

The Gap Widens: The Economic Case for Closing the Funding Gap for Disabled Children's Health & Social Care Services

FINAL REPORT

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1: Introduction

- 1.1 In 2017, the Disabled Children's Partnership (DCP) commissioned Development Economics to estimate the scale of the gap between the (then) current scale of expenditure on health and social care services for disabled children, and the level of expenditure needed to meet gaps in service provision.
- 1.2 This research identified that a funding gap amounting to around £1.56 billion existed in 2017.
- 1.3 Now, in 2021, funding partners including Scope and the Disabled Children's Partnership (DCP) have re-commissioned Development Economics to re-examine the evolution of expenditure on service provision for disabled children in England, and to provide an updated estimate of the scale and nature of the funding gap.
- 1.4 As well as estimating the current size of the funding gap, the new report also examines the type and scale of quantifiable and monetizable benefits that are associated with the scale of funding currently provided on health and social care services that target the specific needs of disabled children. In addition, the report also estimates what additional gains to society could arise if the current gap in service provision were to be eliminated.
- 1.5 The remainder of this report is structured in two parts:
 - Chapter 2 provides an update of the current scale and nature of expenditure on health and social care services targeting the needs of disabled children
 - Chapter 3 presents alternative assessments of the potential costs and benefits associated with different levels of provision for disabled children's health and social care services, in particular:
 - a scenario where current levels of per capita expenditure is maintained; and
 - an alternative scenario where the (updated) gap in current service provision is addressed in full.

2: Current Funding & the Funding Gap

Introduction

- 2.1 This chapter highlights spend by local authorities and the NHS on health and social care services for disabled children aged 0-18 years¹ in England for 2019 and estimates the current services spend funding gap.
- 2.2 The 2019/2020 funding gap analysis has been undertaken in a very similar manner to that employed in the 2017 study. Key tasks of the 2019 assessment have included:
- A short questionnaire was sent to charities included in the Disabled Children's Partnership in August 2021.
 - A thorough literature and data review to establish current health and social care services spend on disabled children.
 - Analysis of the DCP survey from the 2017 funding gap research which gathered information on the extent to which current Council and Clinical Commissioning Group (CCG) spend on health and social care services in England was sufficient; the proportional decrease/increase in spend required by local authorities and the NHS to ensure that all disabled children receive a sufficient level of health and social care services.
 - An update to the 2017 funding gap model, reflecting the new data, social and healthcare costs and 2019/2020 prices.
- 2.3 The calculation of current and required health and social care services spend involved the following tasks:
- Estimation of current public expenditure on social care services for disabled children
 - Estimation of current public expenditure on health services for disabled children
 - Estimation of the current funding gap for social and health care services for disabled children.
- 2.4 More details of the methodology used in the assessment and the resulting findings are set out under sub-headings in the remainder of this chapter.

¹ In some cases, spend estimates do not cover the full age range, 0-18 years, further information on this point can be found in the methodology section of this paper.

Current social care services spend on disabled children

- 2.5 Total expenditure of local authorities on social care services for children was drawn from the S251 Outturn LA and school expenditure tables for financial year 2019-2020. Three spending categories are used as a proxy for children's social care, these being services for looked-after children, safeguarding children and young people's services and family support services.
- 2.6 In the absence of data from the S251 Outturn LA and School Expenditure Tables for financial year 2020/2021, due to be published in December 2021. Analysis from the Institute of Fiscal Studies, highlighting the financial impact of the COVID-19 crisis on council budgets in 2020-2021, has been used to estimate spend on social care services for children in 2020/2021. The study estimated an increase in expenditure of £386 million for the financial year 2020/2021 for children's social care.²
- 2.7 In 2017, Freedom of Information (FOIs) requests were submitted to all Councils in England, as part of the previous funding gap assessment. The FOIs estimated that local authority expenditure on social care services for disabled children amounted to around 9.5% of total spend on children's social care services. For the purpose of calculating current spend on social care for disabled children in 2019 and 2020 and given a lack of evidence and trend data, the 9.5% percentage relationship in 2016/2019, is assumed to carry forward to spend in 2019 and 2020.

Current health care services spend on disabled children

- 2.8 A thorough literature and data review was undertaken to establish current healthcare services spend on disabled children.
- 2.9 Six categories of disabilities have been used to define 'all disability' for children in England. These categories included: Mental health, Autistic spectrum disorder, Life-limiting or life-threatening conditions, Learning disabilities, Vision and Hearing impairments. Please see the table below for an explanation of disabilities included under each category. In many cases Physical Disability is included in the 'Life-limiting or life-threatening conditions' category, for example cerebral palsy, brain injury, muscular dystrophy or under the category 'sensory' impairment. It is recognised that the estimates won't cover all types of Physical Disability, and this is due to the limitations of data and research available.
- 2.10 The elements used to estimate total healthcare service costs for disabled children (where possible) include: prescribed drugs, inpatient care, GP contacts, accident and emergency (A&E) visits and outpatient attendances. Due to data limitations, it has not been possible to estimate the full healthcare services costs for a number of the disability categories. For example, it was not possible to calculate the costs of A&E visits and prescribed drugs for children with Life-limiting conditions.

² <https://ifs.org.uk/publications/15371>

- 2.11 For each disability category, the methodology has aimed to concentrate on each disability from the point of view of it being the main diagnosis for the child or young person and so has sought to estimate healthcare service costs with that in mind.
- 2.12 If applicable, healthcare service costs are updated to 2019/2020 using the NHS cost inflation index (NHSCII) derived from the Unit Costs Health and Social Care 2020, PSSRU, the most up to date publication at this time.
- 2.13 The literature and data review findings highlight very limited freely available public data that specifically identified spend on healthcare services for children and disabled children. Hence, the method has been, to draw upon existing studies, where possible.
- 2.14 The data and literature sources of information for healthcare services spend for each disability category can be found in Appendix A.1.

Method used to estimate the current funding gap for health & social care services

- 2.15 Estimates of the additional funding required to sufficiently meet the health and social care services need of disabled children in England draw on findings from a DCP survey undertaken as part of the 2017 funding gap research.
- 2.16 All 45 of the DCP charities received a short questionnaire which gathered information on the following: total number of disabled children/young people/parent carers that they supported; definitions for disabilities; the extent to which current Council and CCG spend on health and social care services in England was sufficient; the proportional decrease/increase in spend required by local authorities and the NHS to ensure that all disabled children receive a sufficient level of health and social care services.
- 2.17 The results from the survey were the main basis on which the percentage increase/decrease in spend required to sufficiently meet the needs of disabled children was calculated for health and social care services in England in 2019/2020.
- 2.18 A weighted average of the percentage increase/decrease in spend for health and social care was taken based on the proportion that each represented of total cost and testing of the weights through sensitivity analysis was completed.
- 2.19 Weighted percentages were applied to current healthcare and social care spend for 2019/2020 to arrive at the additional social and health care services spend required for 2019/2020.

Estimates of the current health and social care services spend estimates & funding gap

- 2.20 Total expenditure by local authorities on children's social care services amounted to **£9.11 billion** in 2019/2020. The corresponding figures for 2020/2021 is **£9.50 billion**.
- 2.21 Of the total spend on children's social care services, it is estimated that total expenditure by local authorities for disabled children equated to **£954 million** in 2019/2020 and **£995 million** in 2020/2021.

- 2.22 Current healthcare services spend on disabled children defined as expenditure on prescribed drugs, inpatient care, GP contacts, accident and emergency (A&E) visits and outpatient attendances is estimated to be **£2.54 billion** in 2019/2020 and **£2.65 billion** in 2020/2021.
- 2.23 Aggregating the above figures for social and health care spend, provides a total figure for current health and social care services spend in 2019/2020. This is projected to be around **£3.50 billion** and **£3.64 billion** in 2020/2021.
- 2.24 In order to sufficiently meet the health and social care services need of disabled children in England, it is estimated that an additional **£465 million to £680 million** spend is required for social care services by local authorities and **£1.40 billion to £1.69 billion** by the NHS every year or an additional **£1.86 billion to £2.36 billion** in total for health and social care spend annually.
- 2.25 This research finds that the funding gap in disabled children's health and social care has continued to grow reaching **£2.1 billion** (mid-point figure) from the latest data available in 2019/20 - an increase of over £500 million since 2016/17. This includes a **£573 million** (mid-point figure) funding gap in disabled children's social care, and a **£1.5 billion** (mid-point figure) gap in disabled children's NHS spending.
- 2.26 Further details of the breakdown of current expenditure on health & social care services for disabled children are presented in an appendix to this report.

3: Future Funding Scenarios

Introduction

- 3.1 The previous chapter has provided up-to-date estimates of the current costs of health and social care provision for disabled children in England. This expenditure is estimated to amount to £3,495 million in 2019/2020, rising to £3,640 million in 2020/2021.
- 3.2 The previous chapter also provided updated estimates of the additional expenditure that would be required to address existing gaps in service provision, i.e., to meet in full the health and social care needs of England's disabled children.
- 3.3 This research has found that an additional £465 million to £680 million spend would be required to provide in full for social care services by local authorities. It also found that an additional £1,398 million to £1,685 million of public spending would need to be spent by the NHS to address in full the health care needs of disabled children in England.
- 3.4 The overall scale of resources to meet in full social and health care needs of disabled children would amount to an additional £1,863 million to £2,365 million annually.
- 3.5 The purpose of this chapter is to extend this analysis further, by:
 - Estimating the potential longer-term costs of health and social care provision for disabled children and their families, in response to demographic change and other factors, of maintaining current extent of service provision for each disabled child (i.e., by assuming that the current extent of service provision neither improves nor deteriorates)
 - Quantifying the potential benefits to the public Exchequer that are associated with health and social care provision for disabled children.
 - Assessing and quantifying what the long-term costs and benefits of enhanced support for disabled children would be under a scenario where the current gaps in service provision are addressed in full.

Approach to the assessment

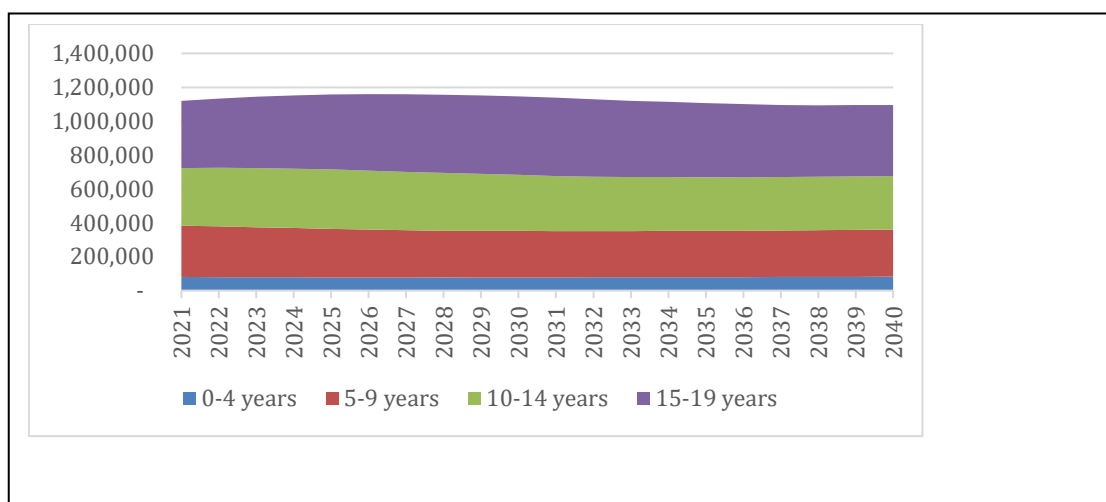
- 3.6 The assessment involves the construction of two forward-looking scenarios over the timeframe 2021-2040 (i.e., a 20-year assessment period). The rationale for a choice of a 20-year period is to consider the effects of service provision over (approximately) the length of time needed for a child with disabilities born in 2021 to reach adulthood.
- 3.7 The assessment utilises a discounted cash flow model of the estimated annual expenditure on health and social care services targeting disabled children and their families under two alternative scenarios:

- Scenario 1: Maintenance of current levels of per capita provision for Disabled Children’s services over the 2021-2040 period
- Scenario 2: Increase in service provision to address in full the current gap in provision in Disabled Children’s services over the 2021-2040 period.

3.8 The scenarios are predicated on estimates of the potential future numbers of disabled children (and families with disabled children) in England. These estimates have been obtained by combining current (2018-based) population projections for England by single year of age available from the Office for National Statistics (ONS), with current estimates of the number of disabled children of different ages (also obtained from ONS data).

3.9 Based on these data sources, it is assumed that the overall population of disabled children would rise from 1.119 million in 2021 to 1.159 million by 2027, before starting to reduce slightly thereafter. By 2040, the population of disabled children in England is assumed to be 1.096 million.

Fig 3.1: Anticipated future population of disabled children, England, 2021-2040



3.10 Future levels of expenditure on health and social care services targeting disabled children have been estimated by applying assumptions of per capita expenditure under Scenario 1, and the uplift of average expenditure per child in order to address in full the existing funding gap for Scenario 2.

3.11 Estimated post-2021 levels of expenditure on health and social care services in support of disabled children have been converted into a present value by applying a discount factor of 3.5% per annum.

Types of Future Expenditure Savings or Revenue Gains Included in the Analysis

3.12 A range of potential future public expenditure savings and potential future Exchequer receipts have been included in the quantified analysis. These are summarised in brief below:

Indicator	Rationale for Inclusion
The potential for savings in downstream health or social care expenditure	Enhanced (i.e., fully adequate) levels of investment in health and social care services for disabled children at an earlier stage has the potential to reduce the need for more intensive (and expensive) therapies, treatments, and support services at a later stage of childhood or adulthood. ³
Tax receipts from enhanced economic participation of disabled children and their families	<p>Enhanced levels of investment in health and social care services for disabled children at an earlier stage has the potential to enhance the rates of participation and attainment of disabled children in education and training. This in turn has the potential to increase the proportion of disabled children participating in the workforce when they reach adulthood, and to raise their skills and qualifications and consequently their earning power and their contribution to contribute to Exchequer receipts through direct and indirect taxation.</p> <p>Similarly, enhanced levels of support for the families of disabled children would be expected to result in a proportion of parents being able to either return to the workforce or to increase the average number of hours they work.</p> <p>Additional support for families of disabled children can also be expected to lead to improvements in the educational attainment of non-disabled siblings of disabled children, which would in turn lead to enhanced future earnings potential and also their potential for contributing to Exchequer receipts through direct and indirect taxation.</p>
Savings in future levels of Social Protection expenditure	A further gain linked to enhanced levels of economic participation and earnings is the potential for some reduction in public expenditure on social protection programmes that are linked to household income, such as Council Tax rebates and Carer’s Allowance.

3.13 Apart from the types of gains set out above that are capable of being readily quantified and monetised, there are other types of potential benefits associated with levels of support for disabled children’s health and social care services that have not been included in the quantified analysis. These could include the following:

- The potential for public expenditure savings linked to levels of marital breakdown linked to stress and pressures on mental health
- The potential for expenditure savings linked to reduced levels of need for social housing

³ For example, academic research has identified that early family-centred care interventions focused on children with development disabilities that aim to provide optimal stimulation for development in a safe, stable, and nurturing environment can significantly improve opportunities for these children to achieve their full potential and thrive.

- Societal welfare gains linked to a potential increase in levels of volunteering undertaken by parents of disabled children.

Scenario 1 Results

3.14 As indicated in the Introduction, Scenario 1 is based on a continuation of current levels of health and social care service provision for disabled children throughout the 2021-2040 period. The results of the scenario are summarised in the table below:

Table 3.1: Scenario 1: Continuation of current levels of per capita service provision, 2021-2040

Indicator	Present Value of costs and benefits £millions (2021 prices)
Costs	
PV Costs of social care for Disabled Children	15,865
PV Costs of health-care services for Disabled Children	42,255
PV Overall costs of services for Disabled Children	58,121
Benefits	
PV Health & Social Care Savings, of which:	18,831
<i>Mental health related service savings</i>	3,452
<i>Respite residential care & support savings</i>	2,272
<i>Day care support savings</i>	5,714
<i>Physical treatment cost savings</i>	7,393
PV Tax receipts linked to increased economic participation of disabled children reaching adulthood	7,501
PV Tax receipts linked to increased economic participation of siblings of disabled children reaching adulthood	2,778
PV Tax receipts linked to increased economic participation of parents of disabled children	35,804
PV of additional savings in (Social Welfare) Benefits expenditure (c.f. Scenario 1)	0 ⁴
PV of the Sum of Benefits	64,914
Net Present Value (PV of Benefits minus PV of Costs)	6,794

3.15 The estimated Present Value (PV) of maintained current levels of provision over the 2021-2040 period amounts to £58,121 million, of which 27% is accounted for by social care expenditure and 73% by health care expenditure.

3.16 The overall value of Exchequer receipts and savings on future spending liabilities associated with this expenditure amounts to a PV of £64,914 million over the same period. This total includes a reduction of £18,831 million in future expenditure on health and care services that would otherwise be required (i.e., this is the PV of future expenditure that would be required if early intervention does not take place). This sub-total in turn includes:

- £3,452 million of future public expenditure savings on mental health services
- £2,272 million of future public expenditure savings on respite and residential care

⁴ This type of benefit is only relevant to Scenario 2 considered below.

- £5,714 million future public expenditure savings on day care support for families
- £7,393 million of future public expenditure savings on the costs of physical health treatment and therapies.

3.17 Other key components of the aggregate total of gains linked to current levels of provision include:

- Future tax receipts generated via the earnings and expenditure of earned income made on the part of disabled children who reach adulthood and who can participate more fully in the workforce because of treatment and support programmes that are currently being delivered (but for whom anticipated levels of participation and earnings would be lower if these programmes did not exist at their current level). This total is estimated to have a PV of £7,501 million
- Similarly, raised levels of future labour market participation and earnings of siblings of disabled children when they reach adulthood that are associated with current levels of service provision is estimated to have a PV of £2,778 million.
- In addition, the future tax receipts associated with enhanced labour market participation and earnings of the parents of disabled children linked to current levels of service provision is estimated to have a PV of £35,804 million.

3.18 (Note: under the second scenario there is an addition type of potential benefit to consider. This is the potential for reductions expenditure on social protection programme entitlements paid to families of disabled children. Some of these payments are means-tested, and the potential for additional individual and household earnings following additional workforce participation means that potential levels of associated benefit income could be lower as levels of earned income increase. However, under the 'business as usual' assumptions of Scenario 1, no change in entitlements is assumed to take place, so these potential public expenditure savings do not occur).

3.19 Considering all of these costs and benefits, the overall net value associated with current levels of health and social care service provision targeting disabled children and their families amount to a positive Net Present Value (NPV) of £6,794 million.

3.20 The implication of this result is that the current level of public expenditure on health and social care services for disabled children is expected to be associated with net value for public revenues amounting to just under £6.8 billion over a 20-year assessment period.

3.21 It should be noted that the NPV would be larger if the time period of the assessment were extended further. This is because the future earnings potential of many disabled children (and their siblings) who would otherwise not be working extends beyond the 2040 cut-off date for our assessment.

Scenario 2 Results

- 3.22 Scenario 2 is predicated on increasing levels of expenditure on the health and social needs of disabled children in England so that needs are met in full. Although raising levels of expenditure would obviously place a greater burden on public expenditure, one longer term impact is expected to be the generation of additional future public revenue (through enhanced economic participation and earnings of some disabled children and some family members).
- 3.23 In addition, there is an additional type of gain that was not considered for Scenario 1. This concerns the potential for a reduction in the aggregate value of public expenditure on social protection paid to households with disabled children: the mechanism envisaged to work here is that in some situations where parents are working more and earning more, in some cases the increase in household earnings would be sufficient to lead to reduced entitlement for certain types of income-related social welfare payments (however, note that it is assumed that in the majority of individual cases the typical overall impact on household income would be positive – i.e., that the loss of benefit payments for the average household in this situation would be more than offset by gains in earnings).
- 3.24 It may be noted that the extent of the current gap in support identified by the previous chapter was expressed as a range. To start with, the assessment of the PV of costs and benefits of increased support utilises an approximate mid-point of the range. (Note: a 'worst-case' variation – which considers the high-end of the potential range of costs – is assessed separately later in this chapter). The results of the second scenario are summarised in the table below:

Table 3.2 Scenario 2: Enhanced levels of service provision (address in full current gaps in support), based on an approximate mid-point of the funding gap, 2021-2040

Indicator	Present Value of costs and benefits £millions (2021 prices)
Costs	
PV Costs of social care for Disabled Children	24,858
PV Costs of health-care services for Disabled Children	66,485
PV Overall costs of services for Disabled Children	91,343
Benefits	
PV Health & Social Care Savings, of which:	21,898
<i>Mental health related service savings</i>	4,380
<i>Respite residential care & support savings</i>	2,612
<i>Day care support savings</i>	7,413
<i>Physical treatment cost savings</i>	7,763
PV Tax receipts linked to increased economic participation of disabled children reaching adulthood	16,200
PV Tax receipts linked to increased economic participation of siblings of disabled children reaching adulthood	5,937
PV Tax receipts linked to increased economic participation of parents of disabled children	60,069
PV of additional savings in (Social Welfare) Benefits expenditure (c.f. Scenario 1)	2,669
PV of the Sum of Benefits	106,773
Net Present Value (PV of Benefits minus PV of Costs)	15,430

- 3.25 Under Scenario 2 (mid-point costs), the estimated PV of maintained current levels of provision over the 2021-2040 period amounts to £91,343 million. This represents a cumulative PV increase of £33,222 million (57%) compared to the equivalent total under Scenario 1.
- 3.26 On the other hand, the overall estimated value of future Exchequer receipts (and savings on future spending liabilities) associated with this expenditure amounts to a PV of £106,773 million over the same period. This represents an increase of £41,859 million (64%) compared to the equivalent total under Scenario 1.
- 3.27 The components of the estimated increase in cumulative aggregate quantified benefits are:
- An increase of £3,067 million in future savings on health and care services expenditure (compared to levels expected under 'business as usual' Scenario 1). Overall future savings of this type have a PV total of £21,898 million under this scenario.
 - An increase of future tax receipts on the part of disabled children who reach adulthood and enter the workforce from 2021 onwards. This component – which is considered over the period up to 2040 only – is expected to be worth £8,699 million more (in PV terms) compared to the equivalent total under Scenario 1.
 - An increase in the aggregate value of future tax receipts on the part of (some) siblings of disabled children – when they begin to reach adulthood and potentially enter the workforce from 2021 onwards – which is expected to be worth £3,159 million more (in PV terms) under Scenario 2 compared to the equivalent total under Scenario 1.
 - An increase in the aggregate value of future tax receipts made by (some) parents of disabled children, which is expected to be worth £24,265 million more (in PV terms) under Scenario 2 compared to the equivalent total under Scenario 1.
- 3.28 In tandem with the expected earnings of some parents with disabled children, there is also scope for savings in earnings related social protection payments for some parents and households in this category. Overall, the value of these expenditure savings has an expected PV of £2,669 million over the 2021-2040 timeframe.
- 3.29 The net effect of these various results is that the estimated Net Present Value of future expenditure on health and social care services targeted at disabled children amounts to £15,430 million over the 2021-2040 period. This amounts to an increase in NPV worth £8,637 million compared to the equivalent total generated by Scenario 1.

Sensitivity test: increased cost of filling gaps in current service provision

- 3.30 The result set out above is predicated on the additional costs of addressing current gaps in service provision being close to the mid-point of the ranges identified in the previous chapter. However, it is of course possible that these costs could be higher, i.e., towards or at the top end of the range of costs identified in the previous Chapter.
- 3.31 On this basis, it is prudent to assess what the impact on Scenario 2 would be if the costs are higher than assumed in the previous sub-section.

- 3.32 Under the variant Scenario 2, the estimated future value of associated benefits is unchanged. The focus of the sensitivity test, therefore, is to explore the scale of the increase in the PV of costs and the concomitant decrease in the NPV result of the scenario variant.
- 3.33 The scenario results associated with substitution of 'top-end of the range' values for the potential levels of expenditure needed to meet in full current gaps in service provision are set out in the table below.

Table 3.3: Scenario 2b: Enhanced levels of service provision (addressing in full current gaps in support), based on 'high end' values for increased expenditure, 2021-2040

Indicator	Present Value of costs and benefits £millions (2021 prices)
Costs	
PV Costs of social care for Disabled Children	27,169
PV Costs of health-care services for Disabled Children	70,271
PV Overall costs of services for Disabled Children	97,440
PV of the Sum of Benefits	106,773
Net Present Value (PV of Benefits minus PV of Costs)	9,333

- 3.34 Under this variant scenario, the PV of costs rises to £97,440 million, an increase of £6,097 million (6.7%) compared to the central case for this scenario.
- 3.35 However, despite the increase in costs:
- The NPV result is clearly still a figure that is substantially above zero, thereby demonstrating that the increase in expenditure that would be needed to address the funding gap would be revenue-positive from the perspective of the Exchequer over the 20-year term used for the assessment.
 - Moreover, the value of the NPV under this scenario variant – i.e., even with much more adverse assumptions – is larger than the equivalent result for Scenario 1. That is, the adverse case version of Scenario 1 generates a larger net public revenue result than does maintaining 'business as usual' for service provision to disabled children and their families.

Conclusions and implications

- 3.36 The current level of spend of health and social care services targeting the needs of disabled children is substantial, at around £3.64 billion per annum. However, apart from addressing the needs of a vulnerable group of children and their families, expenditure on these services generates significant levels of economic and social benefit. In particular:
- Provision of these services enables a significant proportion of parents of disabled children to participate to a greater extent in the labour market than would be possible if the support services were not available.

- Investment in current health and social services in many individual cases averts the need for more expensive treatments, therapies, and interventions later in life.
- In addition, investment in health and social care services now increases the chances of a greater proportion of disabled children to participate in education and eventually to gain qualifications and skills that are relevant to the needs of the future labour market.

3.37 Overall, future maintenance of the current levels of per capita investment in health and social care services for disabled children would be expected to generate net benefits with a net present value of around £6.79 billion (£6,794 million) over a 20-year appraisal period (2021-2040).

3.38 However, the assessment here is that increased levels of investment to meet in full the current and expected future health and social care needs of disabled children has the potential to yield an even greater amount of value (i.e., NPV) from a fiscal perspective.

3.39 The extent of the current funding gap has been identified as a range between circa £1,863 million and £2,365 million per annum. However, meeting in full the future needs of the anticipated population of disabled children in England has the potential to generate NPV of between £9,333 million and £15,430 million over the period to 2040.

3.40 It should also be noted that these NPV results pertain to a 20-year assessment period. The value of the net benefits would likely to significantly greater if the assessment period were extended beyond 20 years.

3.41 It should also be emphasised that there are other types of societal benefits (such as progress towards equalities objectives) that are important but cannot be readily quantified and/or monetised and have therefore not been included in the calculation of NPV.

4: Appendix 1: A.1: Disability definitions, healthcare services spend data and limitations

<i>Disability definition</i>	<i>Sources of information and estimate limitations</i>
<p>Mental health Defined as conduct disorder, emotional disorder, hyperkinetic disorder and co-morbid disorders as these are the most frequently occurring conditions for children and adolescents with respect to mental health.</p>	<p>An estimate of 2019 healthcare service costs for children with mental health as a primary disability has been derived from the study 'Paying the Price (2008): The cost of Mental Health care in England to 2026 (The King's Fund).' Costs were estimated on the basis of primary diagnosis and for children and young people aged 5-15 years of age. It was estimated that there were 653,883 children with mental health as a primary disability in 2019 with healthcare service costs of £197 million.</p> <p>The elements used to estimate total healthcare service costs for disorders affecting children and adolescents were: prescribed drugs, inpatient care, GP contacts, accident and emergency (A&E) visits and outpatient attendances.</p> <p>Estimate limitations: Age range covered is 5-15 years, so this figure is an underestimation of healthcare service spend.</p>
<p>Autistic spectrum disorder (ASD) Defined as individuals with ASD with intellectual disability and individuals without intellectual disability.</p>	<p>An estimate of 2011 healthcare service costs from the study <i>Costs of ASD in the UK and US (2014)</i> has been used.⁵ On the basis of population-based studies, the study assumes that 0.1% of all children aged 0-3 years have ASD, that their condition is diagnosed and receive some type of service response. For children of all other ages, a 1.1% prevalence rate is assumed.</p> <p>The study provides comprehensive estimates of costs associated with ASDs, for individuals with and without intellectual disability (ID), an important distinction given that cognitive impairments, separate from impairments associated with ASDs, may significantly influence</p>

⁵ Author Affiliations: Personal Social Services Research Unit, London School of Economics and Political Science (Buescher,Knapp).

	<p>costs. Studies report that 40% to 60% of people with ASDs also have ID, a 50% split was therefore applied to the population figures after prevalence rates had been accounted for.</p> <p>The study did not produce a breakdown by constituent parts of the UK, but the authors assured the consultants that there was no strong reason to assume that the figures could not be divided up on the basis of population data. Prevalence rates were applied to 2019 population estimates for England from the Office of National Statistics.</p> <p>Healthcare service costs are updated to 2019/2020 using the NHS cost inflation index (NHSCII) derived from the Unit Costs Health and Social Care 2020, PSSRU.</p> <p>As far as possible, the costs include service use attributable to ASDs only. It is estimated (based on 2019 population estimates and the prevalence rates stated above) that there were around 106,113 children aged 0-17 years with ASD (with ID and without) as a primary disability in 2019 and this equates to healthcare service costs of £154 million in 2019.</p> <p><i>Estimate limitations: The age range covered is 0-17 years, so this figure is a slight underestimation of healthcare service spend. The number of children with ASD's is for 2019 based on prevalence rates used in 2011, hence the number could be higher or lower in 2019. Medical service costs include inpatient, outpatient, emergency, physician, pharmacy, <u>other healthcare professional, home health care, and out-of-pocket costs</u> – the last three costs underlined are not defined as healthcare service costs and hence the figure may be a slight overestimation of spend.</i></p>
<i>Disability definition</i>	<i>Sources of information and estimate limitations</i>
<p>Life-limiting (LLC) or life-threatening condition (LTC)</p> <p>The definition for Life-limiting or life-threatening conditions includes seven disease groups as set out in table below. The groups and ICD10 codes are derived from The Directory of Life-Limiting Conditions - a list of nearly four hundred ICD10</p>	<p>An estimate of 2011/2012 healthcare services costs (including inpatient, outpatient attendances, diagnostic and routing testing and GP visits) for the West Midlands were extrapolated to an England level and uprated to 2019/2020 prices using the NHS cost inflation index (NHSCII) derived from the Unit Costs Health and Social Care 2020, PSSRU. The healthcare services costs are drawn from The Big Study for Life-limited Children & their Families, 2013, Together for Shorter Lives.</p>

codes associated with diseases that can limit life in children.

Table 1: Categorisation of children's life-limiting and threatening conditions

Disease group	Description of conditions included in disease group	ICD10 codes
Congenital and chromosomal	Includes children with chromosomal conditions such as Downs, Patau, Edwards Syndromes and other less common abnormalities. Also children with congenital abnormalities of the central nervous system such as lissencephaly, hydrocephalus, microcephaly. Also children with congenital heart disease, short bowel, biliary atresia.	Mainly Q codes. (Congenital malformations, deformations and chromosomal abnormalities) Some K codes (Diseases of the digestive system).
CNS Static encephalopathy	Non-progressive CNS disease including cerebral palsy, developmental delay and epilepsy, Brain injury, Birth asphyxia, Hypoxic ischaemic encephalopathy.	Mainly G codes (Diseases of the nervous system). Some P codes (Certain conditions originating in the perinatal period) e.g. 'Brain injury/'birth injury', 'hypoxic ischaemic encephalopathy'.
CNS progressive	Disease often categorised as 'Progressive Intellectual and Neurological Deterioration (PIND)' characterised by loss of skills. Includes children with mucopolysaccharidoses (Hurlers, Hunters, Sanfilippo), lipofuscinosis (Juvenile, Late infantile and Infantile Batters), leucodystrophies (Adrenoleucodystrophy, metachromatic leucodystrophy, Krabbes), Rett's, Juvenile Huntington's. Most conditions in this group are inherited as single gene and/or mitochondrial disorders.	Mainly E codes (Endocrine, nutritional and metabolic diseases). Some G codes (Diseases of the nervous system).
Neuromuscular	Duchenne muscular dystrophy, Spinal muscular atrophy, Congenital muscular dystrophy, Ataxia telangiectasia, Friedreich's ataxia. These are also inherited as single gene recessive or x-linked conditions or as mitochondrial disorders.	Mainly G codes (Disease of the nervous system).
Cancer	Solid tumours, Brain tumours, Cancer of blood and lymphatic systems.	C codes (Neoplasms).
Pulmonary and respiratory	Cystic Fibrosis (single recessive gene disorder), Chronic lung disease (sometimes resulting from prematurity)	Cystic fibrosis E 84.9. Chronic lung disease J88.4.
Other	Endocrine and renal disorders. Immunodeficiency. Trauma (for instance due to road traffic accident).	B & D (Immunodeficiency), E (endocrine), K (digestive), M (musculoskeletal), N (genitourinary), S & T (Injury and trauma).

Source: The Big Study for Life-limited Children & their Families, 2013, Together for Shorter Lives.

Prevalence rates for children with life-limiting conditions are taken from the study Fraser et al (2020) 'Make Every Child Count estimating current and future prevalence of children and young people with life-limiting conditions in the UK.' Three scenarios are presented, prevalence rates from Model 2 'Less Conservative' have been used for the purposes of the 2019 funding gap update. Model 1 'Most Conservative' and Model 3 'Least Conservative' are the alternative models presented in the 'Make Every Child Count' report. Model 2 predicts that the number of children with life-limiting conditions would rise to 87,910 for England in 2019.

An extrapolation of the West Midlands results to an England level places healthcare service costs for children with life-limiting and life-threatening conditions at £714 million in 2019/2020.

Estimate limitations: Age range covered is 0-19 years, so this figure may be a slight overestimation of healthcare service spend. Furthermore, it is likely that the healthcare services cost results for the Big Study in the West Midlands itself, may well have been an underestimation of the true spend costs.

Disability definition

Learning Disabilities

Sources of information and estimate limitations

Costs are taken from a re-analysis of OPCS disability surveys, in particular the study - Kavanagh S. and Opit, L (1998) The Cost of Caring: The Economics of Providing for the Intellectually Disabled, Politea Social Science Research Series, London, Re-analysis of OPCS disability surveys, including adjustment for the mid-1990s balance of care.

The above study highlights average weekly costs (1994-1995 prices) accrued to primary and secondary health care for children (0-16 years) resident in private households and communal establishments.

	<p>Healthcare costs are updated to 2019/2020 using the NHS cost inflation index (NHSCII) derived from the Unit Costs Health and Social Care 2020, PSSRU, and equate to £951 million.</p> <p>The number of children with learning disabilities is estimated to be approximately 355,000 for those aged 0-17 years in the UK. This estimate has been calculated using learning disability prevalence rates from Public Health England (2016) and population data from the Office for National Statistics (2021).</p> <p><i>Estimate limitations: The age range covered for health care costs is 0-16 years, whilst the number of children with learning disabilities is for those aged 0-17 years.</i></p>
<p>Sensory impairments</p> <ul style="list-style-type: none"> i) Hearing impairments ii) Vision impairments <p>We are aware that children and young people may have multi-sensory impaired or single sensory impairments with additional disabilities. However, we have focused on one or the other due to data limitations.</p>	<p>Costs for hearing impairments are based on those found in the study, Chorozoglou M, Mahon M, Pimperton H, et al (2018). Societal costs of permanent childhood hearing loss at teen age: a cross-sectional cohort follow-up study of universal new born hearing screening. The study is based on the age group 13-20 years.</p> <p>Annual mean health service use cost estimates are for the hearing impaired. Health service use costs include Outpatient care, inpatient care attendance and A&E care attendance. Costs for GP visits are also included in the study.</p> <p>The Consortium for Research in Deaf Education (CRIDE) 2019 report for England estimates that there were 46,404 deaf children aged 0-19 years with permanent or temporary deafness on the Council's services caseloads. The CRIDE report is based on a 2018/2019 survey on education provision for deaf children in England. This estimate was used as a proxy for the number of children also receiving health care services for hearing impairments. (2019/2020 survey figures are reported to have had fewer responses due to the start of the pandemic, therefore 2018/2019 figures are deemed more reliable and reflective of the current state of play).</p> <p>Healthcare service costs were updated to 2019/2020 using the NHS cost inflation index (NHSCII) derived from the Unit Costs Health and Social Care 2020, PSSRU and are estimated to be £74 million.</p>

Estimate limitations: The healthcare costs are for 13-20 year olds only, given the lack of evidence and data, it has been assumed that the costs are similar for other age groups. This will result in either an under or over estimation of healthcare service spend. The Chorozoglou study does not include spend for GP visits, or prescribed drugs. Hence the estimate costs for 2019/2020 do not do so either, resulting in an underestimation of health care spend.

Costs for vision impairments

The RNIB Benchmarking Toolkit Sight Loss May 2021, highlights that there are 20,290 children and young people (0-18 years) blind or partially sighted in England. In the absence of data and research on the healthcare service costs of vision impairments, data ('Expenditure on problems of vision) from the 2017/2018 CCG Programme Budgeting Expenditure Dataset (per 1,000 overall weighted population) was used to estimate healthcare service spend for children with vision impairments.

The programme budgeting category "problems of vision" was used as a proxy for vision impairments. The care setting spend categories used for the purpose of our analysis include: primary care prescribing, emergency care (including A&E), inpatient and outpatient care, diagnostic imaging, critical care, drugs and devices and community and integrated care. Annual healthcare services spend on problems of vision was estimated to be £29,122 per 1,000 overall weighted population in England, this figure was updated to 2019/2020 prices using NHS cost inflation index (NHSCII) derived from the Unit Costs Health and Social Care 2020, PSSRU.

Multiplying a per person healthcare cost by the number of 0-18 year olds in England gives an estimate of £452 million spend on healthcare costs for children with problems of vision.

Estimate limitations: The healthcare services spend estimate assumes a similar cost per person for children and adults alike. The spend data from the CCG Programming Budgeting Benchmarking Budgeting Expenditure does not single out 'problems of vision' as the primary disability.

