

# **Service models guidance: individuals with intellectual disabilities and behaviour that challenges**

## **Economic Appendix C3**

Scenario and threshold analysis for different packages of respite care compared to standard care for children and adults

This report was produced by the Personal Social Research Unit at the London School of Economics and Political Science. PSSRU (LSE) is an independent research unit and is contracted as a partner of the NICE Collaborating Centre for Social Care (NCCSC) to carry out the economic reviews of evidence and analyses.

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## 1. Aims and introduction

This report answers the question, when is extra respite care cost-effective?

We are doing this analysis because the Guideline Committee made a resource-intensive recommendation for respite care without any robust evidence on effectiveness or cost-effectiveness (i.e. randomised controlled trials – RCTs – or comparative studies).

The recommendation is: ‘Respite should be reliably available on a regular and continuing basis’.<sup>1</sup>

The difficulty of assessing whether this recommendation is cost-effective is that it does not recommend specific types or intensities of respite care.

There are many different types and intensities of respite care, and instead of trying to analyse every possible configuration of respite care options, we illustrated a range of respite care intensities, and our analysis is based on those examples.

We illustrated the costs of 7 different respite care package intensities for children and 10 different respite care package intensities for adults: these costs range widely from approximately £5,000 per year to more than £72,000 per year. The Guideline Committee members were satisfied with the range of respite options we included for the analysis.

To reiterate: in the absence of a specific recommendation on respite care, the approach we take in this report allows us to approximate *when a certain intensity* of respite care is cost-effective.

Cost-effectiveness is influenced by changes in quality of life and public sector service use (costs). This analysis aims to show the levels of quality of life improvements and the levels of cost savings that have to occur in order to make various respite care intensities cost-effective. In the absence of research evidence, this exercise is a second-best solution in helping people decide whether respite care can be cost-effective.

### 1.1 Example care packages for children with intellectual disabilities and behavior that challenges

We illustrated 7 example respite care packages for children. These include 2 low-intensity, 3 medium-intensity and 2 high-intensity respite care packages. Descriptions of these packages, unit costs, and total costs are provided in

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<sup>1</sup> The actual term used in the guideline recommendations is “short breaks” following feedback from stakeholders that this was the preferred term. However, the Guideline committee used the term “respite” throughout their considerations of the cost effectiveness of “short breaks” and has been retained for accuracy.

Table 1 and Table 2 below. The range of respite care package costs for children is between £5,249 and £72,649 per child per year (2015/16 prices).

## **1.2 Example care packages for adults with intellectual disabilities and behavior that challenges**

We illustrated 10 example respite care packages for adults. These include 2 low-intensity, 4 medium-intensity and 4 high-intensity respite care packages. Descriptions of these packages, the unit costs, and total costs are provided in Table 3 and Table 4 below. The range of respite care package costs for adults is between £5,011 and £33,229 per adult per year (2015/16 prices).

**Table 1** Examples of low to medium intensity (cost) care packages for children

	<b>Low intensity 1</b>	<b>Low intensity 2</b>	<b>Medium intensity 1</b>	<b>Medium intensity 2</b>	<b>Medium intensity 3</b>
<b>Total cost of respite per year</b>	<b>£5,249</b>	<b>£10,499</b>	<b>£18,492</b>	<b>£27,241</b>	<b>£33,415</b>
<b>Respite 1</b>	<b>Home support</b> Term-time (38 weeks) 6 hours per week	<b>Home support</b> Term-time (38 weeks) 12 hours per week	<b>Home support</b> Term-time (38 weeks) 10 hours per week	<b>Home support</b> Term-time (38 weeks) 20 hours per week	<b>Overnight support</b> 52 weeks 5 days/week 12 hours/night
Unit cost	£23/hour	£23/hour	£23/hour	£23/hour	£182 for 24 hours
Cost	£5,249	£10,499	£8,749	£17,498	£23,672
<b>Respite 2</b>			<b>Day-care (summer)</b> 14 weeks 5 days/week 12 hours/day	<b>Day-care (summer)</b> 14 weeks 5 days/week 12 hours/day	<b>Day-care (summer)</b> 14 weeks 5 days/week 12 hours/day
Unit cost			£139/day	£139/day	£139/day
Cost			£9,743	£9,743	£9,743

**Table 2** Examples of high intensity care (cost) packages for children

	<b>High intensity 1</b>	<b>High intensity 2</b>
<b>Total respite cost per year</b>	<b>£62,832</b>	<b>£72,649</b>
<b>Respite 1</b>	<b>Residential care</b> 5 days/week 38 weeks	<b>Residential care</b> 5 days/week 52 weeks
Unit cost	£279/24 hours	£279/24 hours
Cost	£53,089	£72,649
<b>Respite 2</b>	<b>Day-care (summer)</b> 14 weeks 5 days/week 12 hours/day	
Unit cost	£139/day	
Cost	£9,743	

**Table 3** Examples of low and medium intensity care (cost) packages for adults

	Low intensity 1	Low intensity 2	Medium intensity 1	Medium intensity 2	Medium intensity 3	Medium intensity 4
<b>Total respite cost per year</b>	<b>£5,011</b>	<b>£8,464</b>	<b>£8,816</b>	<b>£9,946</b>	<b>£13,826</b>	<b>£14,957</b>
<b>Respite 1</b>	<b>Day care</b> 3 days/month	<b>Home support</b> 28 days/year 12 hours/day	<b>Day-time support</b> 24 days/year 12 hours/day	<b>Home support</b> 3 days/month 12 hours/day	<b>Day-time support</b> 24 days/year 12 hours/day	<b>Home support</b> 3 days/month 12 hours/day
Unit cost	£139/day	£23/hour	£23/hour	£23/hour	£23/hour	£23/hour
Cost	£5,011	£7,736	£6,631	£9,946	£6,631	£9,946
<b>Respite 2</b>		<b>Overnight support</b> 8 nights/year 12 hours/night	<b>Overnight support</b> 24 nights/year 12 hours/night		<b>Overnight support</b> 24 nights/year 12 hours/night	<b>Day care</b> 3 days/month
Unit cost		£182 for 24 hours	£182 for 24 hours		£182 for 24 hours	£139/day
Cost		£728	£2,185		£2,185	£5,011
<b>Respite 3</b>					<b>Day care</b> 3 days/month 8 hours/day	
Unit cost					£139/day	
Cost					£5,011	

**Table 4** Examples of high intensity care (cost) packages for adults

	<b>High intensity 1</b>	<b>High intensity 2</b>	<b>High intensity 3</b>	<b>High intensity 4</b>
<b>Total respite cost per year</b>	<b>£23,207</b>	<b>£25,393</b>	<b>£29,581</b>	<b>£33,229</b>
<b>Respite 1</b>	<b>Home support</b> 12 weeks 7 days/week 12 hours/day	<b>Home support</b> 12 weeks 7 days/week 12 hours/day	<b>Home support</b> 12 weeks 7 days/week 12 hours/day	<b>Home support</b> 12 weeks 7 days/week 12 hours/day
Unit cost	£23/hour	£23/hour	£23/hour	£23/hour
Cost	£23,207	£23,207	£23,207	£23,207
<b>Respite 2</b>		<b>Overnight support</b> 24 nights/year 12 hours	<b>Overnight support</b> 70 nights/year 12 hours	<b>Day care</b> 3 days/month 12 months
Unit cost		£182 for 24 hours	£182 for 24 hours	£139/day
Cost		£2,256	£6,373	£10,021

### 1.3 Unit costs of respite care

The costs of respite care are at 2015/16 prices, based on data in the Unit Costs of Health and Social Care Compendium (Curtis and Burns 2015). These unit costs include the cost of the individual organising the activity (salary costs) plus on-costs (pension and national insurance contributions), training, qualifications, direct and indirect overheads, capital costs and, if relevant, the costs of travelling.

Recognising that there is variation in unit costs across the country, we undertook sensitivity analysis on unit costs by using the reported lower and upper cost estimates from the Unit Costs of Health and Social Care Compendium.

The type and mean cost of respite provided varies: it can involve home support, home sitting, day care, family-based overnight support, residential care, after-school clubs, weekend clubs, general groups, and activity holidays (2015/16 prices) (Curtis and Burns 2013: 99).

**Table 5** Respite care unit costs, 2015/16 prices

<b>Respite</b>	<b>Mean</b>	<b>Lower</b>	<b>Upper</b>
Home support (per hour)	£23	19	27
Home sitting (per hour)	£20	12	28
Day care (per day, 8 hours)	£139	106	219
Family-based overnight support (per 24 hours)	£182	150	241
Residential care (per night/24 hours)	£279	74	431
After-school clubs (per session)	£297	255	352
Weekend clubs (per session)	£331	315	344
General groups (per session)	£354	104	654
Activity holidays (per break)	£1365	120	3937
<b>Note:</b> Unit costs were inflated to 2015/16 prices, based on originally reported values from 2012/13 (Curtis and Burns 2016: 99). Inflation rate used was 1.047%, based on PSS annual percentage increases for adult services, across all sectors (Curtis and Burns 2016: 197).			

## 2. Methods

The method we use to determine when these intensities of respite care can be cost-effective is based on assumptions about QALY gains and cost-offsets. Cost-offsets occur when using an intervention results in a reduction in the use of services in the future.

In the first step, we undertake a threshold analysis where we calculate the minimum QALY gains that the care packages would have to generate in order to be cost-effective at £20,000 per QALY. For example, if the yearly cost of respite care is £5,000, then it would have to generate 0.25 QALYs for the year



in order to be cost-effective. In this step, we assume that there are no changes in health and social care service use as a result of receiving respite care. Put another way, we are assuming that the provision of respite does not cause service use patterns in health and social care to increase or decrease. This first step is important because it serves as a benchmark to compare the results of the analysis when we do make assumptions about the impact of respite care on costs and QALYs in the second and third steps.

In the second step, we ask the Guideline Committee to estimate how receiving respite care would affect QALYs for the caregiver, the individual with learning disability and behavior that challenges, and any siblings. This step assumes that there are no changes in health, social care, or education costs as a result of receiving respite care (no changes in costs apart from the costs of respite care). The QALYs generated from the Guideline Committee are then compared to the minimum QALYs required from the first step. If the QALYs generated by the Guideline Committee are larger than the results from the threshold analysis, then this indicates that respite care is likely to be cost-effective based on Guideline Committee assumptions.

In the third step, we assume that providing respite care results in a reduction of service use in the future, and therefore a reduction in some costs. This was based on assumptions made by the Guideline Committee. Specifically, the Guideline Committee advised that respite care could reduce the likelihood of a placement breakdown at home, and therefore preventing admission into residential care for the individual with learning disabilities and behavior that challenges. The Guideline Committee were not sure how other services would be affected and we describe our assumptions regarding those services in the relevant section in the report. This section also includes sensitivity analyses to check how much the results change (and whether it remains cost-effective) depending on changes to the assumptions on service use. This analysis does not make assumptions about QALY gains. The results from this step are then used to understand if respite care has the potential to be cost-effective on the basis of it being cost-savings alongside the assumptions made about QALY gains as described by the Guideline Committee in step 2.

Taken together, the several analyses we undertake provide a range of different assumptions which help us to understand whether it is plausible for respite care to be cost-effective in the absence of robust evidence from randomized controlled trials.

### **3. Analysis**

#### **3.1 Threshold analysis**

How many QALYs does a certain intensity of respite care have to generate in order to be cost-effective at a threshold of £20,000 per QALY?<sup>2</sup>

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<sup>2</sup> We use the conservative threshold of £20,000 per QALY at NICE's request (rather than using the upper limit of £30,000 per QALY) because there is considerable uncertainty in our analysis.

- a. In this scenario we assume respite care does not impact on the use of public sector services (in particular, health, social care, and education). The results are presented in Table 6.

**Table 6** How many QALYs need to be generated for the care package to be cost-effective at a threshold of £20,000 per QALY?

<b>Child service user: respite care packages</b>										
Care package intensity	Low		Medium			High				
	1	2	1	2	3	1	2	3		
Minimum QALYs required per year	0.26	0.52	0.92	1.36	1.67	3.62	3.63	4.11		
<b>Adult service users: respite care packages</b>										
Care package intensity	Low		Medium				High			
	1	2	1	2	3	4	1	2	3	4
Minimum QALYs required per year	0.25	0.42	0.44	0.50	0.69	0.75	1.16	1.27	1.32	1.41

### 3.2 Guideline Committee assumptions about QALYs gained as a result of receiving respite care

The Guideline Committee should consider whether the minimum QALYs presented in step 1 (Table 6) is plausible. To help in this decision, we refer to the EQ-5D.

The ED-5D measures health-related quality of life, which forms the basis of the QALY. The EQ-5D measures whether individuals have no problems, some problems, or severe problems in 5 areas: anxiety/depression, pain/discomfort, self-care, usual activities, and mobility.

Our analysis depends on three questions:

1. How many QALYs might an individual have without respite care (as measured by the EQ-5D)?
2. How much of an impact could respite care have on improving an individual's QALY?
3. Based on the answer to question 1 and 2, above, are those assumed improvements larger or smaller than the minimum QALY gains illustrated in Table 6?

If the assumptions about improvements are *larger* than the QALYs in Table 6, then the Guideline Committee have decided that it is that those intensities of respite care are *possibly* cost-effective at a threshold of £20,000 per QALY.

### 3.2.1 How many QALYs might an individual have before receiving respite care?

To answer question 1, we asked the Guideline Committee members to assess what individuals' QALYs might be if they did not have respite care. This was in the context of the current provision of services available to most families.

Specifically, we asked the Guideline Committee to assess whether the absence of respite care would lead to a negative impact ("severe" or "some" problems) in any of the 5 areas of the EQ-5D.

Using the EQ-5D calculator provided by NICE, we generated corresponding QALYs based on the Guideline Committee's responses (Szende, Devlin, and Oppe, no date, [http://www.economicnetwork.ac.uk/health/Other\\_resources](http://www.economicnetwork.ac.uk/health/Other_resources)). This EQ-5D calculator is based on UK population preferences. Table 10 shows corresponding QALYs using the EQ-5D calculator.

Sixteen Guideline Committee members participated in the survey. Their answers are as follows:

#### a. The individual with learning disability and behaviour that challenges

There was strong agreement from the Guideline Committee that not having respite care would negatively affect the areas of self-care, ability to undertake usual activities, and anxiety/depression (81% said yes, 19% said no).

There was less agreement as to whether the absence of respite care would negatively affect the individual's mobility (63% said yes, 31% said no, and 6% did not know) and pain/discomfort (56% said yes, 38% said no, and 6% did not know) (Table 7).

**Table 7** Guideline Committee responses on the impact of not having respite care on the individual with learning disability and behaviour that challenges

Domain	Don't know	No	Yes
Mobility	6%	31%	63%
Self-care	0%	19%	81%
Ability to do usual activities	0%	19%	81%
Pain/discomfort	6%	38%	56%
Anxiety/depression	0%	19%	81%

#### b. Caregiver

There was strong agreement from the Guideline Committee that the absence of respite care would have a negative impact on the caregiver’s ability to undertake usual activities and anxiety/depression (94% said yes, 6% said no) and pain/discomfort (75% said yes, 19% said no, 6% did not know).

There was less agreement as to whether the absence of respite care would negatively impact the caregiver’s mobility (44% said yes, 38% said no, and 19% did not know) and self-care (56% said yes, 31% said no, and 13% did not know) (Table 8).

**Table 8** GC response on the impact on caregivers

Domain	Don't know	No	Yes
Mobility	19%	38%	44%
Self-care	13%	31%	56%
Ability to do usual activities	0%	6%	94%
Pain/discomfort	6%	19%	75%
Anxiety/depression	0%	6%	94%

c. Siblings

There was strong agreement from the Guideline Committee that the absence of respite care would have a negative impact on siblings’ anxiety/depression (88% said yes, 13% said no) and ability to undertake usual activities (81% said yes, 19% said no).

There was less agreement as to whether the absence of respite care would negatively impact siblings’ self-care (50% said yes, 44% said no, and 6% did not know).

There was little support for the possibility that the absence of respite care would negatively impact siblings’ mobility (50% said no effect, 25% said yes, 25% did not know) and pain/discomfort (44% said no effect, 44% said yes, 13% did not know) (Table 9).

**Table 9** GC response on the impact on siblings

Domain	Don't know	No	Yes
Mobility	25%	50%	25%
Self-care	6%	44%	50%
Ability to do usual activities	0%	19%	81%
Pain/discomfort	13%	44%	44%
Anxiety/depression	0%	13%	88%

We decided that if 70% or more of the Guideline Committee agreed then we would include those areas of the EQ-5D in the analysis. As such, this analysis assumes a negative impact in the following areas of the EQ-5D:

- Individual with learning disability and behaviour that challenges
  - a. Anxiety/depression
  - b. Ability to undertake usual activities
  - c. Self-care
- Caregiver
  - d. Anxiety/depression
  - e. Ability to undertake usual activities
  - f. Pain/discomfort
- Sibling
  - g. Anxiety/depression
  - h. Ability to undertake usual activities

For example, caregivers are assumed to have 0.19 QALYs and this is based on the Guideline Committee assumption that they have ‘severe problems’ in the areas of ability to undertake usual activities, anxiety/depression, and pain/discomfort and ‘no problems’ in the areas of self-care and mobility.

On the other hand, caregivers are assumed to have 0.68 QALYs based on the Guideline Committee assumption that they have “some problems” (and not severe problems) in those three aforementioned areas.

If individuals were in perfect health, then they would have 1 QALY, as represented by each individual having “no problems” in each of the five areas of the EQ-5D.

**Table 10** Potential QALYs before receiving respite care

	Individual with learning disability and behaviour that challenges	Caregiver	Sibling
Severe problems	0.09	0.19	0.37
Some problems	0.68	0.68	0.78
No problems	1.0	1.0	1.0

### 3.2.2 Are there QALY estimates for our population in the literature?

Some Guideline Committee members and NICE asked us to check whether assumed QALYs were plausible and realistic. They thought that our QALY assumptions (before receiving respite care) might be unrealistic and too low. In other words, that we might have overestimated the negative impact of **not** having respite care on people’s QALYs.

NICE have asked us to dig deeper and see if we could find evidence about QALYs elsewhere in the research literature.

In summary, we found that our QALY assumptions were *substantially lower* when compared to QALYs for somewhat similar population groups.

However, we cannot be entirely sure that our QALY estimates are too low because those studies have limitations – either because:

- (1) the populations were not for people with learning disability and behaviour that challenges or
- (2) because of limitations in the methods used to measure QALYs

In our search we did not find QALYs for:

- individuals with learning disabilities and behaviour that challenges
- their caregivers
- their siblings

However, we did find evidence from:

- children with autism
- caregivers of older people with dementia

### **Evidence from children with autism**

We found 1 study with a moderate sample size (n=154) (NICE 2015, NG 11, p 232-43, citing Tilford et al 2012). This was based on a sample of children with autism, aged between 7 and 14 years.

The strength of using that study is that the sample is based on different levels of aggression, hyperactivity, compulsive behaviour and attention, all of which are related to behaviour that challenges (NICE 2015, NG 11, p 232-33, citing Tilford et al 2012).

This study has limitations because:

- they did not measure QALYs using the EQ-5D tool that NICE requires and
- the study is not from the UK (study is based on data from Canada and the USA)

Nevertheless, that study found QALYs to range between 0.50 and 0.82 for children with autism. Our assumptions ranged between 0.09 QALYs and 0.68 QALYs, which depended on whether we assumed “severe” or “some” problems. In conclusion, some of our assumptions are substantially lower than what was found in that one non-UK study.

### **Evidence from caregivers of individuals with dementia**

We found 4 studies that measured QALYs for caregivers of older people with dementia (Woods et al 2012, Knapp et al 2013, Aguirre et al 2014, Charlesworth et al 2008).

The strength of those studies is that they measured QALYs using the EQ-5D and these studies come from the UK.

However this study is limited because caregiving hours were not reported and it is not clear whether they are comparable enough to caregivers of individuals with learning disabilities and behaviour that challenges who live with their children. This means that, for some of the studies, we do not know enough about what those QALY scores reflect.

Nevertheless, those 4 UK studies found QALYs ranging from 0.73 to 0.95. Our assumptions ranged from 0.19 to 0.68 QALYs, which depended on whether we assumed “severe” or “some” problems. In conclusion, some of our assumptions are substantially lower than what was found in those 4 UK studies.

### **3.2.3 What does the Guideline Committee think of those QALY estimates?**

After reviewing the available research, the Guideline Committee decided to stick to their original QALY estimates for people with learning disability and behaviour that challenges, their caregivers, and siblings.

#### *QALYs for individuals with learning disabilities and behaviour that challenges*

They believed that QALYs for people with learning disabilities and behaviour that challenges could very well be very low.

1. If challenging behaviour is very extreme, that would indicate stress, and therefore lower quality of life. If carers cannot cope, then individuals would not have their needs met, become stressed, and their behaviour may become challenging.

#### *QALYs for caregivers*

The Guideline Committee also believed that QALYs for caregivers could be very low. NICE challenged the Guideline Committee in saying that caregivers of those with dementia had higher levels of quality of life and asked the Guideline Committee to demonstrate how caring for those with learning disability and behaviour that challenges was more difficult?

1. The GC responded by saying that dementia caregivers do not experience stigma and blame, whereas caregivers of people with learning disabilities and behaviour that challenges do experience stigma and blame.
2. Caregivers of people with dementia have hope that this caregiving experience will end, whereas for caregivers of people with learning

disabilities and behaviour that challenges, they find out their child has behaviour that challenges at age 4 and they realise this lasts the entire lifetime. There is a feeling of hopelessness and desperation.

3. Caregivers of people with dementia do not lose the support of their family and social networks whereas caregivers of people with LD and BtC often have their marriages ended and their family and social support often falls away.
4. Caregivers of older people with dementia are dealing with individuals who are most likely weaker than they, whereas caregivers of people with learning disabilities and behaviour that challenges are usually dealing with greater physical risks as the individuals are younger and stronger than they.
5. Caregivers of people with dementia may not always living with the individual, or if they are, they are not simultaneously providing care to other people (i.e. children) whereas caregivers of people with learning disabilities and behaviour that challenges are providing care to other people simultaneously.
6. People with dementia most likely do not have a 3:1 ratio of staffing as seen in day care or residential homes, whereas people with severe behaviour that challenges is likely to have a staffing ratios of 3:1 and even in those cases there is still staff burnout.

#### *QALYs for siblings*

1. As their parent is unable to provide time and support, siblings might not be able to undertake their usual activities and this can lead to feeling depressed.
2. As the parent's time is consumed by caregiving, the emotional needs of the sibling is unlikely to be met, and sustained lack of support can lead to feelings of emotional distress.
3. The sibling is likely to feel stigma.
4. The sibling is unable to have a 'normal' living environment as the home may need to be drastically changed to accommodate the individual with learning disability and behaviour that challenges.
5. Changes in the home environment and the needs of the individual with behaviour that challenges might mean they are unable to or have difficulty carrying out usual activities, including inviting over their friends.

#### **3.2.4 What did the Guideline Committee assume about the effect of respite care on improving people's QALYs?**



The Guideline Committee advised that respite could lead to large, moderate, or small improvements on the EQ-5D. This is represented as an improvement from:

- “large improvement” severe to no problems
- “moderate improvement” severe to some problems
- “small improvement” some to no problems

Those improvements were based on a mix of assumptions and research that:

- respite care is assumed to be effective in improving QALYs for individuals with learning disability and behaviour that challenges, their caregivers, and siblings
- the intensity of respite care provision corresponds to a reduction in caregiving hours which would improve caregiver and siblings’ QALYs.

This assumption is supported in research. One UK study and one Swedish study focusing on caregivers of people with dementia found that caregivers’ self-reported health was strongly correlated with time spent caring and caregivers’ perceived burden (Hounscome 2011, p.396, citing Andren and Elmstahl 2008 and Dixon et al 2006).

**Table 11** Assumed potential QALY gains *after* receiving respite care

	Severe → None	Severe → Some	Some → None
Individual with learning disability and behaviour that challenges	+0.91	+0.58	+0.32
Caregiver	+0.81	+0.60	+0.32
Sibling	+0.63	+0.41	+0.22
*QALY gains in this table are based on Guideline Committee assumptions.			

Based on the results in Table 11, we then perform scenario analyses which ask whether various intensities of respite care is cost-effective depending on the total QALYs gained depending on family size.

**Table 12** Total QALY gains for different family sizes and assumptions about who is affected

Family unit		QALY gains		
		“Large improvement”	“Moderate improvement”	“Small improvement”
		Severe → No problems	Severe → Some problems	Some → No problems
1 person	Individual LD BtC	+0.91	+0.58	+0.32
2 people	+ 1 Individual LD BtC + 1 caregiver	+1.71	+1.19	+0.64
3 people	+ 1 Individual LD BtC + 1 caregiver + 1 sibling	+2.34	+1.60	+0.86
	+ 1 Individual LD BtC + 2 caregivers	+2.52	+1.79	+0.96
4 people	+ 1 Individual LD BtC + 1 caregiver + 2 siblings	+2.97	+2.00	+1.08
	+ 1 Individual LD BtC + 1 sibling + 2 caregivers	+3.15	+2.20	+1.17
5 people	+ 1 Individual LD BtC + 2 caregivers + 2 siblings	+3.78	+2.61	+1.39
<p>Note: LD BtC = learning disability and behaviour that challenges</p> <p>The results in this table are obtained by summing the figures in Table 11.</p>				

By comparing Table 6 with Table 12 (above), we can check whether the minimum QALY gains required are plausible. This comparison is illustrated in Table 13 and Table 14 (for children and adults with learning disabilities and behaviour that challenges, respectively).

### **3.3 Results from comparison of threshold analysis to Guideline Committee assumptions about QALY gains**

Table 13 (for children) and Table 14 (for adults) show that, assuming no changes in public sector service use (costs), there are potentially cost-effective respite care packages that could be provided. In Tables 13 and 14, cost-effective scenarios are indicated with “yes” whereas non cost-effective scenarios are indicated with “no.”

Table 13 and 14 are understood by comparing the QALYs in the top row to the QALYs in the left column. The QALYs in the top row are the minimum QALY gains that are needed to make respite care cost-effective. The QALYs in the left-most column are Guideline Committee assumptions about the potential QALY gains as a result of receiving respite care.

For example, the minimum QALYs required for low-intensity respite care #1 is 0.26 QALYs, if we assume that there is only 1 person benefitting from respite care (the person with learning disability and behaviour that challenges), then the Guideline Committee have assumed a QALY gain of 0.91 QALYs. Since the Guideline Committee assumption is greater than the minimum QALYs required (0.91 vs. 0.26 QALYs), respite care is cost-effective in this scenario, and therefore that box is marked with a “yes.” If we assume that there are 2 people benefitting (the person with learning disability and behaviour that challenges and their caregiver) then the Guideline Committee assumed a potential QALY gain of 1.72 QALYs. This scenario shows that respite care is also cost-effective since the Guideline Committee assumption is greater than the minimum QALYs required (1.72 vs. 0.26 QALYs).

#### **Observations from the analysis**

1. If we assume that the impact of respite care on QALYs results in small improvements, then more costly and intensive respite care packages are not plausibly cost-effective.

However, costly and intensive respite care packages are plausibly cost-effective if we assume that respite care delivers moderate or large improvements.

2. More costly and intensive respite care packages are plausibly cost-effective if we assume that QALY gains accrue to more people, i.e. the individual with learning disability with behaviour that challenges and their caregiver(s) and sibling(s).
3. It is important to emphasize that these scenarios assume that as a result of receiving respite care, there are no significant changes in the use of public sector services (i.e. healthcare services, social care services, education services, etc.).

**Table 13** Children’s respite care packages: the plausibility of respite care being cost-effective assuming no changes in service use

<b>Minimum QALYs for the care package to be cost-effective at £20,000/QALY</b>									
Intensity of respite care			Low		Medium			High	
			1	2	1	2	3	1	2
Minimum QALYs required to be cost-effective			0.26 QALYs	0.52 QALYs	0.92 QALYs	1.36 QALYs	1.67 QALYs	3.14 QALYs	3.63 QALYs
<b>Assumed QALYs gained per year, in total, depending on family size</b>									
<b>Scenario 1: Large improvements in QALYs</b>									
1 person	Individual LD BtC	0.91 QALYs	Yes	Yes	Yes/No	No	No	No	No
2 people	+ 1 Individual LD BtC + 1 caregiver	1.72 QALYs	Yes	Yes	Yes	Yes	Yes	No	No
3 people	+ 1 Individual LD BtC + 1 caregiver + 1 sibling	2.34 QALYs	Yes	Yes	Yes	Yes	Yes	No	No
	+ 1 Individual LD BtC + 2 caregivers	2.52 QALYs	Yes	Yes	Yes	Yes	Yes	No	No
4 people	+ 1 Individual LD BtC + 1 caregiver + 2 siblings	2.97 QALYs	Yes	Yes	Yes	Yes	Yes	No	No
	+ 1 Individual LD BtC + 1 sibling + 2 caregivers	3.15 QALYs	Yes	Yes	Yes	Yes	Yes	Yes/No	No
5 people	+ 1 Individual LD BtC + 2 caregivers + 2 siblings	3.78 QALYs	Yes	Yes	Yes	Yes	Yes	Yes	Yes
<b>Scenario 2: Moderate improvements in QALYs</b>									
1 person	Individual LD BtC	0.59 QALYs	Yes	Yes	No	No	No	No	No
2 people	+ 1 Individual LD BtC + 1 caregiver	1.19 QALYs	Yes	Yes	Yes	No	No	No	No
3 people	+ 1 Individual LD BtC + 1 caregiver + 1 sibling	1.60 QALYs	Yes	Yes	Yes	Yes	No	No	No
	+ 1 Individual LD BtC + 2 caregivers	1.79 QALYs	Yes	Yes	Yes	Yes	Yes	No	No
4 people	+ 1 Individual LD BtC + 1 caregiver + 2 siblings	2.00 QALYs	Yes	Yes	Yes	Yes	Yes	No	No
	+ 1 Individual LD BtC + 1 sibling + 2 caregivers	2.20 QALYs	Yes	Yes	Yes	Yes	Yes	No	No
5 people	+ 1 Individual LD BtC + 2 caregivers + 2 siblings	2.61 QALYs	Yes	Yes	Yes	Yes	Yes	No	No

<b>Scenario 3: Small improvements in QALYs</b>									
1 person	Individual LD BtC	0.32 QALYs	Yes	No	No	No	No	No	No
2 people	+ 1 Individual LD BtC + 1 caregiver	0.64 QALYs	Yes	Yes	No	No	No	No	No
3 people	+ 1 Individual LD BtC + 1 caregiver + 1 sibling	0.86 QALYs	Yes	Yes	No	No	No	No	No
	+ 1 Individual LD BtC + 2 caregivers	0.96 QALYs	Yes	Yes	Yes	No	No	No	No
4 people	+ 1 Individual LD BtC + 1 caregiver + 2 siblings	1.08 QALYs	Yes	Yes	Yes	No	No	No	No
	+ 1 Individual LD BtC + 1 sibling + 2 caregivers	1.17 QALYs	Yes	Yes	Yes	No	No	No	No
5 people	+ 1 Individual LD BtC + 2 caregivers + 2 siblings	1.39 QALYs	Yes	Yes	Yes	Yes	No	No	No

**Table 14** Adults' respite care packages: the plausibility of respite care being cost-effective assuming no changes in service use

Minimum number of QALYs for the care package to be cost-effective at £20,000/QALY												
Intensity of respite care			Low		Medium				High			
			1	2	1	2	3	4	1	2	3	4
Minimum QALYs required			0.25	0.42	0.44	0.50	0.69	0.75	1.16	1.27	1.32	1.41
Number of QALYs generated (per year, in total) depending on family size												
Scenario 1: Large improvements in QALYs												
1 person	Individual LD BtC	0.91 QALYs	Yes	Yes	Yes	Yes	Yes	Yes	No	No	No	No
2 people	+ 1 Individual LD BtC + 1 caregiver	1.71 QALYs	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
3 people	+ 1 Individual LD BtC + 1 caregiver + 1 sibling	2.34 QALYs	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
	+ 1 Individual LD BtC + 2 caregivers	2.52 QALYs	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
4 people	+ 1 Individual LD BtC + 1 caregiver + 2 siblings	2.97 QALYs	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
	+ 1 Individual LD BtC + 1 sibling + 2 caregivers	3.15 QALYs	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
5 people	+ 1 Individual LD BtC + 2 caregivers + 2 siblings	3.78 QALYs	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Scenario 2: Moderate improvements in QALYs												
1 person	Individual LD BtC	0.59 QALYs	Yes	Yes	Yes	Yes	No	No	No	No	No	No
2 people	+ 1 Individual LD BtC + 1 caregiver	1.19 QALYs	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	No	No
3 people	+ 1 Individual LD BtC + 1 caregiver + 1 sibling	1.60 QALYs	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
	+ 1 Individual LD BtC + 2 caregivers	1.79 QALYs	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
4 people	+ 1 Individual LD BtC + 1 caregiver + 2 siblings	2.00 QALYs	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
	+ 1 Individual LD BtC + 1 sibling + 2 caregivers	2.20 QALYs	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
5 people	+ 1 Individual LD BtC + 2 caregivers + 2 siblings	2.61 QALYs	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Scenario 3: Small improvements in QALYs												
1 person	Individual LD BtC	0.32 QALYs	Yes	No	No	No	No	No	No	No	No	No
2 people	+ 1 Individual LD BtC + 1 caregiver	0.64 QALYs	Yes	Yes	Yes	Yes	No	No	No	No	No	No
3 people	+ 1 Individual LD BtC + 1 caregiver + 1 sibling	0.86 QALYs	Yes	Yes	Yes	Yes	Yes	Yes	No	No	No	No
	+ 1 Individual LD BtC + 2 caregivers	0.96 QALYs	Yes	Yes	Yes	Yes	Yes	Yes	No	No	No	No
4 people	+ 1 Individual LD BtC + 1 caregiver + 2 siblings	1.08 QALYs	Yes	Yes	Yes	Yes	Yes	Yes	No	No	No	No
	+ 1 Individual LD BtC + 1 sibling + 2 caregivers	1.17 QALYs	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	No	No
5 people	+ 1 Individual LD BtC + 2 caregivers + 2 siblings	1.39 QALYs	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes/No

### 3.4 Assuming respite care changes the use of public sector services and costs

The earlier analysis in section 3.3 assumed no changes in public sector services and costs. Put another way: by receiving respite care, we assumed there would be no changes in the use of health, social care, or education services.

In this section we undertake a cost-offset analysis, which explores whether various intensities of respite care could be cost-effective only based on changes in the use of public sector costs. This means, for the time being, this analysis ignores any potential change in QALYs. Put another way, we are assuming that receiving respite care results in no change in people's QALYs.

#### What cost-offsets are included in the analysis?

Given the absence of research on the impact of respite care on public sector costs, this analysis makes assumptions about what public sector services might change as a result of receiving respite care.

In particular, the Guideline Committee advised that the most likely change in service use would be prevention or delay of a placement breakdown (in the family home) that would otherwise lead to a residential placement for both children and adults with learning disabilities and behaviour that challenges.

Therefore, this cost-offset analysis only considers this aspect of service use. The following sections show what data we used for the calculation. The analysis requires the following information:

1. The baseline probability of a placement breakdown for children and adults with learning disability and behaviour that challenges.

2. The typical service use and costs that an individual incurs if they lived in the family home.
3. The typical service use and costs that an individual incurs if they live in a residential placement.
4. Assumptions about the duration that an individual remains in a residential placement after a breakdown in the family home.
5. Assumptions about the effectiveness of respite care on reducing that baseline probability of a breakdown in the family home.

The next section, 3.4.1, presents the data and results for the cost-offset analysis for children, whereas section 3.4.2 presents results for adults.

### 3.4.1 Child with learning disability and behaviour that challenges

- a. **Likelihood of placement breakdown.** Based on available research data, approximately 21.5% of school-aged children with learning disability and behaviour that challenges are in specialist residential education placements. Detail on how this figure was obtained is available in Appendix 1.
- b. **Costs of living in the family home compared to costs of specialist residential education placement.** Lemmi et al. (2015: 10) find that the average cost of services received by children with learning disabilities and behaviour that challenges when living in the family home ranges from £90, £156, and £160/week – an average cost of £136 per week (£7,048/year).<sup>3</sup> These costs include the use of health, social care, and mental health care services. These estimates include some level of respite care, but it is not clear how much.

Lemmi et al (2015) find the cost of 38-week and 52-week residential education placement to be £116,900 and £181,735 per year, respectively.<sup>4</sup> The average cost of these is £149,318 per year.

- c. **The cost-offset analysis.** Figure 1 provides a visual description of the analysis. The data shown in that diagram are the 'base-case' values as it assumes it is the "average" population-level scenario.

The sensitivity analysis shows how much the cost-effectiveness results change when the values move toward extremes. If the results are still cost-effective, that helps us feel more confident in light of highly uncertain data.

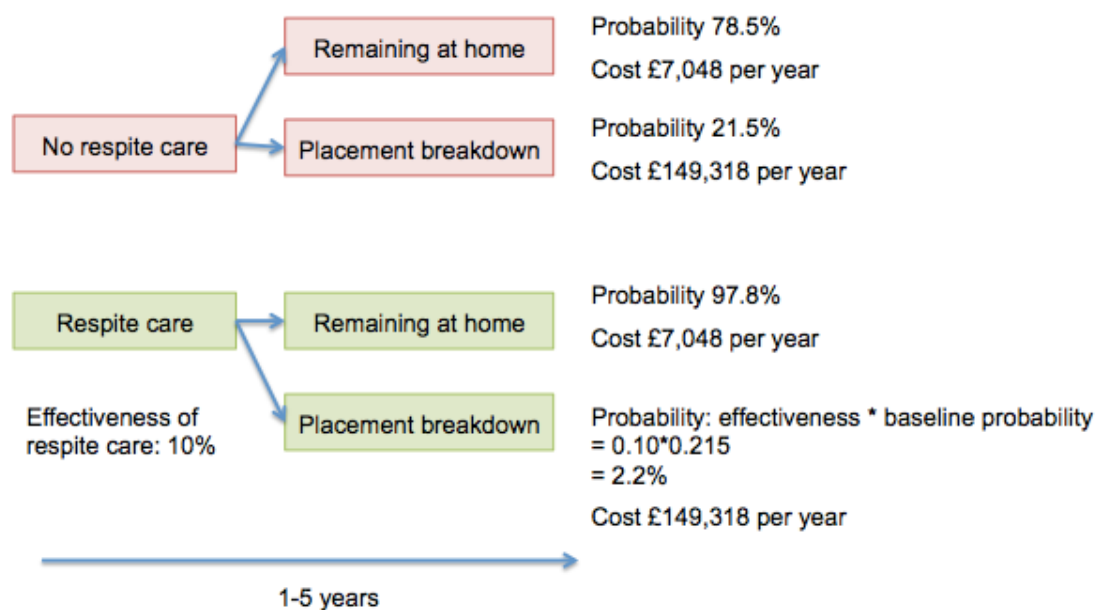
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<sup>3</sup> Inflated from 2012/13 to 2015/16 prices using Curtis and Burns (2016).

<sup>4</sup> Inflated from 2012/13 to 2015/16 prices using Curtis and Burns (2016).



**Figure 1** Base-case cost-offset analysis for children



#### d. Results

**Base-case analysis:** Table 15 shows that respite care is **cost-saving** when assuming:

- 1 year or 5 years residential placement duration
- 21.5% chance of placement breakdown
- 10% effectiveness of respite care in preventing a placement breakdown
- Average cost of residential care is £149,319/year
- 3.5% discount rate over a 5-year period

**Sensitivity analysis:** Table 15 shows that respite care is still **cost-saving** when assuming:

- 1 year or 5 years residential placement duration
- 1% chance of placement breakdown
- 1% effectiveness of respite care in preventing a placement breakdown
- Lower cost estimate of residential care cost is used (£116,900/year)
- 3.5% discount rate over a 5-year period

To use an example to understand Table 15, a scenario that uses a 1-year time horizon shows that respite care at low-level intensity 1 (which costs £12,297) generates a total cost-savings of -£2,946. These results reflect the base-case scenario parameters, such as a 21.5% probability of a placement breakdown, a 10% effectiveness of respite care in reducing that probability of breakdown, and the cost of residential care resulting from a breakdown is £149,318 per year.

**Table 15** Cost-offset analysis: child with learning disabilities and behaviour that challenges

<b>Parameters</b>								
Probability of placement breakdown		Effectiveness of respite care			Cost of residential care, £ / year			
Base-case	Sensitivity analysis	Base-case	Sensitivity analysis		Base-case	Sensitivity analysis		
21.5%	1%	10%	1%		149,318	116,900		
Total costs of living at home + respite care, £ / year								
Low-intensity respite care		Medium-intensity respite care			High-intensity respite care			
1	2	1	2	3	1	2		
12,297	17,547	25,540	34,289	40,463	69,881	79,697		
<b>Changes in total net costs (£)</b>								
<b>1 year time horizon</b>								
Base-case		-2,946	-2,833	-2,661	-2,473	-2,340	-1,708	-1,497
Sensitivity analysis		-10	-214	-196	-247	-164	-101	-80
<b>5-year time horizon (total cost savings – not yearly cost savings)</b>								
Base-case		-13,767	-13,239	-12,436	-11,557	-10,937	-7,981	-6,995
Sensitivity analysis		-49	-998	-918	-1,156	-768	-472	-374
<b>Cost-effective?</b>								
In all of the analyses, both base-case and sensitivity analyses, the results show that respite care, under those assumptions, generates cost-savings.								

### 4.3.2 Adults with learning disability and behaviour that challenges

- a. **Likelihood of placement breakdown.** We do not know the prevalence of adults living in the family home and we do not know the prevalence of adults living in residential care.

**Assumption.** We assume a 10% chance of adults going into residential care or supported living as a result of a placement breakdown in the family home, which we view to be a conservative estimate.

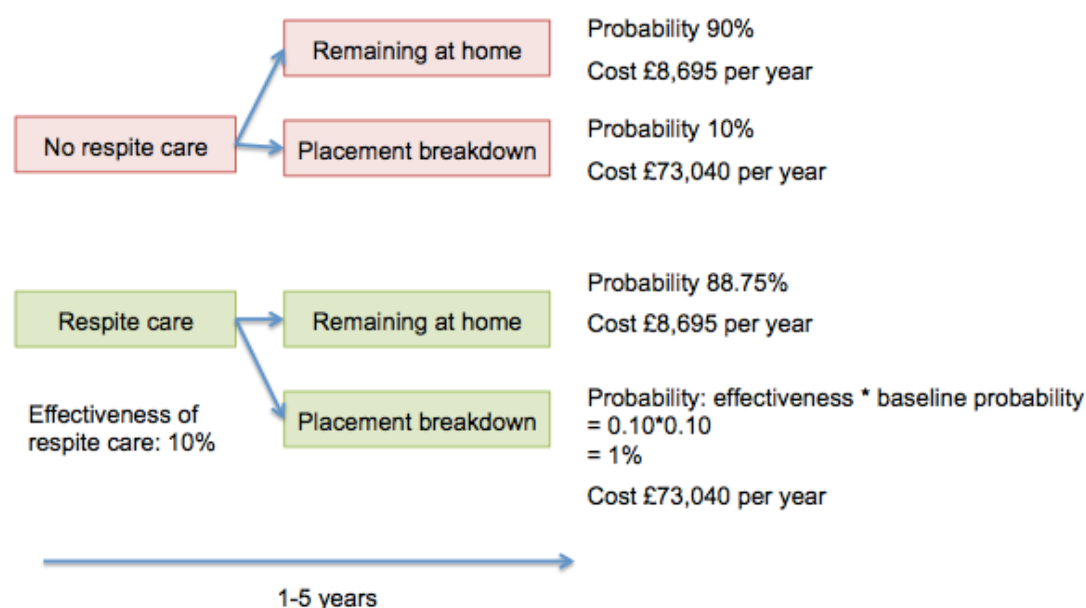
- b. **Costs of living in the family home compared to residential placement or supported living.** Lemmi et al. (2015: 10) find the average cost of services received by adults with learning disabilities and behaviour that challenges when living in the family home ranges from £160 to £174 per week – the mean being £167 per week or £8,695 per year.<sup>5</sup> These costs include health, social care, and mental health services. These estimates include some level of respite care, but the amount is not reported.

Lemmi et al. (2015) find the cost of residential care and supported living is £57,747 and £88,332 per year.<sup>6</sup> We use a mean cost of £73,040 per year.

- c. **The cost-offset analysis.** Figure 2 provides a visual description of the analysis. The data shown in that diagram are the ‘base-case’ values as it assumes it is the “average” population-level scenario.

The sensitivity analysis shows how much the cost-effectiveness results change when the values move toward extremes. If the results are still cost-effective, that helps us feel more confident in light of highly uncertain data.

**Figure 2** Base-case cost-offset analysis for adults



<sup>5</sup> Inflated from 2012/13 to 2015/16 prices using Curtis and Burns (2016).

<sup>6</sup> Inflated from 2012/13 to 2015/16 prices using Curtis and Burns (2016).

## d. Results

### Base-case analysis

Table 16 shows that respite care is **cost-saving** when assuming:

- 1 year or 5 years residential placement duration
- 10% chance of placement breakdown
- 10% effectiveness of respite care in preventing a placement breakdown
- Average cost of residential care or supported living is £73,040/year
- 3.5% discount rate over a 5-year period

### Sensitivity analysis

Table 16 shows that respite care is still **cost-savings** even if we assume:

- 1 year or 5 years residential placement duration
- 1% chance of placement breakdown
- 1% effectiveness of respite care in preventing a placement breakdown
- Lower-cost estimate of residential care and supported living is used (£57,747 per year)
- 3.5% discount rate over a 5-year period

To use an example to understand Table 16, a scenario that uses a 1-year time horizon shows that respite care at low-level intensity 1 (which costs £13,706) generates a total cost-savings of -£593. These results reflect the base-case scenario parameters, such as a 10% probability of a placement breakdown, a 10% effectiveness of respite care in reducing that probability of breakdown, and the cost of residential care resulting from a breakdown is £73,040 per year.

**Table 16** Cost-offset analysis: adult with learning disabilities and behaviour that challenges

<b>Parameters</b>									
Probability of placement breakdown			Effectiveness of respite care				Cost of residential care, £ / year		
Base case		Sensitivity analysis	Base case		Sensitivity analysis	Base case		Sensitivity analysis	
10%		1%	10%		1%	73,040		57,747	
<b>Total costs of living at home + respite care, £ / year</b>									
Low intensity respite care		Medium intensity respite care				High intensity respite care			
1	2	1	2	3	4	1	2	3	4
13,706	17,159	17,511	18,641	22,522	23,652	31,903	38,276	35,059	41,924
<b>Changes in total net costs (£)</b>									
<b>1-year time horizon</b>									
Base case									
-593	-559	-555	-544	-505	-494	-411	-390	-348	-311
Sensitivity analysis									
-4	-41	-40	-39	-35	-34	-26	-24	-19	-16
<b>5-year time horizon (total cost savings – not yearly cost savings)</b>									
Base case									
-2,773	-2,611	-2,595	-2,542	-2,361	-2,308	-1,922	-1,820	-1,625	-1,454
Sensitivity analysis									
-21	-190	-188	-183	-165	-159	-121	-111	-91	-74
<b>Cost-effective?</b>									
In all of the analyses, both base-case and sensitivity analyses, the results show that respite care, under those assumptions, generates cost-savings.									

## 5. Conclusions

Based on the assumptions made by the Guideline Committee, our analysis demonstrates that *additional* respite care, at various intensities, is cost-effective and potentially cost-saving option (from a public-sector perspective) for both child and adults with learning disabilities and behaviour that challenges.

In section 3.3, the analysis assumes no changes in the use of public sector services but the Guideline Committee assumed respite care leads to improvements in people's QALYs (which includes the individual with learning disability and behaviour that challenges, the caregiver, and siblings). In those analyses and using those assumptions, there were intensities of respite care that were cost-effective at £20,000 per QALY.

In section 3.4, the cost-offset analysis assumed that respite care could prevent or delay a breakdown in the family home that would otherwise result in a move into residential care. In these analyses, all intensities of respite care were cost-savings when we assumed time horizons of 1 or 5 years, a baseline probability of placement breakdown to be 21.5% for children and 10% for adults, and when we assumed either a 10% effectiveness of respite care in reducing the likelihood of a placement breakdown. Importantly, respite care remained cost-saving even when we undertook sensitivity analysis and assumed that the baseline probability of breakdown is 1%, that respite care is 1% effective, and when using the lower cost estimates of residential care.

However, as our analysis is mainly built on assumptions, our analysis is very limited and we must stress that these assumptions are not based on evidence from effectiveness or cost-effectiveness studies.

At the same time, in the absence of such evidence, the analysis we conducted in this report is a second-best approach as it helps identify the key assumptions about costs and QALYs that would be necessary in order for different intensities of respite care to be cost-effective or cost-savings.

- As the analyses are based on assumptions, we advise extreme caution in drawing conclusions about the cost-effectiveness of respite care. This is because we do not know the validity of any assumptions made and whether certain scenarios are plausible or not plausible.

For this reason, we are very cautious about using these analyses when guiding commissioning and provision decisions. We are only confident about the potential range of respite care costs used in the analyses. Beyond that, these scenarios analyses are speculative and their validity cannot be confirmed.

More research is needed to understand the intensities, costs, effectiveness, and cost-effectiveness of respite care that is currently provided to children and adults with intellectual disabilities and behaviour that challenges.

## **Appendix 1 – Prevalence of children with learning disability and behaviour that challenges in specialist residential education placements**

We estimated that between 5.2% and 21.5% of children with learning disability and behaviour that challenges are in residential education placements. The 5.2% reflects children in local authority maintained special schools. A figure of 21.5% reflects both those in local authority maintained schools and specialist independent schools. These estimates do not include the potential number of children with learning disability and behaviour that challenges who may be in non-maintained special schools (4084 children) (Pinney et al. 2014: 18). This is because the researchers did not have enough information to estimate the percentage of those 4084 children who may have learning disability and behaviour that challenges.

It is important to note that these estimates (5.2% and 21.5%) were pieced together using the available but limited amount of research. This is because there is poor data collection in this area. This conclusion is supported in research.

Researchers recognise that there is a lack of comprehensive data collection around: (1) the total number of children with learning disabilities and behaviour that challenges in specialist residential schools, (2) the types of placement they are in, and (3) the costs of those placements (Pinney et al. 2014: 4).

Estimates of 5.2% and 21.5% are based on these data (below).

We have estimated that 5.2% of children with learning disabilities and behaviour that challenges are in local authority maintained specialist residential schools. This is based data that:

- There are 41,547 children with learning disability and behaviour that challenges (NICE 2015: 23, citing Emerson et al. 2014: 4).
- Focusing on school-aged children between ages 6 to 18, this amounts to approximately 26,256 or children with learning disabilities and behaviour that challenges (Emerson et al 2014: 4).
- Emerson et al. (2014: 4) estimates that there are 1360 children with learning disabilities and behaviour that challenges are in local authority maintained specialist residential schools (NICE 2015).
- Therefore:  $1360/26,256$  school-aged children = 5.2%.

We have estimated that 21.5% of children with learning disabilities and behaviour that challenges are in local authority maintained specialist residential schools. This is based on numbers from above plus:

- In 2013, Pinney et al. (2014: 19) estimated that there were 11,265 children in independent specialist residential placements (Pinney et al. 2014: 19) with a statement of special education needs, and that in 2008, 38% of children in those settings had statements for learning

disability or autism spectrum disorder (Pinney et al. 2014: 4, 17); they then assume that approximately 4280 more children might be categorised as having learning disability and behaviour that challenges.

- If we include estimates from independent specialist residential placements, then the total prevalence in specialist residential schools is around 21.5% (5640/26,256).

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