BMJ Open

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

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2017-018729
Article Type:	Research
Date Submitted by the Author:	17-Jul-2017
Complete List of Authors:	Solmi, Francesca; University College London, Division of Psychiatry Melnychuk, Mariya; University College London , Department of applied health research Morris, Stephen; University College London, Department of Applied Health Research
Primary Subject Heading:	Mental health
Secondary Subject Heading:	Health economics, Epidemiology
Keywords:	Child disability, living standards, compensating variation, propensity score matching, disability benefits

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

Francesca Solmi, PhD[1,2]; Mariya Melnychuk, PhD[1]; Stephen Morris, PhD[1]

[1]*Department of Applied Health Research, University College London, London, UK*

[2]*Division of Psychiatry, University College London, London, UK*

Corresponding author:

Dr Francesca Solmi,
UCL Division of Psychiatry
6th Floor, Wing B, Maple House
149 Tottenham Court Road,
London W1T 7NF

E: francesca.solmi@ucl.ac.uk
P: 02076799643 (ext: 09643)

Keywords: Child disability; living standards; disability benefits; compensating variation; propensity score matching.

Competing interests:

The authors declare no competing interests.

Funding

This work was supported by the Policy Research Unit in the Health of Children, Young People and Families, which is funded by the Department of Health Policy Research Programme. This is an independent report commissioned and funded by the Department of Health. The views expressed are not necessarily those of the Department.

ABSTRACT

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

Design: Repeated cross-sectional survey.

Setting: UK general population

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

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

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

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

Strengths and Limitations

- Strengths of this study are the use of: (i) large and rich dataset representative of the UK population; (ii) disability domains employed in the Disability Discrimination Act (DDA) consistent with definitions applicable to policy settings; and, (iii) novel analytical approach based on propensity score matching.
- Limitations of this study are: (i) its cross-sectional design; (ii) difficulties in disentangling physical and mental health disabilities (which are often co-occurring); and, (iii) data limitations making it problematic to account for severity of disability and to measure living standards.

INTRODUCTION

Families of children suffering from chronic conditions and physical and mental health disabilities incur significantly higher costs than those of their healthy counterparts.[1–5] These costs are primarily accounted for by more frequent visits to inpatient and outpatient departments and by greater use of prescribed drugs,[1–3] although evidence also suggests that the need to provide or secure informal care adds to the financial burden of child disability for these families.[4,5] Previously, UK studies have estimated the cost of having a disabled child at about £79-£100 per week[4] and that under the benefits arrangements at the time (1997) families of disabled children were undercompensated by £30-£80 per week [4] and by £28 in 2001.[5] More recent evidence has estimated that in the UK families of severely disabled children require up to an additional £79 per week to be able to meet the same living standards of those without disabled children, a figure that does not find correspondence in disability benefits that these families receive (i.e., up to £71 per week).[6]

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

A socio-economic gradient exists in the distribution of child mental health disorders [11–13]. In the 2004 B-CAMHS, prevalence of diagnosable child mental health conditions was higher among single-parent (15.6%) compared to married or co-habiting (7.7%) households; among families with low (16.1%) compared to high (5.3%) income; and among families whose parents had no academic qualifications (17.0%) compared to those with university degrees (4.4%) [14]. Evidence exists that life adversities are a risk factor for the onset of mental health conditions as well as that mental health problems of the child can lead to family breakdown and unemployment [14].

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

engage in risk-behaviours such as alcohol and drug use with detrimental effects on employment prospects [15]. Similarly, childhood experience of economic hardship can result in long-term adverse health outcomes via the persistence of lower socio-economic status [15].

Since 1992, in the UK, families of children affected by disability have been eligible to receive a non-means-tested weekly Disability Living Allowance (DLA).[16] The rationale for these benefits is that they "*may help with the extra costs of looking after a child who: is under 16; has difficulties walking or needs more looking after than a child of the same age who doesn't have a disability*".[16] The amount of benefits that the family is entitled to receive largely depends on the severity of the child's condition, which is determined by the disability service centre often in conjunction with external assessments. In 2014, under the care component of DLA, children could receive either £21.80 (if they needed a little help during the day or night), £55.10 (if they needed frequent supervision), or £82.30 (if they needed constant help day and night, or were terminally ill) per week. Under the mobility component of DLA, children were entitled to receive between £21.80 (if they could walk but needed supervision outdoors) and £57.45 (if they could not walk, if walking represented a health risk, or if they were blind) per week.

Previous UK studies have shown that families of disabled children incur high costs, but were however unable to attribute these extra expenditures to either physical or mental health disability, which has been shown to inflict a substantial economic burden in other settings.[2,3] In the absence of literature exploring the cost of child mental health disability to families, and the rising prevalence of these problems, the aims of this study are to: (1) investigate the cost to families of having a child with a mental health disability; (2) compare the costs of mental health versus physical health disability; and, (3) examine how these costs vary by economic deprivation. We use repeated cross-sectional data from the Family Resources Survey (2004/05 – 2011/12).

MATERIALS AND METHODS

Sample

We employed data from eight consecutive rounds of data collection from the Family Resources Survey (FRS) covering the financial years 2004/05 to 2011/12. The FRS is a repeated cross-sectional survey of private households in the UK undertaken by the Department of Work and Pensions (DWP) with the aim of collecting data on the financial and social circumstances of private households. Although representativeness of the older age groups within the population might be limited in FRS

due to the focus on private households (nursing and retirement homes are not included), the overall sample, used in this study, is representative of the UK population [18], and our focus on families with children under 16 years of age means this is unlikely to introduce a bias.

Our sample includes all children aged 0-15 years and their families with complete data on all variables included in the model covariates and necessary to estimate the CV (i.e. income and living standards). We excluded families with more than one disabled child because of difficulties separating the effects of multiple disabled children in the same family (2.7% of total children).

Child mental and physical health disability

In line with the definition of disability included in the Disability Discrimination Act (DDA) 1995 and 2005, the FRS defines a child as having a disability if they have a longstanding illness lasting longer than 6 months and affecting their ability to undertake daily activities. Families were asked if their child had any longstanding illness, disability or infirmity. Families responding 'yes' were directed to a set of follow up questions asking which area of the child's life was affected by their disability. Possible answers were: mobility; lifting; manual dexterity; continence (i.e. bladder control); communication (i.e. speech, hearing, or eyesight); memory and learning; recognition of physical danger; physical coordination; other; or, none of these areas. As we were not able to define their disability either as affecting physical or mental health, we excluded children whose family claimed had a disability but subsequently said that none of these areas where affected by disability (3.4% of total children).

Of these eight disability domains, we assume that memory and learning, and recognition of physical danger can be attributable solely to mental health problems, as they are related to cognitive impairment. We assume all other areas primarily reflect physical health problems [19], but acknowledge these domains could also be affected by, or affect, mental health status. For ease of explanation, we will hereafter refer to memory and learning, and recognition of physical danger as 'mental health' disability areas, and mobility, lifting, manual dexterity, continence, communication, and physical coordination as 'physical health' disability areas.

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

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

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

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

- Comparison A: Group 1 versus Group 6;
- Comparison B: Group 2 versus Group 6;
- Comparison C: Group 3 versus Group 6;
- Comparison D: Group 4 versus Group 6;
- Comparison E: Group 5 versus Group 6.

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

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

- Comparison F: Group 3 versus Group 6 and Group 2;

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

Living standards

Material deprivation is measured in the FRS through a set of 21 questions asking whether the family: (i) can afford and has; (ii) would like to have, but cannot afford; or (iii) can afford, but does not want a number of goods previously identified as necessities by families without (10 questions) and with (11 questions) children [21]. We employed a sub-set of these questions (M= 12) asked to the whole sample at each survey wave included in our study and developed a living standards index (*LSI*) using prevalence weighting [22] with weights representing the proportion of families considering the item a necessity. We calculated the *LSI* as follows:

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

In Eq.(1), x_i is a binary variable indicating whether the family can afford each item (1='yes, can afford and has it'; or 'yes, can afford, but does not want', 0=would like to have, but cannot afford), w_i is the proportion (i.e. weight) of respondents who consider the item desirable, as defined above [22] and *M* is the number of items.

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

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

Income

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

standards is dependent upon their receipt. We inflated incomes to 2011/12 prices. We did not employ an equivalised measure of income for ease of interpretation of the results (i.e., our unit of analysis is the benefit unit and equivalised income is a measure of income per person); however, in order to account for family composition we included variables indicating number of adults and ages of children in the matching stage of the analyses (see below), in line with previous literature [23,24]. Values of net income are reported 'per week' in the FRS.

Other variables

In our analyses we match families with and without a disabled child on a number of socio-demographic and socio-economic characteristics of the families and their children. We included indicators of the child's age (linear term) and gender (male/female); two linear terms for number of dependent children in the family (range 1-8) and number of years of schooling after the age of 18 years (i.e. the age at which compulsory education ends in the UK) of the head of the household and their marital status (single/couple); presence of a disabled adult (yes/no), and to account for family wealth, a categorical variable indicating family savings banded in five categories.

We also included a categorical indicator for survey year and UK Government Office Region (London; South East; Rest of England; Northern Ireland, Wales and Scotland[1]).

Data analysis

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

We employed the 'compensating variation' (CV) approach to calculate the cost of child disability, which has been previously used in studies of disability in adults [17]. The CV can be defined as the additional income that a family with a disabled child needs to be able to achieve the same living standards of a family that is similar in all other respects but without a disabled child. More details on the theoretical approach can be found in the supplementary material. We used Propensity Score Matching (PSM) [25,26] to match families according to comparisons A – F and calculate the CV (i.e. the mean income difference). It has been suggested that this approach, by simulating a randomised controlled trial setting, can provide a more unbiased estimate of the income difference than parametric models in observational studies [17].

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

We calculated propensity scores (i.e. predicted probabilities) from multivariate probit regression models with each of our group allocations in the comparisons defined above (Comparisons A to H) as the outcome (e.g., for Comparison A, participation in Group 1 is coded 1 and Group 6 is coded 0, all other groups are coded as missing). In all models the independent variables were child age and gender, number of children and disabled adults in the family, years of schooling of the main respondent, marital status, family savings, government region and survey year. Additionally, for comparisons F, G, and H we also controlled for areas of disability (other than those defining the Group) as covariates. For all models we calculated areas under the receiver operating characteristic (ROC) to estimate goodness of fit of the model. More details on the PSM theoretical approach are in the supplementary material.

For each matching pair obtained with this matching approach we calculated the CV and 95% CI [28]. Finally, we compared the CV with the mean (SD) amount of disability benefits received by each group. All our analyses were run using Stata13.[29]

RESULTS

Sample characteristics

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

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

Child disability

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

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

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

Compensating variation

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

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

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

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

Benefits

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

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

DISCUSSION

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

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

additional £33 per week compared to families of non-disabled children to achieve the same living standards. This difference was even greater for families with low living standards (£42). When we compared children with both mental health areas affected by disability as well as possible comorbid conditions related to physical health we did not find an overall difference in income, however we found a high and positive CV of approximately £61 for children of families with low LS. In comparison, families in the same LS group, with children affected by physical health had a positive, but smaller in magnitude, CV (£25). When we tested the relative impact of mental and physical health on the CV, by allowing our comparator group to have disabilities in the opposite domains of the one under investigation, we found a positive and significant CV for children affected in both mental health disabilities who live in families with low LS (£53).

We compared these amounts against benefits received, in order to investigate if these families were adequately compensated for the costs associated with their child's disability. We found that overall children with any mental health disabilities were adequately compensated (CV=£33, mean benefits=£34) and so were families of children with physical health disabilities with low LS (CV=£25, mean benefits= £26). We also found, however, that families of children with any or both mental health disabilities with low LS were undercompensated under the current benefit scheme (any mental health: CV=£42, mean benefit=£34; both mental health: CV=£61, mean benefits=£46).

These results suggest that mental health disabilities in childhood are associated with substantial costs, which need to be borne by their families. In other words, families of children with mental health disabilities need to have higher income in order to achieve the same living standards of a family without a disabled child. These costs appear to be higher when there are co-occurring mental and physical disabilities, possibly an indicator of severity of the condition, and for more economically deprived families. These families also appear to be undercompensated under current benefit arrangements.

Our findings on the cost of child disability are lower from those found by Dobson and colleagues estimating the cost of child disability to the family at £100 per week [4,5]. Compared to these studies, we also found that undercompensation occurred to a lower extent, in the range of £8-£15 and only for deprived families with children with mental health disabilities, as opposed to £30-£80 [4] and £24 [5]. One reason for this difference could be that these studies employed convenience sampling (i.e. selecting children with more severe disabilities and living in more deprived settings) and different definitions of disability, which did not clearly distinguish between mental and physical health.

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

In conclusion, we found that mental health in childhood and adolescence is associated with high costs, which need to be borne by the family. Our findings indicate that families of children from more disadvantaged backgrounds are currently undercompensated by the disability benefits system. Based on these findings we suggest that mental health should be better defined as a criterion for receiving benefits and that the amount of disability benefits that a family is entitled to receive are subject to means testing, so that families from more deprived socio-economic backgrounds could be entitled to higher benefits amounts.

Acknowledgments

The authors would like to thank members of the Policy Research Unit for the health of children, young people and families: Terence Stephenson, Catherine Law, Amanda Edwards, Ruth Gilbert, Helen Roberts, Cathy Street, Russell Viner and Miranda Wolpert.

Authors' contributions

Francesca Solmi: Contributed to designing research question and study designed, analyzed data, wrote manuscript.

Maria Melnychuk: Contributed to designing research question and study designed, analyzed data, contributed to manuscript revision.

Steve Morris: Contributed to designing research question and study designed, contributed to manuscript revision, supervised data analyses and the overall project.

BIBLIOGRAPHY

1. Newacheck PW, Inkelas M, Kim SE. Health Services Use and Health Care Expenditures for Children With Disabilities. *Pediatrics*. 2004;114(1).
2. Ringel JS, Sturm R. National estimates of mental health utilization and expenditures for children in 1998. *J Behav Health Serv Res*. 2001;28(3):319-333.
3. Chan E, Zhan C, Homer CJ, CC L, KN S, R P. Health Care Use and Costs for Children With Attention-Deficit/Hyperactivity Disorder. *Arch Pediatr Adolesc Med*. 2002;156(5):504. doi:10.1001/archpedi.156.5.504.
4. Dobson B, Middleton S. *Paying to Care: The Cost of Childhood Disability*. York, UK; 1998.
5. Dobson B, Middleton S, Beardsworth A. *The Impact of Childhood Disability on Family Life*. York, UK; 2001.
6. Melnychuck M, Solmi F, Morris S. Using compensating variation to measure the costs of child disability in the UK. *Eur J Heal Econ*. 2017.
7. Merikangas KR, Nakamura EF, Kessler RC. Epidemiology of mental disorders in children and adolescents. *Dialogues Clin Neurosci*. 2009;11(1):7-20.
8. WHO. *Caring for Children and Adolescents with Mental Disorders. Setting WHO Directions*. Geneva; 2003.
9. Foundation N. *Social Trends and Mental Health: Introducing the Main Findings.* London, UK; 2013.
10. Murphy M, Fonagy P. Chapter 10: Mental Health Problems in Children and Young People, Our Children Deserve Better: Prevention Pays. In: *Annual Report of the Chief Medical Officer 2012*. ; 2012.
11. Emerson E, Hatton C. *The Mental Health of Children and Adolescents with Learning Disabilities in Britain*. Lancaster, UK; 2007.
12. Meltzer H, Gatward R, Goodman R, Ford T. *The Mental Health of Children and Adolescents in Great Britain*. London, UK; 2000.
13. van Oort FVA, van der Ende J, Wadsworth ME, Verhulst FC, Achenbach TM. Cross-national comparison of the link between socioeconomic status and emotional and behavioral problems in youths. *Soc Psychiatry Psychiatr Epidemiol*. 2010;46(2):167-172. doi:10.1007/s00127-010-0191-5.
14. Green H, McGinnity A, Meltzer H, Ford T, Goodman R. *Mental Health of Children and Young People in Great Britain, 2004*. Lodon, UK; 2004.
15. Knapp M, Iemmi V. The economic case for better mental health. In: *Annual Report of Chief Medical Officer 2013. Public Mental Health Priorities: Investing in the Evidence*. London:

Department of Health; 2013.

16. Disability Living Allowance (DLA) for Children. https://www.gov.uk/disability-living-allowance-children/overview. Published 2015. Accessed July 17, 2015.
17. Hancock R, Morciano M, Pudney S. Nonparametric estimation of a compensating variation: the cost of disability. *ISER Work Pap Ser*. December 2013.
18. Evans D. *Family Resources Survey. United Kingdom, 2010/11*. London, UK; 2012.
19. Office for Disability Issues. *Equality Act 2010 Guidance. Guidance on Matters to Be Taken into Account in Determining Questions Relating to the Definition of Disability*.; 2010.
20. Kieling C, Baker-Henningham H, Belfer M, et al. Child and adolescent mental health worldwide: evidence for action. *Lancet*. 2011;378(9801):1515-1525. doi:10.1016/S0140-6736(11)60827-1.
21. McKay S, Collard S. *Developing Deprivation Questions for the Family Resources Survey*. Vol 13.; 2004.
22. Hallerod B. The Truly Poor: Direct and Indirect Consensual Measurement of Poverty in Sweden. *J Eur Soc Policy*. 1995;5(2):111-129. doi:10.1177/095892879500500203.
23. Morciano M, Hancock R, Pudney S. Disability Costs and Equivalence Scales in the Older Population in Great Britain. *Rev Income Wealth*. February 2014:n/a-n/a. doi:10.1111/roiw.12108.
24. Zaidi A, Burchardt T. COMPARING INCOMES WHEN NEEDS DIFFER: EQUIVALIZATION FOR THE EXTRA COSTS OF DISABILITY IN THE U.K. *Rev Income Wealth*. 2005;51(1):89-114. doi:10.1111/j.1475-4991.2005.00146.x.
25. Rosenbaum PR, Rubin DB. The central role of the propensity score in observational studies for causal effects. *Biometrika*. 1983;70(1):41-55. doi:10.1093/biomet/70.1.41.
26. Heckman JJ, Ichimura H, Todd P. Matching as an econometric evaluation estimator. *Rev Econ Stud*. 1998;65:261-294.
27. Sianesi B. Implementing Propensity Score Matching Estimation with STATA. In: *UK Stata Users Group, VII Meeting*. London, UK; 2001.
28. Abadie A, Imbens GW. Large Sample Properties of Matching Estimators for Average Treatment Effects. *Econometrica*. 2006;74(1):235-267. doi:10.1111/j.1468-0262.2006.00655.x.
29. StataCorp. Stata Statistical Software: release 13. 2013.

TABLES and FIGURES

Figure 1. Distribution of LSI

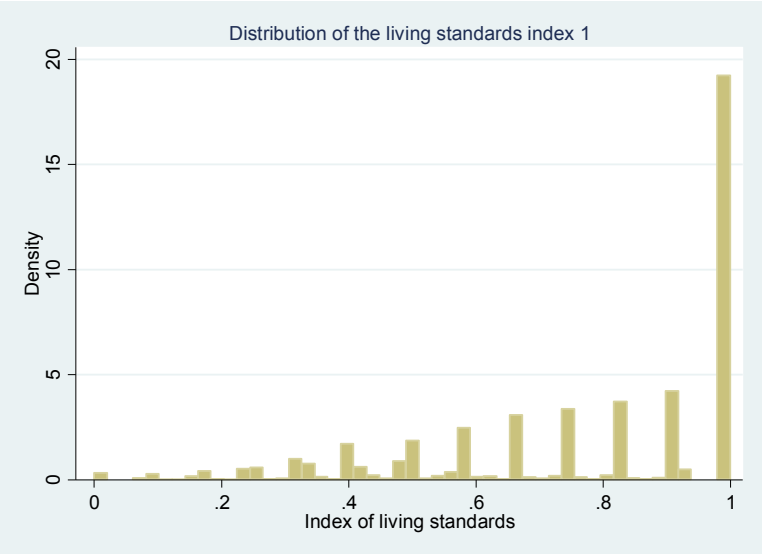


Table 1: sample characteristics

		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	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%)

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**	**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

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

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

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

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

Table 3: Compensating variation

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

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

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

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

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

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

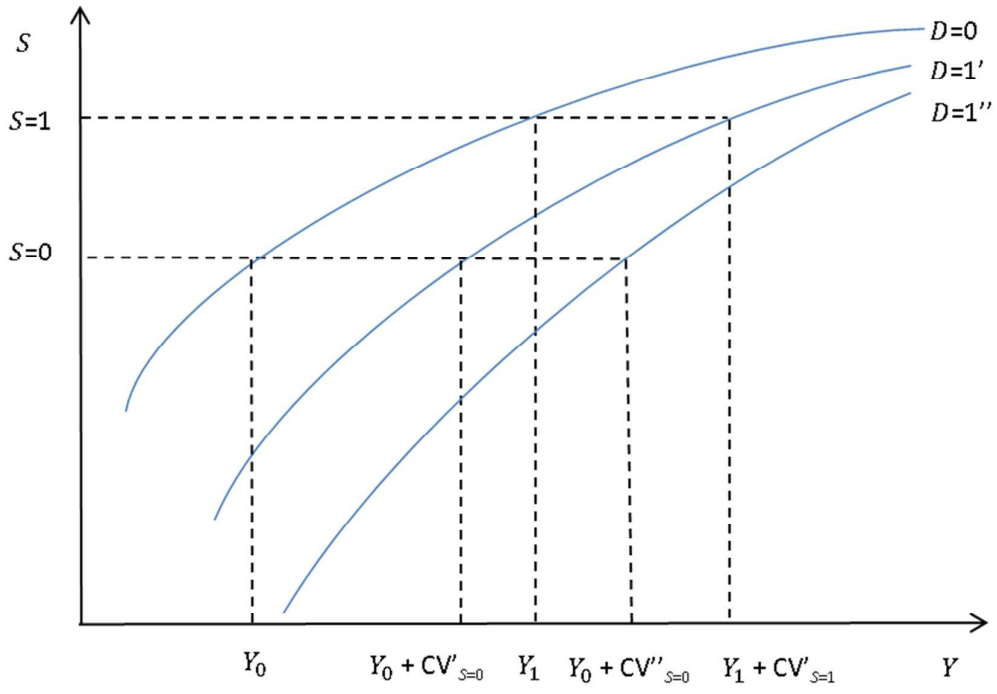
Theoretical approach: Compensating Variation

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

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

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

Figure S1: Compensating variation



Theoretical Approach: Propensity Score Matching

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

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

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

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

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

	Item No	Recommendation	PAGE
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	2
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	4-5
Objectives	3	State specific objectives, including any prespecified hypotheses	5
Methods			
Study design	4	Present key elements of study design early in the paper	6
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	6
Participants	6	(*a*) *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	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	6-9
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	6-9
Bias	9	Describe any efforts to address potential sources of bias	14
Study size	10	Explain how the study size was arrived at	6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	6-9
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	9-10
		(*b*) Describe any methods used to examine subgroups and interactions	~~N/A~~ 9-1
		(*c*) Explain how missing data were addressed	9-10
		(*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	N/A
		(*e*) Describe any sensitivity analyses	N/A

Continued on next page

Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	10
		(b) Give reasons for non-participation at each stage	N/A
		(c) Consider use of a flow diagram	N/A
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	10
		(b) Indicate number of participants with missing data for each variable of interest	10
		(c) *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	12-13
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	14
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	14
Generalisability	21	Discuss the generalisability (external validity) of the study results	14
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	1

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

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

BMJ Open

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

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2017-018729.R1
Article Type:	Research
Date Submitted by the Author:	22-Sep-2017
Complete List of Authors:	Solmi, Francesca; University College London, Division of Psychiatry Melnychuk, Mariya; University College London , Department of applied health research Morris, Stephen; University College London, Department of Applied Health Research
Primary Subject Heading:	Mental health
Secondary Subject Heading:	Health economics, Epidemiology
Keywords:	Child disability, living standards, compensating variation, propensity score matching, disability benefits

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

Francesca Solmi, PhD[1,2]; Mariya Melnychuk, PhD[1]; Stephen Morris, PhD[1]

[1]*Department of Applied Health Research, University College London, London, UK*

[2]*Division of Psychiatry, University College London, London, UK*

Corresponding author:

Dr Francesca Solmi,
PsyLife Lab, UCL Division of Psychiatry
6th Floor, Wing B, Maple House
149 Tottenham Court Road,
London W1T 7NF

E: francesca.solmi@ucl.ac.uk
P: 02076799643 (ext: 09643)

Keywords: Child disability; living standards; disability benefits; compensating variation; propensity score matching.

Competing interests:

The authors declare no competing interests.

Funding

This work was supported by the Policy Research Unit in the Health of Children, Young People and Families, which is funded by the Department of Health Policy Research Programme. This is an independent report commissioned and funded by the Department of Health. The views expressed are not necessarily those of the Department.

ABSTRACT

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

Design: Repeated cross-sectional survey.

Setting: UK general population

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

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

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

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

Strengths and Limitations

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

INTRODUCTION

Families of children suffering from chronic conditions and physical and mental health disabilities incur significantly higher costs than those of their healthy counterparts.[1–5] These costs are primarily accounted for by more frequent visits to inpatient and outpatient departments and by greater use of prescribed drugs,[1–3] although evidence also suggests that the need to provide or secure informal care adds to the financial burden of child disability for these families.[4,5] Previously, UK studies have estimated the cost of having a disabled child at about £79-£100 per week[4] and that under the benefits arrangements at the time (1997) families of disabled children were undercompensated by £30-£80 per week [4] and by £28 in 2001.[5] More recent evidence has estimated that in the UK families of severely disabled children require up to an additional £79 per week to be able to meet the same living standards of those without disabled children.[6]

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

A socio-economic gradient exists in the distribution of child mental health disorders [11–13]. In the 2004 B-CAMHS, prevalence of diagnosable child mental health conditions was higher among single-parent (15.6%) compared to married or co-habiting (7.7%) households; among families with low (16.1%) compared to high (5.3%) income; and among families whose parents had no academic qualifications (17.0%) compared to those with university degrees (4.4%) [14]. Evidence exists that life adversities are a risk factor for the onset of mental health conditions as well as that mental health problems of the child can lead to family breakdown and unemployment [14].

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

prospects [15]. Similarly, childhood experience of economic hardship can result in long-term adverse health outcomes via the persistence of lower socio-economic status [15].

Since 1992, in the UK, families of children affected by disability have been eligible to receive a non-means-tested weekly Disability Living Allowance (DLA).[16] The rationale for these benefits is that they "*may help with the extra costs of looking after a child who: is under 16; has difficulties walking or needs more looking after than a child of the same age who doesn't have a disability*".[16] The amount of benefits that the family is entitled to receive largely depends on the severity of the child's condition, which is determined by the disability service centre often in conjunction with external assessments. In 2017, under the care component of DLA, children could receive either £22 (if they needed a little help during the day or night), £55.65 (if they needed frequent supervision), or £83.10 (if they needed constant help day and night, or were terminally ill) per week. Under the mobility component of DLA, children were entitled to receive between £22 (if they could walk but needed supervision outdoors) and £58 (if they could not walk, if walking represented a health risk, or if they were blind) per week.

Previous UK studies have shown that families of disabled children incur high costs, but were however unable to attribute these extra expenditures to either physical or mental health disability, which has been shown to inflict a substantial economic burden in other settings.[2,3] In the absence of literature exploring the cost of child mental health disability to families, and the rising prevalence of these problems, the aims of this study are to: (1) investigate the cost to families of having a child with a mental health disability; (2) compare the costs of mental health versus physical health disability to assess whether such stratification is needed when considering disability benefits; and, (3) examine how these costs vary by economic deprivation in order to assess whether means testing of DLA should be considered.

MATERIALS AND METHODS

Sample

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

focus on private households (nursing and retirement homes are not included), the overall sample, used in this study, is representative of the UK population [17], and our focus on families with children under 16 years of age means this is unlikely to introduce a bias.

In the FRS households are defined as 'a single person or group of people living at the same address who either share one meal a day or share the living accommodation, i.e. a living room'. Each household may include one or more benefit unit, 'a single adult or couple living as married and any dependent children'. A dependent child is a 'child younger than 16 years or an unmarried 16 to 19-year-old in full time non-advanced education'.[18] In this study, for simplicity we refer to benefit units as 'families' and consider children as our main unit of analyses, as matching was done at child-level. Our sample includes children aged 0-15 years and their families who had complete data on all variables included in the model covariates and necessary to estimate the CV (i.e. income and living standards). We excluded all the children from families with more than one disabled child because of difficulties separating the effects of multiple disabled children in the same family (2.7% of total children). In families with only one disabled child who had siblings we excluded the siblings to avoid within-family matching.

Child mental and physical health disability

In line with the definition of disability included in the Disability Discrimination Act (DDA) 1995 and 2005, the FRS defines a child as having a disability if they have a longstanding illness lasting longer than 6 months and affecting their ability to undertake daily activities. Families were asked if their child had any longstanding illness, disability or infirmity. Families responding 'yes' were directed to a set of follow up questions asking which area of the child's life was affected by their disability. Possible answers were: mobility; lifting; manual dexterity; continence (i.e. bladder control); communication (i.e. speech, hearing, or eyesight); memory and learning; recognition of physical danger; physical coordination; other; or, none of these areas. As we were not able to define their disability either as affecting physical or mental health, we excluded children whose family claimed had a disability but subsequently said that none of these areas where affected by disability (3.4% of total children).

Of these eight disability domains, we assume that memory and learning, and recognition of physical danger can be attributable solely to mental health problems, as they are related to cognitive impairment. We assume all other areas primarily reflect physical health problems [19], but

acknowledge these domains could also be affected by, or affect, mental health status. For ease of explanation, we will hereafter refer to memory and learning, and recognition of physical danger as 'mental health' disability areas, and mobility, lifting, manual dexterity, continence, communication, and physical coordination as 'physical health' disability areas.

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

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

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

- Comparison A: Group 1 versus Group 6;
- Comparison B: Group 2 versus Group 6;
- Comparison C: Group 3 versus Group 6;
- Comparison D: Group 4 versus Group 6;
- Comparison E: Group 5 versus Group 6.

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

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

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

Living standards

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

From these questions we developed a living standards index (*LSI*) using prevalence weighting [22] with weights representing the proportion of families considering the item a necessity. We calculated the *LSI* as follows:

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

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

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

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

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

Income

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

Other variables

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

We also included a categorical indicator for survey year and UK Government Office Region (London; South East; Rest of England; Northern Ireland, Wales and Scotland[1]).

Data analysis

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

We employed the 'compensating variation' (CV) approach to calculate the cost of child disability, which has been previously used in studies of disability in adults[24] and children.[6] The CV can be defined as the additional income that a family with a disabled child needs to be able to achieve the same living standards of a family that is similar in all other respects but without a disabled child. More details on the theoretical approach can be found in the supplementary material and in Figure S1. We used Propensity Score Matching (PSM) [26,27] to match families according to comparisons A – F and calculate the CV (i.e. the mean income difference). It has been suggested that this approach, by simulating a randomised controlled trial setting, can provide a more unbiased estimate of the income difference than parametric models in observational studies [24].

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

For each matching pair obtained with this matching approach we calculated the CV and its 95% CI [28]. As sensitivity analyses we estimated the compensating variation matching disabled children using 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.

(defining the radius as a quarter of a the propensity score standard deviation). All our analyses were run using Stata13.[29]

RESULTS

Sample characteristics

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

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

Child disability

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

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

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

Among families with high living standards, families of children affected in any of the physical or mental health disability areas or in both the mental health areas, regardless of other areas affected, had lower income compared to families of children without disabilities.

Benefits

As seen in Table 3, across all LS groups combined families of children with both mental health disabilities (Group (4)) received the highest amount of weekly benefits (mean value £45.95), followed by those with any mental health disabilities (Group (3); £34.48), and those with any physical health disabilities (Group (5); £26.22) (Table 3). Note these groups included children with both mental and physical disabilities. Children only affected in either or both mental health areas received on average £17.40 per week (Group (1)) whilst those affected in any or all physical health domains only received £10.63 (Group (2)). The amount of benefits received did not vary by LS, reflecting the absence of means testing for disability benefits. None of the children in the non-disabled group were receiving any disability benefits.

Compensating variation

Over and above their net income (including benefits received) families of children with any (Group 3) or both mental health disabilities (Group 4) needed an additional £49.31 (95% confidence interval (CI): 21.95; 76.67) and £57.56 (95% CI: 17.69; 97.44), respectively, a week in order to achieve the same living standards of similar families without a disabled child (Group 6; Comparisons C and D, respectively), across both levels of LS (Table 4). We also found evidence that families of children with any physical health disability (Group 2) needed an additional £35.86 (95%CI: 13.77; 57.96) per week to meet the living standards of families without disabled children (Group 6; Comparison E). When pooling across living standards, we did not find any other differences in any of the other disability groups.

When we split the sample by low and high levels of living standards, we found that in some cases families with low LS with a disabled child needed a higher net income to meet the same LS of families without a disabled child. Specifically, we found that families of a child with any mental health disability or both mental health disabilities (with or without physical disabilities) required an extra £59.28 (95%CI: 41.38; 77.18), Group 3, Comparison C) and £81.37 (95%CI: 53.35; 109.38, Group 4, Comparison D) a week more than a family without a disabled child. We also found an income difference, albeit smaller, for families of children with disability affecting physical health

compared to families of non-disabled children, with the former needing an extra £42.18 (95%CI: 26.38; 57.97, Group 5, Comparison E) more a week to achieve the same LS.

When we compared children affected by disability in any, or both mental health areas and in any physical health areas, regardless of the presence of other disabilities, against children without disabilities and other with physical and mental health disabilities respectively (i.e., in comparisons F - H), we found weak evidence that families of children with both mental health areas affected by disabilities needed an extra £47.45 (95% CI: -0.41; 95.30) more per week to achieve the same LS if in the low LS category (Table 4). Although, we did not find any evidence of differences for the other groups, in particular those with high living standards, there was an indication that children in group 1 (any mental health disability with no physical health disability), and group 4 (both mental health disabilities regardless of physical health disabilities) were adequately compensated, although the latter case only among children with greater LS. We did not find evidence of any other group differences.

Sensitivity analyses and model checks

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

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

DISCUSSION

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

We found no difference in income between families of children with a disability affecting any or all areas associated with mental health problems only and families of non-disabled children. When we allowed for existence of physical health comorbidities, we found that these families needed an additional £49.31 per week over and above existing net incomes (including disability benefits) compared to families of non-disabled children to achieve the same living standards, with an even greater amount needed if children's disability affected both mental health domains (£57.56). These difference were, again, even greater for families with low living standards (£59.28 and £81.37, respectively). In comparison, families with children affected by physical health had a positive, but smaller in magnitude, CV (£35.86), which was, similarly to what was observed for mental health disability, was higher among families with low LS (£42.18). When we tested the relative impact of mental and physical health on the CV, by allowing our comparator group to have disabilities in the opposite domains of the one under investigation, we found a positive, though weak, CV for children affected in both mental health disabilities who live in families with low LS (£47.45). These findings suggest that all these groups are undercompensated by the benefits system.

These results suggest that mental health disabilities in childhood are associated with substantial costs which need to be borne by their families. In other words, families of children with mental health disabilities need to have higher income in order to achieve the same living standards of a family without a disabled child. These costs appear to be higher when there are co-occurring mental and physical disabilities, possibly an indicator of severity of the condition, and for more economically deprived families. As benefits were already included in our income measure, the compensating variation represents the amount by which families appear to be undercompensated under current benefit arrangements.

Our findings on the cost of child disability are lower from those found by Dobson and colleagues estimating the cost of child disability to the family at £100 per week [4,5]. Compared to these studies, we also found that under-compensation occurred to a lower extent, in the range of £8-£15 and only for deprived families with children with mental health disabilities, as opposed to £30-£80 [4] and £24 [5]. One reason for this difference could be that these studies employed convenience sampling (i.e. selecting children with more severe disabilities and living in more deprived settings) and different definitions of disability, which did not clearly distinguish between mental and physical health.

This study had several strengths. It employed a large and rich dataset representative of the UK population. The FRS also makes use of the disability domains employed in the DDA to define areas

affected by disability, which makes it consistent with definitions applicable to policy settings. We also employed a novel approach which allowed us to match families not only based on their propensity scores distribution, but also on the values of living standards with exact matching to the first decimal digit. Nevertheless, several limitations should be accounted for. First, we could only give an approximate definition of mental and physical health disability, knowing that areas which we have considered as physical health could be affected as a result of mental health disability only. Nevertheless, our approach represents a first attempt at both costing the impact of mental health disabilities on families and disentangling the relative effect of mental and physical health disability. We were also unable to explore the effect of severity of disability or of different types of disabilities given the nature of the available variables. Future studies should attempt to include specific diagnoses, perhaps including sub-clinical presentations as separate categories in order to account for varying degrees of severity. A total of 10% had missing data on LS measures; although we calculated our index re-scaling the latter to the number of questions each family had answered, it is not possible to rule out the possibility that under/over-estimation of the LSI value for these families could have occurred. Moreover, our living standards measure provides an indication of what goods the family can afford, but not of their quality. However, values of mean income by low/high LSI seemed to suggest that the latter adequately describes the intended groups. The sample size for some of our disability definitions was small meaning that we could have incurred in type II error and failed to observe an income difference when indeed there was one. Due to the cross-sectional nature of the study, it was not possible to estimate the CV in the absence of benefits, as the latter contribute, when received, to the LS achieved by the family. This approach would have given a clearer indication of the income difference between families with and without a disabled child. In fact, based on our estimates, we are not able to tell, if we do not observe a difference in income, whether an actual difference would have occurred in the absence of the benefits system. By comparing the CV to the amount of benefits received, we however attempted to estimate whether the family was currently over or undercompensated. Our propensity score model could have been improved by including more precise indications of family structure and parental education, as well as a greater number of family and child characteristics, such as a clearer specification of parental physical or mental health disability. Future studies should endeavor to be more inclusive in order to improve model prediction. We used data covering the financial years 2004/05 to 2011/12, which are not the most current available. This choice was motivated by a change in the definition of disability in 2012/13 to include a separate mental health domain. Although using post-2012/13 data would have resulted in a clearer definition of mental health and more recent estimates, we would not have had enough statistical power for our analyses. Nevertheless, we found that the amount of DLA

received across disability groups in our sample was consistent with 2011/12 and current DLA figures, suggesting that our findings bear relevance for current policy. Finally, some of our families, especially in adjacent years, could have been recruited in more than one wave of FRS data collection, meaning that our samples might have not been totally independent.[30] However, given the large size of our sample we believe that it is unlikely that this could have biased our results.

In conclusion, we found that mental health in childhood and adolescence is associated with high costs, which need to be borne by the family. Our findings indicate that families of children from more disadvantaged backgrounds are currently undercompensated by the disability benefits system. Based on these findings we suggest that mental health should be better defined as a criterion for receiving benefits and that the amount of disability benefits that a family is entitled to receive are subject to means testing, so that families from more deprived socio-economic backgrounds could be entitled to higher benefits amounts.

Acknowledgments

The authors would like to thank members of the Policy Research Unit for the health of children, young people and families: Terence Stephenson, Catherine Law, Amanda Edwards, Ruth Gilbert, Helen Roberts, Cathy Street, Russell Viner and Miranda Wolpert.

Data Sharing: The dataset used in these analyses is publicly available on https://www.ukdataservice.ac.uk/

BIBLIOGRAPHY

1. Newacheck PW, Inkelas M, Kim SE. Health Services Use and Health Care Expenditures for Children With Disabilities. Pediatrics. 2004;114(1).
2. Ringel JS, Sturm R. National estimates of mental health utilization and expenditures for children in 1998. J Behav Health Serv Res. 2001 Aug;28(3):319–33.
3. Chan E, Zhan C, Homer CJ, CC L, KN S, R P. Health Care Use and Costs for Children With Attention-Deficit/Hyperactivity Disorder. Arch Pediatr Adolesc Med. 2002 May;156(5):504.
4. Dobson B, Middleton S. Paying to care: The cost of childhood disability. York; 1998.
5. Dobson B, Middleton S, Beardsworth A. The Impact of Childhood Disability on Family Life. York; 2001.
6. Melnychuk M, Solmi F, Morris S. Using compensating variation to measure the costs of child disability in the UK. Eur J Heal Econ. 2017 Apr 13;1–15.
7. Merikangas KR, Nakamura EF, Kessler RC. Epidemiology of mental disorders in children and adolescents. Dialogues Clin Neurosci. 2009 Jan;11(1):7–20.
8. WHO. Caring for children and adolescents with mental disorders. Setting WHO directions. Geneva; 2003.
9. Foundation N. Social trends and mental health: introducing the main findings. London, UK; 2013.
10. Murphy M, Fonagy P. Chapter 10: Mental Health Problems in Children and Young People, Our Children Deserve Better: Prevention Pays. In: Annual Report of the Chief Medical Officer 2012. 2012.
11. Emerson E, Hatton C. The Mental Health of Children and Adolescents with Learning Disabilities in Britain. Lancaster, UK; 2007.
12. Meltzer H, Gatward R, Goodman R, Ford T. The Mental Health of Children and Adolescents in Great Britain. London, UK; 2000.
13. van Oort FVA, van der Ende J, Wadsworth ME, Verhulst FC, Achenbach TM. Cross-national comparison of the link between socioeconomic status and emotional and behavioral problems in youths. Soc Psychiatry Psychiatr Epidemiol. 2010 Feb;46(2):167–72.
14. Green H, McGinnity A, Meltzer H, Ford T, Goodman R. Mental health of children and young people in Great Britain, 2004. Lodon, UK; 2004.
15. Knapp M, Iemmi V. The economic case for better mental health. In: Annual Report of Chief Medical Officer 2013 Public Mental Health Priorities: Investing in the Evidence. London: Department of Health; 2013.
16. Disability Living Allowance (DLA) for children. 2015.

17. Evans D. Family Resources Survey. United Kingdom, 2010/11. London, UK; 2012.
18. Evans D. Family Resources Survey. 2012.
19. Office for Disability Issues. Equality Act 2010 Guidance. Guidance on matters to be taken into account in determining questions relating to the definition of disability. 2010.
20. Kieling C, Baker-Henningham H, Belfer M, Conti G, Ertem I, Omigbodun O, et al. Child and adolescent mental health worldwide: evidence for action. Lancet. 2011 Oct 22;378(9801):1515–25.
21. McKay S, Collard S. Developing deprivation questions for the Family Resources Survey. Vol. 13, Institute for Social and Economic Research (ISER). 2004.
22. Hallerod B. The Truly Poor: Direct and Indirect Consensual Measurement of Poverty in Sweden. J Eur Soc Policy. 1995 Jan 1;5(2):111–29.
23. Morciano M, Hancock R, Pudney S. Disability Costs and Equivalence Scales in the Older Population in Great Britain. Rev Income Wealth. 2014;(September).
24. Hancock R, Morciano M, Pudney S. Nonparametric estimation of a compensating variation: the cost of disability. ISER Work Pap Ser. 2013 Dec 4;
25. Zaidi A, Burchardt T. COMPARING INCOMES WHEN NEEDS DIFFER: EQUIVALIZATION FOR THE EXTRA COSTS OF DISABILITY IN THE U.K. Rev Income Wealth. 2005 Mar;51(1):89–114.
26. Rosenbaum PR, Rubin DB. The central role of the propensity score in observational studies for causal effects. Biometrika. 1983 Apr;70(1):41–55.
27. Heckman JJ, Ichimura H, Todd P. Matching as an econometric evaluation estimator. Rev Econ Stud. 1998;65:261–94.
28. Abadie A, Imbens GW. Large Sample Properties of Matching Estimators for Average Treatment Effects. Econometrica. 2006 Jan;74(1):235–67.
29. StataCorp. Stata Statistical Software: release 13. College Station, TX: StataCorp LP; 2013.
30. Department of Work and Pensions. Uncertainty in Family Resources Survey-based analysis. 2006.

TABLES and FIGURES

Figure 1. Distribution of living standard index

Table 1: sample characteristics

	All, N (%)	Child disability					
		No disability N (%)	Any Mental Health only N(%);P (χ^2)	Any Physical Health only N (%);P (χ^2)	Any Mental Health N (%); P (χ^2)	Both Mental Health N (%); P (χ^2)	Any Physical Health N (%); P (χ^2)
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%)

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

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

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

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

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

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

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

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

Table 4: Compensating variation (£ per week)

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

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

**** p≤0.05 *0.1>p>0.05**

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

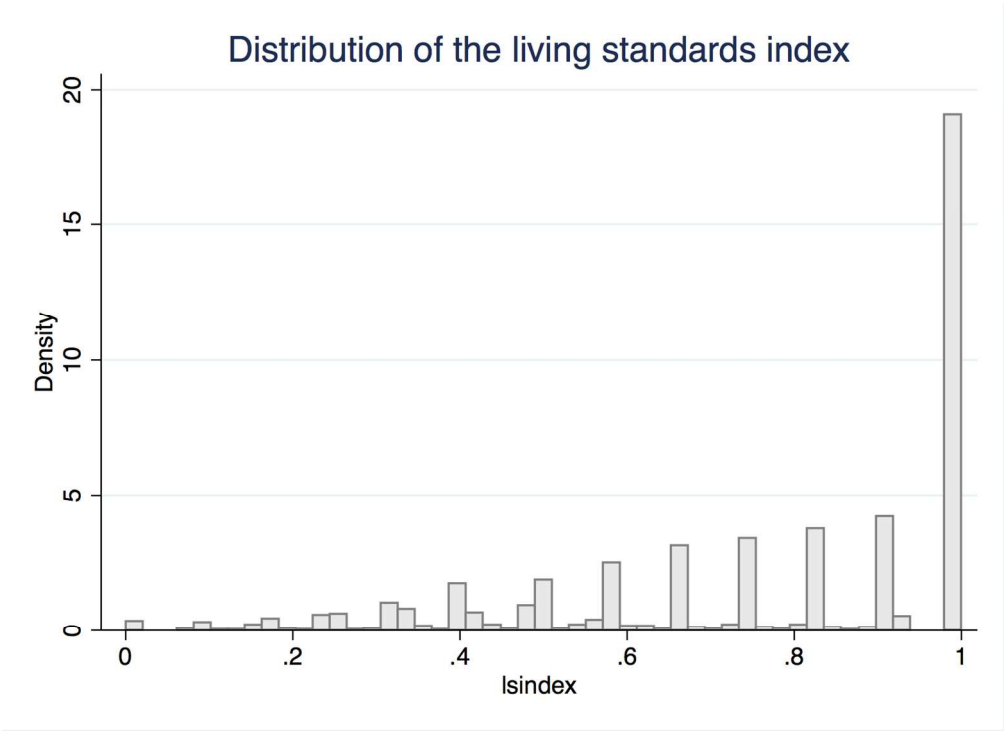


Figure 1. Distribution of living standard index

139x101mm (300 x 300 DPI)

Table S1: Definitions of disability groups

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**

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

**= necessarily present for definition

Yellow cells indicate primary domains for group definition

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

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

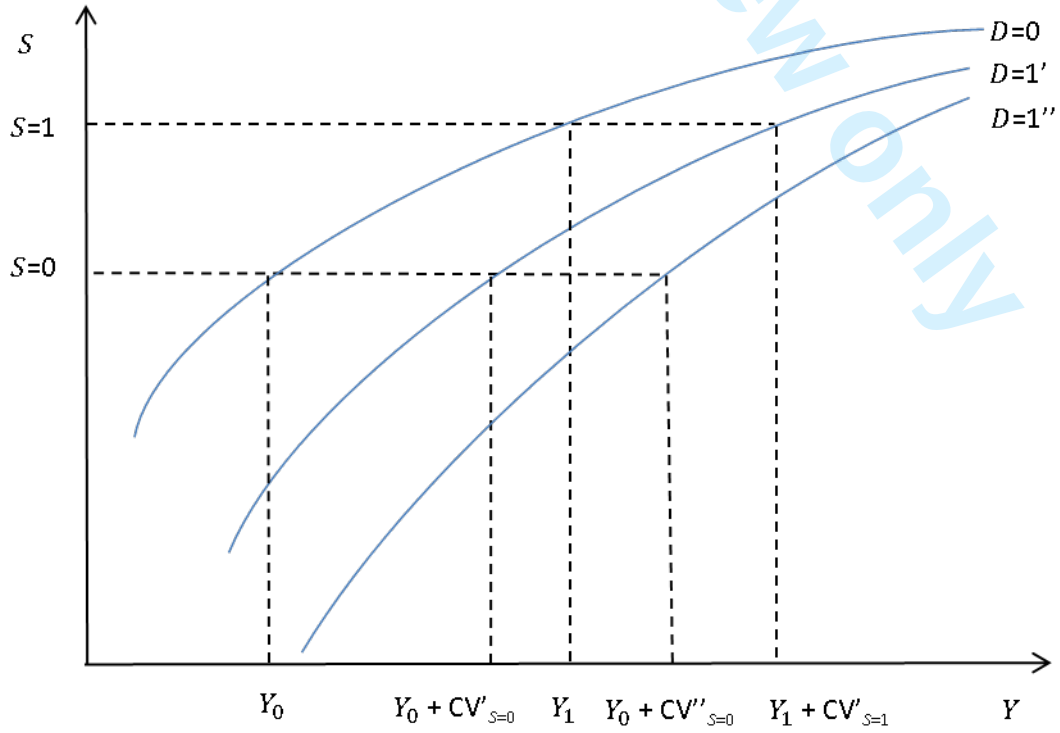
Theoretical approach: Compensating Variation

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 and convex, due to diminishing returns to *S* as *Y* increases; and, (ii) *D* =1' lies below *D* =0 though they tend towards one another at higher levels of *Y*. At a given level of living standards such as *S* =0 the CV is the difference between the income that a family with a disabled child (*D* =1') needs to have (= $Y_0 + CV'_{S=0}$) compared to the income of a family without a disabled child (*D* =0) (=Y_0) to achieve the same living standard (*S* =0). Based on our assumptions this difference will decrease at higher levels of living standards. For instance, the CV between *D* =1' and *D* =0 for *S* =1 (where S =1 > *S* =0) will correspond to $Y_1 + CV'_{S=1}$, which is smaller than $Y_0 + CV'_{S=0}$.

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

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

Figure S1: Compensating variation



Theoretical Approach: Propensity Score Matching

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

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

We matched families using nearest neighbor 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:

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

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

Sensitivity analyses

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

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

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

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

All models were balanced.

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]

(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]

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.

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

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

	Item No	Recommendation	PAGE
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	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, 5-6
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	2, 5-6
Participants	6	(*a*) *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	6-9
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	6-9
Bias	9	Describe any efforts to address potential sources of bias	13
Study size	10	Explain how the study size was arrived at	5-6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	6-9
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	12-13
		(*b*) Describe any methods used to examine subgroups and interactions	N/A
		(*c*) Explain how missing data were addressed	10-11
		(*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)	N
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	11-12
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	11-13
		(*b*) Report category boundaries when continuous variables were categorized	
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	
Discussion			
Key results	18	Summarise key results with reference to study objectives	13-14
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	15
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	13-15
Generalisability	21	Discuss the generalisability (external validity) of the study results	15
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	1

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

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

BMJ Open

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

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2017-018729.R2
Article Type:	Research
Date Submitted by the Author:	27-Oct-2017
Complete List of Authors:	Solmi, Francesca; University College London, Division of Psychiatry Melnychuk, Mariya; University College London , Department of applied health research Morris, Stephen; University College London, Department of Applied Health Research
Primary Subject Heading:	Mental health
Secondary Subject Heading:	Health economics, Epidemiology
Keywords:	Child disability, living standards, compensating variation, propensity score matching, disability benefits

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

Francesca Solmi, PhD[1,2]; Mariya Melnychuk, PhD[1]; Stephen Morris, PhD[1]

[1]*Department of Applied Health Research, University College London, London, UK*

[2]*Division of Psychiatry, University College London, London, UK*

Corresponding author:

Dr Francesca Solmi,
PsyLife Lab, UCL Division of Psychiatry
6th Floor, Wing B, Maple House
149 Tottenham Court Road,
London W1T 7NF

E: francesca.solmi@ucl.ac.uk
P: 02076799643 (ext: 09643)

Keywords: Child disability; living standards; disability benefits; compensating variation; propensity score matching.

Competing interests:

The authors declare no competing interests.

Funding

This work was supported by the Policy Research Unit in the Health of Children, Young People and Families, which is funded by the Department of Health Policy Research Programme. This is an independent report commissioned and funded by the Department of Health. The views expressed are not necessarily those of the Department.

ABSTRACT

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

Design: Repeated cross-sectional survey.

Setting: UK general population

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

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

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

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

Strengths and Limitations

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

INTRODUCTION

Families of children suffering from chronic conditions and physical and mental health disabilities incur significantly higher costs than those of their healthy counterparts.[1–5] These costs are primarily accounted for by more frequent visits to inpatient and outpatient departments and by greater use of prescribed drugs,[1–3] although evidence also suggests that the need to provide or secure informal care adds to the financial burden of child disability for these families.[4,5] Previously, UK studies have estimated the cost of having a disabled child at about £79-£100 per week[4] and that under the benefits arrangements at the time (1997) families of disabled children were undercompensated by £30-£80 per week [4] and by £28 in 2001.[5] More recent evidence has estimated that in the UK families of severely disabled children require up to an additional £79 per week to be able to meet the same living standards of those without disabled children.[6]

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

A socio-economic gradient exists in the distribution of child mental health disorders [11–13]. In the 2004 B-CAMHS, prevalence of diagnosable child mental health conditions was higher among single-parent (15.6%) compared to married or co-habiting (7.7%) households; among families with low (16.1%) compared to high (5.3%) income; and among families whose parents had no academic qualifications (17.0%) compared to those with university degrees (4.4%) [14]. Evidence exists that life adversities are a risk factor for the onset of mental health conditions as well as that mental health problems of the child can lead to family breakdown and unemployment [14].

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

prospects [15]. Similarly, childhood experience of economic hardship can result in long-term adverse health outcomes via the persistence of lower socio-economic status [15].

Since 1992, in the UK, families of children affected by disability have been eligible to receive a non-means-tested weekly Disability Living Allowance (DLA).[16] The rationale for these benefits is that they "*may help with the extra costs of looking after a child who: is under 16; has difficulties walking or needs more looking after than a child of the same age who doesn't have a disability*".[16] The amount of benefits that the family is entitled to receive largely depends on the severity of the child's condition, which is determined by the disability service centre often in conjunction with external assessments. In 2017, under the care component of DLA, children could receive either £22 (if they needed a little help during the day or night), £55.65 (if they needed frequent supervision), or £83.10 (if they needed constant help day and night, or were terminally ill) per week. Under the mobility component of DLA, children were entitled to receive between £22 (if they could walk but needed supervision outdoors) and £58 (if they could not walk, if walking represented a health risk, or if they were blind) per week.

Previous UK studies have shown that families of disabled children incur high costs, but were however unable to attribute these extra expenditures to either physical or mental health disability, which has been shown to inflict a substantial economic burden in other settings.[2,3] In the absence of literature exploring the cost of child mental health disability to families, and the rising prevalence of these problems, the aims of this study are to: (1) investigate the cost to families of having a child with a mental health disability; (2) compare the costs of mental health versus physical health disability to assess whether such stratification is needed when considering disability benefits; and, (3) examine how these costs vary by economic deprivation in order to assess whether means testing of DLA should be considered.

MATERIALS AND METHODS

Sample

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

focus on private households (nursing and retirement homes are not included), the overall sample, used in this study, is representative of the UK population [17], and our focus on families with children under 16 years of age means this is unlikely to introduce a bias.

In the FRS households are defined as 'a single person or group of people living at the same address who either share one meal a day or share the living accommodation, i.e. a living room'. Each household may include one or more benefit unit, 'a single adult or couple living as married and any dependent children'. A dependent child is a 'child younger than 16 years or an unmarried 16 to 19-year-old in full time non-advanced education'.[18] In this study, for simplicity we refer to benefit units as 'families' and consider children as our main unit of analyses, as matching was done at child-level. Our sample includes children aged 0-15 years and their families who had complete data on all variables included in the model covariates and necessary to estimate the CV (i.e. income and living standards). We excluded all the children from families with more than one disabled child because of difficulties separating the effects of multiple disabled children in the same family (2.7% of total children). In families with only one disabled child who had siblings we excluded the siblings to avoid within-family matching.

Child mental and physical health disability

In line with the definition of disability included in the Disability Discrimination Act (DDA) 1995 and 2005, the FRS defines a child as having a disability if they have a longstanding illness lasting longer than 6 months and affecting their ability to undertake daily activities. Families were asked if their child had any longstanding illness, disability or infirmity. Families responding 'yes' were directed to a set of follow up questions asking which area of the child's life was affected by their disability. Possible answers were: mobility; lifting; manual dexterity; continence (i.e. bladder control); communication (i.e. speech, hearing, or eyesight); memory and learning; recognition of physical danger; physical coordination; other; or, none of these areas. As we were not able to define their disability either as affecting physical or mental health, we excluded children whose family claimed had a disability but subsequently said that none of these areas where affected by disability (3.4% of total children).

Of these eight disability domains, we assume that memory and learning, and recognition of physical danger can be attributable solely to mental health problems, as they are related to cognitive impairment. We assume all other areas primarily reflect physical health problems [19], but

acknowledge these domains could also be affected by, or affect, mental health status. For ease of explanation, we will hereafter refer to memory and learning, and recognition of physical danger as 'mental health' disability areas, and mobility, lifting, manual dexterity, continence, communication, and physical coordination as 'physical health' disability areas.

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

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

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

- Comparison A: Group 1 versus Group 6;
- Comparison B: Group 2 versus Group 6;
- Comparison C: Group 3 versus Group 6;
- Comparison D: Group 4 versus Group 6;
- Comparison E: Group 5 versus Group 6.

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

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

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

Living standards

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

From these questions we developed a living standards index (*LSI*) using prevalence weighting [22] with weights representing the proportion of families considering the item a necessity. We calculated the *LSI* as follows:

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

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

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

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

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

Income

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

Other variables

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

We also included a categorical indicator for survey year and UK Government Office Region (London; South East; Rest of England; Northern Ireland, Wales and Scotland[1]).

Data analysis

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

We employed the 'compensating variation' (CV) approach to calculate the cost of child disability, which has been previously used in studies of disability in adults[24] and children.[6] The CV can be defined as the additional income that a family with a disabled child needs to be able to achieve the same living standards of a family that is similar in all other respects but without a disabled child. More details on the theoretical approach can be found in the supplementary material and in Figure S1. We used Propensity Score Matching (PSM) [26,27] to match families according to comparisons A – H and calculate the CV (i.e. the mean income difference). It has been suggested that this approach, by simulating a randomised controlled trial setting, can provide a more unbiased estimate of the income difference than parametric models in observational studies [24].

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

For each matching pair obtained with this matching approach we calculated the CV and its 95% CI [28]. As sensitivity analyses we estimated the compensating variation matching disabled children using 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.

(defining the radius as a quarter of a the propensity score standard deviation). All our analyses were run using Stata13.[29]

RESULTS

Sample characteristics

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

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

Child disability

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

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

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

Among families with high living standards, families of children affected in any of the physical or mental health disability areas or in both the mental health areas, regardless of other areas affected, had lower income compared to families of children without disabilities.

Benefits

As seen in Table 3, across all LS groups combined families of children with both mental health disabilities (Group (4)) received the highest amount of weekly benefits (mean value £45.95), followed by those with any mental health disabilities (Group (3); £34.48), and those with any physical health disabilities (Group (5); £26.22) (Table 3). Note these groups included children with both mental and physical disabilities. Children only affected in either or both mental health areas received on average £17.40 per week (Group (1)) whilst those affected in any or all physical health domains only received £10.63 (Group (2)). The amount of benefits received did not vary by LS, reflecting the absence of means testing for disability benefits. None of the children in the non-disabled group were receiving any disability benefits.

Compensating variation

Over and above their net income (including benefits received) families of children with any (Group 3) or both mental health disabilities (Group 4) needed an additional £49.31 (95% confidence interval (CI): 21.95; 76.67) and £57.56 (95% CI: 17.69; 97.44), respectively, a week in order to achieve the same living standards of similar families without a disabled child (Group 6; Comparisons C and D, respectively), across both levels of LS (Table 4). We also found evidence that families of children with any physical health disability (Group 2) needed an additional £35.86 (95%CI: 13.77; 57.96) per week to meet the living standards of families without disabled children (Group 6; Comparison E). When pooling across living standards, we did not find any other differences in any of the other disability groups.

When we split the sample by low and high levels of living standards, we found that in some cases families with low LS with a disabled child needed a higher net income to meet the same LS of families without a disabled child. Specifically, we found that families of a child with any mental health disability or both mental health disabilities (with or without physical disabilities) required an extra £59.28 (95%CI: 41.38; 77.18), Group 3, Comparison C) and £81.37 (95%CI: 53.35; 109.38, Group 4, Comparison D) a week more than a family without a disabled child. We also found an income difference, albeit smaller, for families of children with disability affecting physical health

compared to families of non-disabled children, with the former needing an extra £42.18 (95%CI: 26.38; 57.97, Group 5, Comparison E) more a week to achieve the same LS.

When we compared children affected by disability in any, or both mental health areas and in any physical health areas, regardless of the presence of other disabilities, against children without disabilities and other with physical and mental health disabilities respectively (i.e., in comparisons F - H), we found weak evidence that families of children with both mental health areas affected by disabilities needed an extra £47.45 (95% CI: -0.41; 95.30) more per week to achieve the same LS if in the low LS category (Table 4). Although, we did not find any evidence of differences for the other groups, in particular those with high living standards, there was an indication that children in group 1 (any mental health disability with no physical health disability), and group 4 (both mental health disabilities regardless of physical health disabilities) were adequately compensated, although the latter case only among children with greater LS. We did not find evidence of any other group differences.

Sensitivity analyses and model checks

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

In our main analysis, for comparisons A to E the distribution of covariates was balanced between treatment groups (i.e. disabled and non-disabled children) with the exception of years of schooling, which in some models was unbalanced. In models F to H, the distribution of covariates was less well balanced in our main analyses. However, in sensitivity analyses all models were balanced, and since the results in the sensitivity analysis were similar to those of the main analysis, this suggests that this is unlikely to have biased our estimates.

DISCUSSION

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

We found no difference in income between families of children with a disability affecting any or all areas associated with mental health problems only and families of non-disabled children. When we allowed for existence of physical health comorbidities, we found that these families needed an additional £49.31 per week over and above existing net incomes (including disability benefits) compared to families of non-disabled children to achieve the same living standards, with an even greater amount needed if children's disability affected both mental health domains (£57.56). These difference were, again, even greater for families with low living standards (£59.28 and £81.37, respectively). In comparison, families with children affected by physical health had a positive, but smaller in magnitude, CV (£35.86), which was, similarly to what was observed for mental health disability, higher among families with low LS (£42.18). When we tested the relative impact of mental and physical health on the CV, by allowing our comparator group to have disabilities in the opposite domains of the one under investigation, we found a positive, though weak, CV for children affected in both mental health disabilities who live in families with low LS (£47.45). These findings suggest that all these groups are undercompensated by the benefits system.

These results suggest that mental health disabilities in childhood are associated with substantial costs which need to be borne by their families. In other words, families of children with mental health disabilities need to have higher income in order to achieve the same living standards of a family without a disabled child. These costs appear to be higher when there are co-occurring mental and physical disabilities, possibly an indicator of severity of the condition, and for more economically deprived families. As benefits were already included in our income measure, the compensating variation represents the amount by which families appear to be undercompensated under current benefit arrangements.

Our findings on the cost of child disability are lower from those found by Dobson and colleagues estimating the cost of child disability to the family at £100 per week [4,5]. Compared to these studies, we also found that under-compensation occurred to a lower extent, in the range of £8-£15 and only for deprived families with children with mental health disabilities, as opposed to £30-£80 [4] and £24 [5]. One reason for this difference could be that these studies employed convenience sampling (i.e. selecting children with more severe disabilities and living in more deprived settings) and different definitions of disability, which did not clearly distinguish between mental and physical health.

This study had several strengths. It employed a large and rich dataset representative of the UK population. The FRS also makes use of the disability domains employed in the DDA to define areas

affected by disability, which makes it consistent with definitions applicable to policy settings. We also employed a novel approach which allowed us to match families not only based on their propensity scores distribution, but also on the values of living standards with exact matching to the first decimal digit. Nevertheless, several limitations should be accounted for. First, we could only give an approximate definition of mental and physical health disability, knowing that areas which we have considered as physical health could be affected as a result of mental health disability only. Nevertheless, our approach represents a first attempt at both costing the impact of mental health disabilities on families and disentangling the relative effect of mental and physical health disability. We were also unable to explore the effect of severity of disability or of different types of disabilities given the nature of the available variables. Future studies should attempt to include specific diagnoses, perhaps including sub-clinical presentations as separate categories in order to account for varying degrees of severity. A total of 10% had missing data on LS measures; although we calculated our index re-scaling the latter to the number of questions each family had answered, it is not possible to rule out the possibility that under/over-estimation of the LSI value for these families could have occurred. Moreover, our living standards measure provides an indication of what goods the family can afford, but not of their quality. However, values of mean income by low/high LSI seemed to suggest that the latter adequately describes the intended groups. The sample size for some of our disability definitions was small meaning that we could have incurred in type II error and failed to observe an income difference when indeed there was one. Due to the cross-sectional nature of the study, it was not possible to estimate the CV in the absence of benefits, as the latter contribute, when received, to the LS achieved by the family. This approach would have given a clearer indication of the income difference between families with and without a disabled child. In fact, based on our estimates, we are not able to tell, if we do not observe a difference in income, whether an actual difference would have occurred in the absence of the benefits system. By comparing the CV to the amount of benefits received, we however attempted to estimate whether the family was currently over or undercompensated. Our propensity score model could have been improved by including more precise indications of family structure and parental education, as well as a greater number of family and child characteristics, such as a clearer specification of parental physical or mental health disability. Future studies should endeavor to be more inclusive in order to improve model prediction. We used data covering the financial years 2004/05 to 2011/12, which are not the most current available. This choice was motivated by a change in the definition of disability in 2012/13 to include a separate mental health domain. Although using post-2012/13 data would have resulted in a clearer definition of mental health and more recent estimates, we would not have had enough statistical power for our analyses. Nevertheless, we found that the amount of DLA

received across disability groups in our sample was consistent with 2011/12 and current DLA figures, suggesting that our findings bear relevance for current policy. Finally, some of our families, especially in adjacent years, could have been recruited in more than one wave of FRS data collection, meaning that our samples might have not been totally independent.[30] However, given the large size of our sample we believe that it is unlikely that this could have biased our results.

In conclusion, we found that mental health in childhood and adolescence is associated with high costs, which need to be borne by the family. Our findings indicate that families of children from more disadvantaged backgrounds are currently undercompensated by the disability benefits system. Based on these findings we suggest that mental health should be better defined as a criterion for receiving benefits and that the amount of disability benefits that a family is entitled to receive are subject to means testing, so that families from more deprived socio-economic backgrounds could be entitled to higher benefits amounts.

Acknowledgments

The authors would like to thank members of the Policy Research Unit for the health of children, young people and families: Terence Stephenson, Catherine Law, Amanda Edwards, Ruth Gilbert, Helen Roberts, Cathy Street, Russell Viner and Miranda Wolpert.

Data Sharing: The dataset used in these analyses is publicly available on https://www.ukdataservice.ac.uk/

Contributors: Francesca Solmi: Developed research question and study design, analyzed data, and wrote manuscript. Maria Melnychuk: Developed research question and study design, analyzed data, and contributed to manuscript revision. Steve Morris: Developed research question and study design, contributed to manuscript revision, and supervised data analyses and the overall project.

BIBLIOGRAPHY

1. Newacheck PW, Inkelas M, Kim SE. Health Services Use and Health Care Expenditures for Children With Disabilities. Pediatrics. 2004;114(1).
2. Ringel JS, Sturm R. National estimates of mental health utilization and expenditures for children in 1998. J Behav Health Serv Res. 2001 Aug;28(3):319–33.
3. Chan E, Zhan C, Homer CJ, CC L, KN S, R P. Health Care Use and Costs for Children With Attention-Deficit/Hyperactivity Disorder. Arch Pediatr Adolesc Med. 2002 May;156(5):504.
4. Dobson B, Middleton S. Paying to care: The cost of childhood disability. York; 1998.
5. Dobson B, Middleton S, Beardsworth A. The Impact of Childhood Disability on Family Life. York; 2001.
6. Melnychuk M, Solmi F, Morris S. Using compensating variation to measure the costs of child disability in the UK. Eur J Heal Econ. 2017 Apr 13;1–15.
7. Merikangas KR, Nakamura EF, Kessler RC. Epidemiology of mental disorders in children and adolescents. Dialogues Clin Neurosci. 2009 Jan;11(1):7–20.
8. WHO. Caring for children and adolescents with mental disorders. Setting WHO directions. Geneva; 2003.
9. Foundation N. Social trends and mental health: introducing the main findings. London, UK; 2013.
10. Murphy M, Fonagy P. Chapter 10: Mental Health Problems in Children and Young People, Our Children Deserve Better: Prevention Pays. In: Annual Report of the Chief Medical Officer 2012. 2012.
11. Emerson E, Hatton C. The Mental Health of Children and Adolescents with Learning Disabilities in Britain. Lancaster, UK; 2007.
12. Meltzer H, Gatward R, Goodman R, Ford T. The Mental Health of Children and Adolescents in Great Britain. London, UK; 2000.
13. van Oort FVA, van der Ende J, Wadsworth ME, Verhulst FC, Achenbach TM. Cross-national comparison of the link between socioeconomic status and emotional and behavioral problems in youths. Soc Psychiatry Psychiatr Epidemiol. 2010 Feb;46(2):167–72.
14. Green H, McGinnity A, Meltzer H, Ford T, Goodman R. Mental health of children and young people in Great Britain, 2004. Lodon, UK; 2004.
15. Knapp M, Iemmi V. The economic case for better mental health. In: Annual Report of Chief Medical Officer 2013 Public Mental Health Priorities: Investing in the Evidence. London: Department of Health; 2013.
16. Disability Living Allowance (DLA) for children. 2015.

17. Evans D. Family Resources Survey. United Kingdom, 2010/11. London, UK; 2012.
18. Evans D. Family Resources Survey. 2012.
19. Office for Disability Issues. Equality Act 2010 Guidance. Guidance on matters to be taken into account in determining questions relating to the definition of disability. 2010.
20. Kieling C, Baker-Henningham H, Belfer M, Conti G, Ertem I, Omigbodun O, et al. Child and adolescent mental health worldwide: evidence for action. Lancet. 2011 Oct 22;378(9801):1515–25.
21. McKay S, Collard S. Developing deprivation questions for the Family Resources Survey. Vol. 13, Institute for Social and Economic Research (ISER). 2004.
22. Hallerod B. The Truly Poor: Direct and Indirect Consensual Measurement of Poverty in Sweden. J Eur Soc Policy. 1995 Jan 1;5(2):111–29.
23. Morciano M, Hancock R, Pudney S. Disability Costs and Equivalence Scales in the Older Population in Great Britain. Rev Income Wealth. 2014;(September).
24. Hancock R, Morciano M, Pudney S. Nonparametric estimation of a compensating variation: the cost of disability. ISER Work Pap Ser. 2013 Dec 4;
25. Zaidi A, Burchardt T. COMPARING INCOMES WHEN NEEDS DIFFER: EQUIVALIZATION FOR THE EXTRA COSTS OF DISABILITY IN THE U.K. Rev Income Wealth. 2005 Mar;51(1):89–114.
26. Rosenbaum PR, Rubin DB. The central role of the propensity score in observational studies for causal effects. Biometrika. 1983 Apr;70(1):41–55.
27. Heckman JJ, Ichimura H, Todd P. Matching as an econometric evaluation estimator. Rev Econ Stud. 1998;65:261–94.
28. Abadie A, Imbens GW. Large Sample Properties of Matching Estimators for Average Treatment Effects. Econometrica. 2006 Jan;74(1):235–67.
29. StataCorp. Stata Statistical Software: release 13. College Station, TX: StataCorp LP; 2013.
30. Department of Work and Pensions. Uncertainty in Family Resources Survey-based analysis. 2006.

TABLES and FIGURES

Figure 1. Distribution of living standard index

Table 1: sample characteristics

	All, N (%)	Child disability					
		No disability N (%)	Any Mental Health only N(%);P (χ^2)	Any Physical Health only N (%);P (χ^2)	Any Mental Health N (%); P (χ^2)	Both Mental Health N (%); P (χ^2)	Any Physical Health N (%); P (χ^2)
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%)

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

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

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

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

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

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

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

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

Table 4: Compensating variation (£ per week)

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

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

**** p≤0.05 *0.1>p>0.05**

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

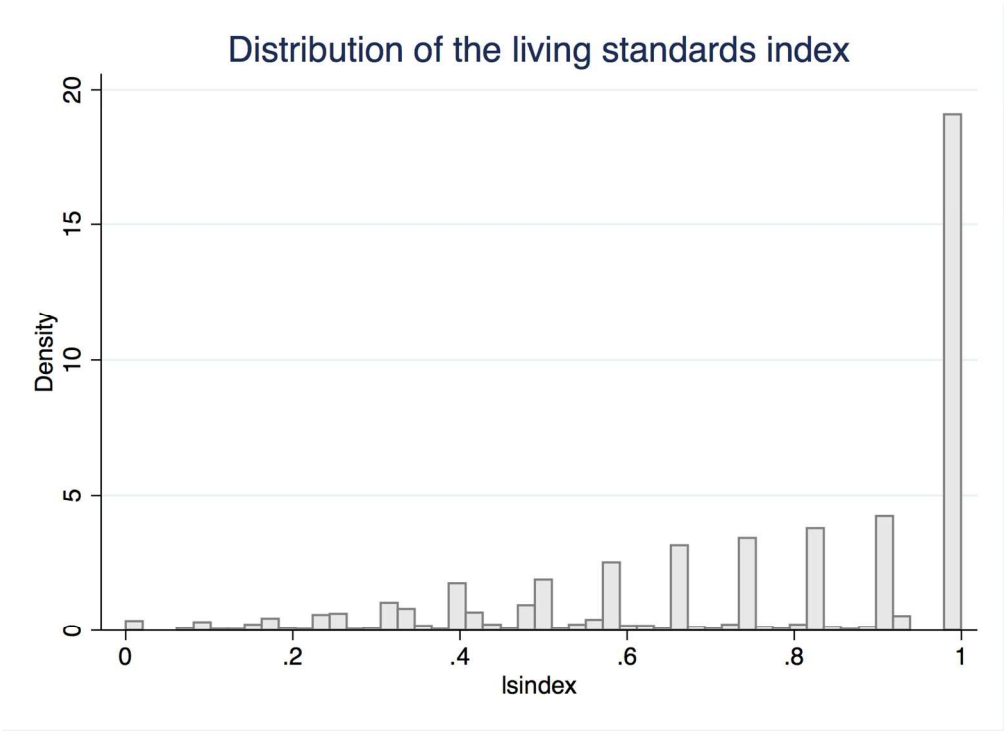


Figure 1. Distribution of living standard index

139x101mm (300 x 300 DPI)

Table S1: Definitions of disability groups

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**

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

**= necessarily present for definition

Yellow cells indicate primary domains for group definition

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

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

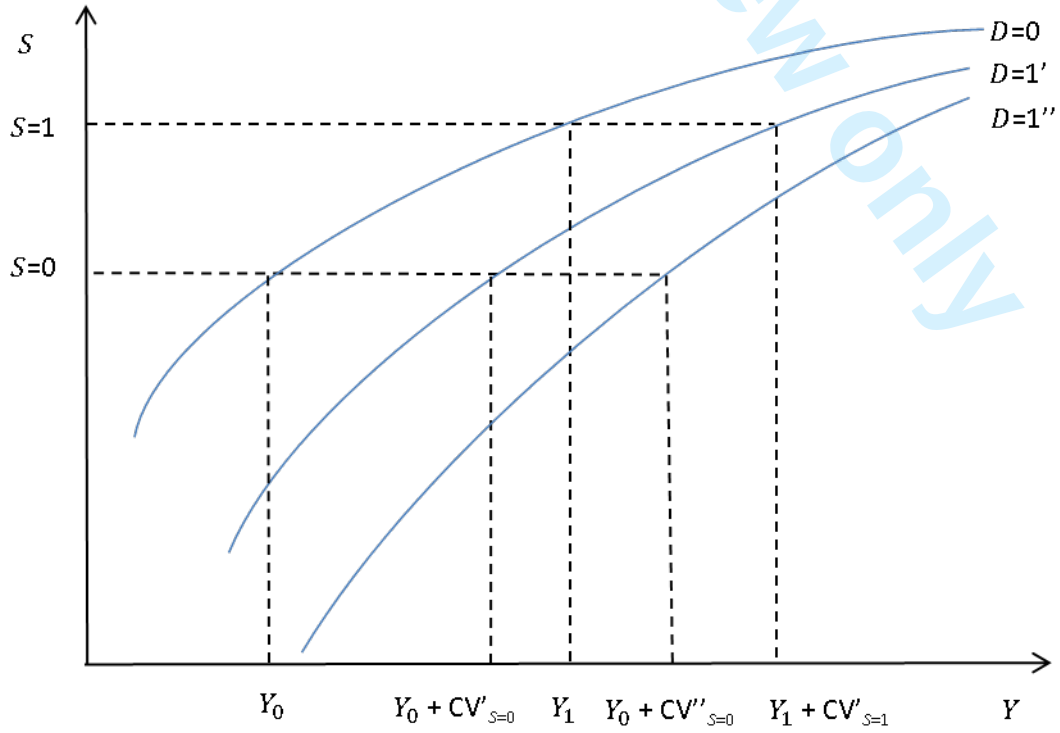
Theoretical approach: Compensating Variation

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 and convex, due to diminishing returns to *S* as *Y* increases; and, (ii) *D* =1' lies below *D* =0 though they tend towards one another at higher levels of *Y*. At a given level of living standards such as *S* =0 the CV is the difference between the income that a family with a disabled child (*D* =1') needs to have (= $Y_0 + CV'_{S=0}$) compared to the income of a family without a disabled child (*D* =0) (=Y_0) to achieve the same living standard (*S* =0). Based on our assumptions this difference will decrease at higher levels of living standards. For instance, the CV between *D* =1' and *D* =0 for *S* =1 (where S =1 > *S* =0) will correspond to $Y_1 + CV'_{S=1}$, which is smaller than $Y_0 + CV'_{S=0}$.

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

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

Figure S1: Compensating variation



Theoretical Approach: Propensity Score Matching

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

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

We matched families using nearest neighbor 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:

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

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

Sensitivity analyses

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

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

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

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

All models were balanced.

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]

(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]

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.

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

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

	Item No	Recommendation	PAGE
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	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, 5-6
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	2, 5-6
Participants	6	(*a*) *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	6-9
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	6-9
Bias	9	Describe any efforts to address potential sources of bias	13
Study size	10	Explain how the study size was arrived at	5-6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	6-9
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	12-13
		(*b*) Describe any methods used to examine subgroups and interactions	N/A
		(*c*) Explain how missing data were addressed	10-11
		(*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)	N
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	11-12
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	11-13
		(*b*) Report category boundaries when continuous variables were categorized	
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	
Discussion			
Key results	18	Summarise key results with reference to study objectives	13-14
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	15
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	13-15
Generalisability	21	Discuss the generalisability (external validity) of the study results	15
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	1

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

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