disability, higher among families with low LS (£42.18). When we tested the relative impact of mental

418 and physical health on the CV, by allowing our comparator group to have disabilities in the opposite

419 domains of the one under investigation, we found a positive, though weak, CV for children affected

420 in both mental health disabilities who live in families with low LS (£47.45). These findings suggest

421 that all these groups are undercompensated by the benefits system.

422

423 These results suggest that mental health disabilities in childhood are associated with substantial

424 costs which need to be borne by their families. In other words, families of children with mental

425 health disabilities need to have higher income in order to achieve the same living standards of a

426 family without a disabled child. These costs appear to be higher when there are co-occurring mental

427 and physical disabilities, possibly an indicator of severity of the condition, and for more economically

428 deprived families. As benefits were already included in our income measure, the compensating

429 variation represents the amount by which families appear to be undercompensated under current

430 benefit arrangements.

431

432 Our findings on the cost of child disability are lower from those found by Dobson and colleagues

433 estimating the cost of child disability to the family at £100 per week [4,5]. Compared to these studies,

434 we also found that under-compensation occurred to a lower extent, in the range of £8-£15 and only

435 for deprived families with children with mental health disabilities, as opposed to £30-£80 [4] and £24 [5].

436 One reason for this difference could be that these studies employed convenience sampling (i.e.

437 selecting children with more severe disabilities and living in more deprived settings) and different

438 definitions of disability, which did not clearly distinguish between mental and physical health.

439

440 This study had several strengths. It employed a large and rich dataset representative of the UK

441 population. The FRS also makes use of the disability domains employed in the DDA to define areas

14

442   affected by disability, which makes it consistent with definitions applicable to policy settings. We

443   also employed a novel approach which allowed us to match families not only based on their

444   propensity scores distribution, but also on the values of living standards with exact matching to the

445   first decimal digit. Nevertheless, several limitations should be accounted for. First, we could only

446   give an approximate definition of mental and physical health disability, knowing that areas which we

447   have considered as physical health could be affected as a result of mental health disability only.

448   Nevertheless, our approach represents a first attempt at both costing the impact of mental health

449   disabilities on families and disentangling the relative effect of mental and physical health disability.

450   We were also unable to explore the effect of severity of disability or of different types of disabilities

451   given the nature of the available variables. Future studies should attempt to include specific

452   diagnoses, perhaps including sub-clinical presentations as separate categories in order to account for

453   varying degrees of severity. A total of 10% had missing data on LS measures; although we calculated

454   our index re-scaling the latter to the number of questions each family had answered, it is not

455   possible to rule out the possibility that under/over-estimation of the LSI value for these families

456   could have occurred. Moreover, our living standards measure provides an indication of what goods

457   the family can afford, but not of their quality. However, values of mean income by low/high LSI

458   seemed to suggest that the latter adequately describes the intended groups. The sample size for

459   some of our disability definitions was small meaning that we could have incurred in type II error and

460   failed to observe an income difference when indeed there was one. Due to the cross-sectional

461   nature of the study, it was not possible to estimate the CV in the absence of benefits, as the latter

462   contribute, when received, to the LS achieved by the family. This approach would have given a

463   clearer indication of the income difference between families with and without a disabled child. In

464   fact, based on our estimates, we are not able to tell, if we do not observe a difference in income,

465   whether an actual difference would have occurred in the absence of the benefits system. By

466   comparing the CV to the amount of benefits received, we however attempted to estimate whether

467   the family was currently over or undercompensated. Our propensity score model could have been

468   improved by including more precise indications of family structure and parental education, as well as

469   a greater number of family and child characteristics, such as a clearer specification of parental

470   physical or mental health disability. Future studies should endeavor to be more inclusive in order to

471   improve model prediction. We used data covering the financial years 2004/05 to 2011/12, which are

472   not the most current available. This choice was motivated by a change in the definition of disability

473   in 2012/13 to include a separate mental health domain. Although using post-2012/13 data would

474   have resulted in a clearer definition of mental health and more recent estimates, we would not have

475   had enough statistical power for our analyses. Nevertheless, we found that the amount of DLA

476 received across disability groups in our sample was consistent with 2011/12 and current DLA figures,

477 suggesting that our findings bear relevance for current policy. Finally, some of our families,

478 especially in adjacent years, could have been recruited in more than one wave of FRS data collection,

479 meaning that our samples might have not been totally independent.[30] However, given the large size

480 of our sample we believe that it is unlikely that this could have biased our results.

481

482 In conclusion, we found that mental health in childhood and adolescence is associated with high

483 costs, which need to be borne by the family. Our findings indicate that families of children from

484 more disadvantaged backgrounds are currently undercompensated by the disability benefits system.

485 Based on these findings we suggest that mental health should be better defined as a criterion for

486 receiving benefits and that the amount of disability benefits that a family is entitled to receive are

487 subject to means testing, so that families from more deprived socio-economic backgrounds could be

488 entitled to higher benefits amounts.

489 **Acknowledgments**

493

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495 https://www.ukdataservice.ac.uk/

496

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498 wrote manuscript. Maria Melnychuk: Developed research question and study design, analyzed data,

499 and contributed to manuscript revision. Steve Morris: Developed research question and study

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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Table 1: sample characteristics

	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)
					Child disability		
Group (comparator)		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%)

20

Table 1 (continued)

			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)**
Group		6	1 (vs. 6)	2 (vs. 6)	3 (vs. 6)	4 (vs. 6)	5 (vs. 6)
Total savings			*p<0.0001*	*p<0.0001*	*p<0.0001*	*p<0.0001*	*p<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			*p<0.0001*	*p<0.0001*	*p<0.0001*	*p<0.0001*	*p<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) *p<0.0001*	8.48(4.30) *p<0.0001*	9.71(3.69) *p<0.0001*	9.42(3.64) *p<0.0001*	8.88(4.03) *p<0.0001*
Age main respondent left full time education	18.08(2.15)	18.10(2.17)	18.53(1.74) *p<0.0001*	18.71(1.73) *p<0.0001*	18.64(1.77) *p<0.0001*	18.71(1.96) *p<0.0001*	18.70(1.78) *p<0.0001*
Number of dependent children in household	2.19(1.00)	2.19(0.99)	2.15(1.07) *p=0.41*	2.12(0.99) *p=0.034*	2.14(1.01) *p=0.035*	2.13(1.01) *p=0.05*	2.11(0.98) *P=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

21

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)

22

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

23

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≤0.05 *0.1>p>0.05

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

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Distribution of the living standards index
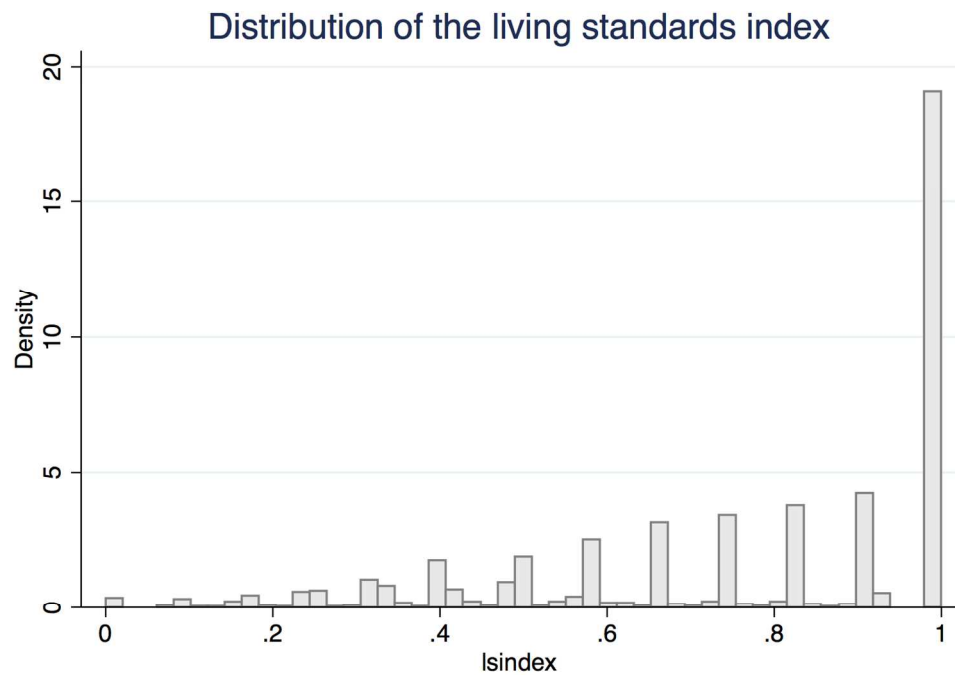

Figure 1. Distribution of living standard index

139x101mm (300 x 300 DPI)

1   **Table S1: Definitions of disability groups**

2

3

Disability Domain	Group 1	Group 2	Group 3	Group 4	Group 5	Group 6
Physical health						
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**
Mental health						
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**

4

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

9

10   •   Group 1: Any (either or both domains) mental disability (no physical disability);

11   •   Group 2: Any physical disability (no mental disability) (group 1 & 2 are mutually exclusive);

12   •   Group 3: Any mental disability (either domains, with or without physical disability);

13   •   Group 4: Both mental disabilities (both domains, with or without physical disability);

14   •   Group 5: Any physical disability (with or without mental disability);

15   •   Group 6: No disability.

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Table S2: Living standard questions in the Family Resources Survey

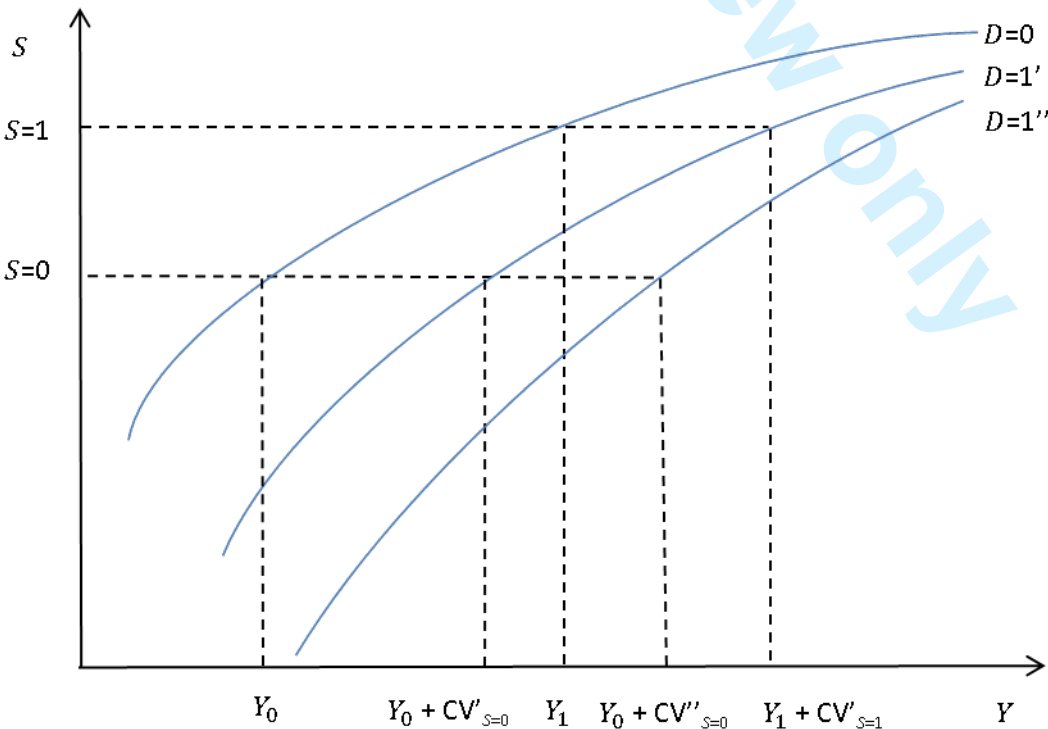| Question	Included	Rationale
Do you (and your family) have a holiday away from home for at least one week a year, whilst not staying with relatives at their home?	YES	
Do you have friends or family around for a drink or meal at least once a month?	NO	Not directly relevant to children's living standards
Do you have two pairs of all-weather shoes for (all members of family)	NO	Depending on disability, might not be applicable to all chidlren
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

18

2

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)

21 and the living standards (S, on the vertical axis) of families without a disabled child ($D = 0$) and with a

22 disabled child ($D = 1'$). We assume that: (i) the curves are upward sloping from left to right and convex, due

23 to diminishing returns to S as Y increases; and, (ii) $D = 1'$ lies below $D = 0$ though they tend towards one

24 another at higher levels of Y. At a given level of living standards such as $S = 0$ the CV is the difference

25 between the income that a family with a disabled child ($D = 1'$) needs to have (= $Y_0 + CV'_{S=0}$) compared to

26 the income of a family without a disabled child ($D = 0$) (=Y_0) to achieve the same living standard ($S = 0$).

27 Based on our assumptions this difference will decrease at higher levels of living standards. For instance, the

28 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

29 $Y_0 + CV'_{S=0}$.

30

31 We hypothesize that families of children with more severe disabilities incur higher costs to achieve the

32 same living standards as families with less severely disabled children. Suppose $D = 1''$ denotes more severe

33 disabilities than $D = 1'$; this is shown in Figure 1 as curve $D = 1''$ lying below curve $D = 1'$. In this case the CV

34 for $S = 0$, corresponds to $Y_0 + CV''_{S=0}$, which is greater than $Y_0 + CV'_{S=0}$.

35

36 In order to employ this approach to investigate our aims, three measures are needed: 1) a definition of

37 child mental and physical health disability; 2) a measure of living standards (LS); and 3) a measure of

38 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:

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

We matched families using nearest neighbor 1:1 matching within a caliper, defined to be one quarter of the standard deviation of the propensity score [25]. 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:

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

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.

4

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

5

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

6

(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.

105

106

7

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

	Item No	Recommendation	
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1-2
		(*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	1, 5
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*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up	
		Case-control study—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	
		Cross-sectional study—Give the eligibility criteria, and the sources and methods of selection of participants	5-6
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed	
		Case-control study—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-
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-
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-
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	12,
		(*b*) Describe any methods used to examine subgroups and interactions	N/A
		(*c*) Explain how missing data were addressed	10
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed	
		Case-control study—If applicable, explain how matching of cases and controls was addressed	
		Cross-sectional study—If applicable, describe analytical methods taking account of sampling strategy	
		(*e*) Describe any sensitivity analyses	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) *Cohort study*—Summarise follow-up time (eg, average and total amount)	11
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time	
		Case-control study—Report numbers in each exposure category, or summary measures of exposure	
		Cross-sectional study—Report numbers of outcome events or summary measures	11-17
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	11-18
		(*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
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
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.