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'.

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 respite care options, we illustrated a range of respite care intensities, and our analysis is based on those examples.

We illustrated the costs of 8 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 £82,000 per year. It is important to note that 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 without actually prescribing a specific type of respite care. This is the only feasible approach given the lack of a specific recommendation and the absence of effectiveness evidence.

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

We illustrated 8 example respite care packages for children. These include 2 low-intensity, 3 medium-intensity and 3 high-intensity respite care packages. Descriptions of these packages, unit costs, and total costs are provided in Table 1 and Table 2 below. The range of respite care package costs for children is between £5,249 and £82,118 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 £36,913 per adult per year (2015/16 prices).

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

	Low intensity 1	**Low intensity 2**	**Medium intensity 1**	**Medium intensity 2**	**Medium intensity 3**
Total cost of respite per year	**£5,249**	**£10,499**	**£18,492**	**£27,241**	**£33,415**
Respite 1	**Home support** Term-time (38 weeks) 6 hours per week	**Home support** Term-time (38 weeks) 12 hours per week	**Home support** Term-time (38 weeks) 10 hours per week	**Home support** Term-time (38 weeks) 20 hours per week	**Overnight support** 52 weeks 5 days/week 12 hour per day
Unit cost	£23/hour	£23/hour	£23/hour	£23/hour	£91 for 12 hours
Cost	£5,249	£10,499	£8,749	£17,498	£23,672
Respite 2			**Day-care (summer)** 5 days/week for 14 weeks	**Day-care (summer)** 5 days/week for 14 weeks	**Day-care (summer)** 5 days/week for 14 weeks
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

	High intensity 1	**High intensity 2**	**High intensity 3**
Total respite cost per year	**£72,301**	**£72,649**	**£82,118**
Respite 1	**Residential care** 5 days/week 38 weeks	**Residential care** 5 days/week 52 weeks	**Residential care** 5 days/week 52 weeks
Unit cost	£279/24 hours	£279/24 hours	£279/24 hours
Cost	£53,089	£72,649	£72,649
Respite 2	**Day-care (summer)** 5 days/week 12 hours/day 14 weeks		**Overnight support** 5 days/week 12 hours/day 52-weeks
Unit cost	£139/day		£91 for 12 hours
Cost	£9,743		£9,469
Respite 3	**Overnight support** 5 days/week, 12 hours/day 52 weeks		
Unit cost	£91 for 12 hours		
Cost	£9,469		

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**
Total respite cost per year	**£5,011**	**£8,464**	**£8,816**	**£9,946**	**£13,826**	**£14,957**
Respite 1	**Day care** 3 days/month 12 months	**Home support** 4 weeks/year 12 hours/day	**Day-time support** 2 days/month 12 hours/day	**Home support** 3 days/week 12 hours/day	**Day-time support** 2 days/month 12 hours/day	**Home support** 3 days/week 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
Respite 2		**Overnight support** 8 nights/year 12 hours	**Overnight support** 24 nights/year 12 hours		**Overnight support** 24 nights/year 12 hours	**Day care** 3 days/month 12 months
Unit cost		£91 / 12 hours	£91/12 hours		£91/12 hours	£139/day
Cost		£728	£2,185		£2,185	£5,011
Respite 3					**Day care** 3 days/month 12 months	
Unit cost					£139/day	
Cost					£5,011	

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

	High intensity 1	**High intensity 2**	**High intensity 3**	**High intensity 4**
Total respite cost per year	**£23,207**	**£25,393**	**£26,364**	**£28,218**
Respite 1	**Home support** 12 hours/day 7 days/week 12 weeks	**Home support** 12 hours/day 7 days/week 12 weeks	**Home support** 12 hours/day 7 days/week 12 weeks	**Home support** 12 hours/day 7 days/week 12 weeks
Unit cost	£23/hour	£23/hour	£23/hour	£23/hour
Cost	£23,207	£23,207	£23,207	£23,207
Respite 2		**Overnight support** 2 days/month 12 hours	**Overnight support** 2 days/month 17 weeks	**Day care** 3 days/month 12 months
Unit cost		£91/12 hours	£91/12 hours	£139/day
Cost		£2,256	£3,156	£5,011

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, using lower and upper estimates detailed in Table 5.

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

Respite	**Mean**	**Lower**	**Upper**
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 night/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
Note: 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 section 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?[1]

[1] 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?

Child service user: respite care packages								
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

Adult service users: respite care packages										
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 is plausible. To help in this decision, we refer to the EQ-5D. What improvements in the EQ-5D would have to be made to generate the minimum QALY gains?

a. The ED-5D measures health-related quality of life, which forms the basis of the QALY. The EQ-5D measures whether individuals have problems or difficulties in 5 domains: anxiety/depression, pain/discomfort, self-care, usual activities, and mobility.

b. Sixteen Guideline Committee members advised that respite care would have different impacts on the individual with learning disability and behaviour that challenges, caregiver and any siblings. In particular:

- The individual with learning disability and behaviour that challenges

  There was strong agreement from the Guideline Committee that receiving respite care would positively 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 respite care would affect the 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 GC response on the impact 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%

- Caregiver

There was strong agreement from the Guideline Committee that respite care would positively affect 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 respite care would affect 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%

- Siblings

There was strong agreement from the Guideline Committee that respite care would positively affect the sibling's 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 respite care would affect the sibling's self-care (50% said yes, 44% said no, and 6% did not know).

There was little support for the possibility that respite care would affect the sibling's 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%

Taking a conservative approach, and only including impacts where there is support from 70% or more of the Guideline Committee, we include these impacts in our analysis.

- Individual with learning disability and behaviour that challenges
  - Anxiety/depression
  - Ability to undertake usual activities
  - Self-care
- Caregiver
  - Anxiety/depression
  - Ability to undertake usual activities
  - Pain/discomfort
- Sibling
  - Anxiety/depression
  - Ability to undertake usual activities

c. The Guideline Committee advised that effective respite was likely to lead to large or moderate improvements on the EQ-5D, representing improvements from 'severe' to 'no problems' or 'some' to 'no problems'. (Table 10). This was based on the intensity of respite care that we illustrated and that it would reduce a significant amount of caregivers' caregiving time.

d. We then used the EQ-5D calculator provided to us NICE to obtain the values shown in Table 10 (Szende, Devlin and Oppe, no date, EuroQoL Group).

   For example, the health state of 0.09 represents that the individual with learning disability and behaviour that challenges has "severe problems" in the areas of self-care, ability to undertake usual activities, and anxiety/depression and "no problems" in the areas of pain/discomfort and mobility. The corresponding gain of 0.9 QALYs is based on an improvement from "severe" to "no problems" in each of the three areas mentioned (self-care, ability to undertake usual activities, and anxiety/depression).

   Likewise, the health state of 0.68 represents that the individual with learning disability and behaviour that challenges has "some problems" in the areas of self-care, ability to undertake usual activities, and anxiety/depression and "no problems" in the areas of pain/discomfort and

mobility. The corresponding gain of 0.3 QALYs is based on an improvement from “some” to “no problems” in each of the three areas mentioned (self-care, ability to undertake usual activities, and anxiety/depression).

Table 10 QALYs for different states on the EQ-5D and QALY gains as a result of improvements to ‘no problems’

Responses to the EQ-5D	Severe problems	Some problems	No problems
Individual with learning disability and behaviour that challenges Health state	0.09	0.68	1.0
QALY gain	+0.9	+0.3	
Caregiver Health state	0.19	0.68	1.0
QALY gain	+0.8	+0.3	
Sibling Health state	0.37	0.78	1.0
QALY gain	+0.6	+0.2	

e. Based on the results in Table 10, we then perform scenario analyses on the impact of total QALYs gained depending on the size of the family unit (Table 11).

Table 11 Total QALY gains for different size family units and assumptions about who is affected

Family unit		**QALY gains**	
		Severe to no problems	Some to no problems
1 person	1 service user	+0.9	+0.3
2 people	1 service user +1 caregiver	+1.7	+0.6
3 people	1 service user +2 caregivers	+2.3	+0.9
3 people	1 service user +1 caregiver, 1 sibling	+2.5	+1.0
4 people	1 service user +1 caregiver, 2 siblings	+3.0	+1.1
5 people	1 service user +2 caregivers, 2 siblings	+3.8	+1.4

f. By comparing Table 6 with Table 11, we can check whether the minimum QALY gains required are plausible. This comparison is illustrated in Table 12 and Table 13 (for children and adults with learning disabilities and behaviour that challenges, respectively).

For example, in deciding whether ‘low intensity-1’ respite care package for a child could be cost-effective (Table 12), we see that the minimum

required QALY gain to be generated by respite care in order for it to be cost-effective would be 0.26. If it is thought that respite has the potential to generate large improvements for just the service user, represented by a move from ‘severe’ to ‘no problems’, a QALY gain of 0.9 is generated. In this case, because 0.9 QALYs is larger than 0.26 QALYs, it is possible that this respite care package could be cost-effective.

A scenario that is not plausible is when we see that the minimum required QALY gain for ‘high-intensity-3’ respite care for the child is 4.11 QALYs and we assume that only the child benefits (0.9 QALYs). Here, the potential benefit to the child (0.9 QALYs) is smaller than the QALY gain required (4.11 QALYs) for respite care to be cost-effective (Table 12).

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

Table 12 (for children) and Table 13 (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, assuming respite care results in large or moderate QALY gains (moving from ‘severe’/‘some’ to ‘no problems’). This is indicated in the boxes with a check ( ).

Table 12 Children's respite care packages: checking the plausibility of respite care being cost-effective under the assumption that there are 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	1	2	3
Minimum QALYs required to be cost-effective		0.26 QALYs	0.52 QALYs	0.92 QALYs	1.36 QALYs	1.67 QALYs	3.62 QALYs	3.63 QALYs	4.11 QALYs
Number of QALYs generated (per year, in total) depending on family unit size									
Scenario: Severe → no problems (large improvements)									
1 person	0.9 QALYs			/					
2 people	1.7 QALYs								
3 people	2.3 QALYs								
3 people	2.5 QALYs								
4 people	3.0 QALYs								
5 people	3.8 QALYs								
Scenario: Some → no problems (moderate improvements)									
1 person	0.3 QALYs								
2 people	0.6 QALYs								
3 people	0.9 QALYs			/					
3 people	1.0 QALYs								
4 people	1.1 QALYs								
5 people	1.4 QALYs								

Table 13 Adults' respite care packages: checking the plausibility of respite care being cost-effective under the assumption that there are 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 unit size											
Scenario: Severe → no problems (large improvements)											
1 person	0.9 QALYs										
2 people	1.7 QALYs										
3 people	2.3 QALYs										
Scenario: Some → no problems (Moderate improvements)											
1 person	0.3 QALYs										
2 people	0.6 QALYs										
3 people	0.9 QALYs										

3.4 Analysis where the Guideline Committee assume that respite care does results in changes to public sector costs and service use

The analyses above assumed no changes in public sector 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 describe a scenario where we assume service use does change. This section assumes that there are no additional QALY gains as a result of respite care (i.e. provision of respite care means that individual's QALYs remain the same).

The Guideline Committee advised that respite care has the potential to prevent or delay a placement breakdown for both children and adults with learning disabilities and behaviour that challenges.

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.

   The Guideline Committee believed this to be a reasonable estimate, but, understanding the limitations of the data, we undertake sensitivity analysis on this number.

b. **Costs of 'standard care' when living in the family home compared to costs of specialist residential education placement.** Iemmi et al. (2015: 10) find that the average cost of services that children with learning disabilities and behaviour that challenges receive when living in the family home ranges from £90, £156, and £160/week – the average cost being £136 per week or £7,048 per year.[2] 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.

   If a placement breakdown occurs, Iemmi 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.[3] The average cost of these is £149,318 per year.

c. **Results**

   Main analysis: Table 14 shows that respite care is **cost-saving** when assuming a 21.5% or 1% chance of placement breakdown, respite care is 1% effective in preventing a placement breakdown, and a residential placement lasts between 1 and 5 years.

   Sensitivity analysis: Table 14 shows that respite care is still **cost-saving** when assuming the lower-estimate of residential care cost is used (£116,900/year), a 21.5% or 1% chance of placement breakdown, respite care is 1% effective in preventing a placement breakdown, and that a residential placement lasts between 1 and 5 years.

   Table 15 shows that respite care is still **cost-savings** when we use the upper estimate of unit costs for respite care and the baseline probability of breakdown is 1% (instead of 21.5%) and we use the mean cost estimate of residential care (£149,319/year).

[2] Inflated from 2012/13 to 2015/16 prices using Curtis and Burns (2016).
[3] Inflated from 2012/13 to 2015/16 prices using Curtis and Burns (2016).

Table 14 Child with learning disabilities and behaviour that challenges: Main analysis, assuming respite care has potential to prevent a placement breakdown

Assuming respite care reduces the likelihood of a placement breakdown									
Intensity of respite care		Low		Medium			High		
		1	2	1	2	3	1	2	3
Costs of additional respite care + living at home (standard care)									
Total cost		£12,297	£17,547	£25,540	£34,289	£40,463	£79,349	£79,697	£89,166
Breakdown probability		21.5% or 1%							
Respite care effectiveness		1%							
Changes in net costs (£)									
Mean estimate of residential care cost (£149,318/year) (average of 38-week and 52-week)									
21.5%	1-yr	-295	-283	-266	-247	-234	-150	-150	-129
	5-yr	-1,377	-1,324	-1,244	-1,156	-1,094	-703	-699	-604
1%	1-yr	-14	-13	-12	-12	-11	-7	-7	-6
	5-yr	-64	-62	-58	-54	-51	-33	-33	-28
Changes in net costs (£)									
Lower-estimate of residential care cost (£116,900/year)									
21.5%	1-yr	-225	-214	-196	-178	-164	-81	-80	-60
	5-yr	-1051	-998	-918	-830	-768	-377	-374	-279
1%	1-yr	-10	-10	-9	-8	-8	-4	-4	-3
	5-yr	-49	-46	-43	-39	-36	-18	-17	-13
Is respite care cost-effective? Under these assumptions, it has potential to be cost-savings.									

Table 15 Child with learning disability and behaviour that challenges: Sensitivity analysis, assuming upper-end unit costs of respite care and assuming 1% baseline probability of placement breakdown

Assuming respite care reduces the likelihood of a placement breakdown									
Intensity of respite care		Low		Medium			High		
		1	2	1	2	3	1	2	3
(£) Costs of additional respite care + living at home (standard care)									
Total cost		£13,252	£19,456	£32,698	£43,038	£53,649	£116,796	£119,150	£131,667
Average of 38-week and 52-week residential care		£149,318							
Cost differential (£) Living at home vs. residential care (average of 38- and 52-week)									
1-year		-136,066	-129,862	-116,620	-106,280	-95,669	-32,522	-30,168	-17,651
5-year discounted (3.5%)		-635,847	-606,856	-544,973	-496,656	-447,067	-151,979	-140,975	-82,486
Breakdown probability		21% or 1%							
Respite care effectiveness		1%							
Changes in net costs (£)									
21.5%	1-yr	-286	-273	-245	-223	-201	-68	-63	-37
	5-yr	-1,335	-1,274	-1,144	-1,043	-939	-319	-296	-173
1%	1-yr	-14	-13	-12	-11	-10	-3	-3	-2
	5-yr	-64	-61	-54	-50	-45	-15	-14	-8
Is respite care cost-effective? Under these assumptions, it has potential to be 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 'standard care' when living in the family home compared to costs of residential placement or supported living.** Iemmi et al. (2015: 10) find that the average cost of services that adults with learning disabilities and behaviour that challenges receive when living in the family home ranges from £160 to £174 per week – the mean being £167 per week or £8,695 per year.[4] These costs include the use of health, social care, and mental health services. These estimates include some level of respite care, but it is not clear how much.

   If a placement breakdown occurs, Iemmi et al. (2015) find that the cost of residential care and supported living is £57,747 and £88,332 per year, respectively. [5] The mean cost of these is £73,040 per year.

c. **Results**

   Main analysis: Table 16 shows that respite care is **cost-saving** when assuming a 10% or 1% chance of placement breakdown, respite care is 1% effective in preventing a placement breakdown, and that a residential placement lasts between 1 and 5 years.

   Sensitivity analysis.
   Table 16 shows that respite care continues to be **cost-savings** even if we assume the lower-cost estimate of residential care were used (£57,747 per year) and assuming a 10% or 1% chance of placement breakdown and assuming that a residential placement lasts between 1 and 5 years.

   Table 17 shows that respite care continues to be **cost-savings** if we use the upper estimate of unit costs to calculate the cost of respite care and assuming a 10% or 1% chance of placement breakdown and assuming that a residential placement lasts between 1 and 5 years.

[4] Inflated from 2012/13 to 2015/16 prices using Curtis and Burns (2016).
[5] Inflated from 2012/13 to 2015/16 prices using Curtis and Burns (2016).

Table 16 Adult: assuming respite care has the potential to prevent a placement breakdown

Assuming respite care reduces the likelihood of a placement breakdown											
Intensity of respite care		Low		Medium				High			
		1	2	1	2	3	4	1	2	3	4
Costs of additional respite care + living at home (standard care)											
Total cost		£13,706	£17,159	£17,511	£18,641	£22,522	£23,652	£31,903	£34,088	£35,059	£36,913
Breakdown probability		10% or 1%									
Respite care effectiveness		1%									
Changes in net costs (£) Average cost of residential care (£73,040/year)											
10%	1-year	-59	-56	-56	-54	-51	-49	-41	-39	-38	-36
	5-year	-277	-261	-259	-254	-236	-231	-192	-182	-177	-169
1%	1-year	-6	-6	-6	-5	-5	-5	-4	-4	-4	-4
	5-year	-28	-26	-26	-25	-24	-23	-19	-18	-18	-17
Changes in net costs (£) Lower-cost estimate of residential care (at £57,747/year)											
10%	1-year	-44	-41	-40	-39	-35	-34	-26	-24	-23	-21
	5-year	-206	-190	-188	-183	-165	-159	-121	-111	-106	-97
1%	1-year	-4	-4	-4	-4	-4	-3	-3	-2	-2	-2
	5-year	-21	-19	-19	-18	-16	-16	-12	-11	-11	-10
Is respite care cost-effective? Under these assumptions, it has potential to be cost-savings											

Table 17 Adult: Sensitivity analysis, assuming upper-end unit costs of respite care

Assuming respite care reduces the likelihood of a placement breakdown											
Intensity of respite care		Low		Medium				High			
		1	2	1	2	3	4	1	2	3	4
Costs of additional respite care + living at home (standard care)											
Total cost		£16,569	£18,800	£19,420	£20,450	£27,294	£28,324	£36,122	£39,011	£40,294	£43,996
Average cost of residential care per year											
Supported living and residential care		£73,040									
Cost differential (£) Living at home vs. residential care (£73,040/year, average of supported living and residential care)											
1-year		-65,166	-62,935	-62,315	-61,285	-54,441	-53,412	-45,613	-42,725	-41,441	-37,739
5-year discounted (3.5% rate)		-304,525	-294,099	-291,204	-286,392	-254,408	-249,596	-213,153	-199,655	-193,656	-176,357
Breakdown probability		10% or 1%									
Respite care effectiveness		1%									
Changes in net costs (£) Assuming a probability of placement breakdown of 10% or 1%											
10%	1-year	-65	-63	-62	-61	-54	-53	-46	-43	-41	-38
	5-year	-305	-294	-291	-286	-254	-250	-213	-200	-194	-176
1%	1-year	-7	-6	-6	-6	-5	-5	-5	-4	-4	-4
	5-year	-30	-29	-29	-29	-25	-25	-21	-20	-19	-18
Is respite care cost-effective? Under these assumptions, it has potential to be cost-savings											

5. Conclusions

Our analysis demonstrates that *additional* respite care, at various intensities, is plausibly a 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 one scenario (as shown in section 3.3) where we assume there are no changes in the use of public sector services, but that the Guideline Committee assumed respite care is likely to have a large or moderate effect on QALY gains for the family (which includes the individual with learning disability and behaviour that challenges, the caregiver, and potential siblings) then there are many intensities (but not all) at which respite care is cost-effective at £20,000 per QALY.

In another scenario (as shown in section 3.4), where the Guideline Committee assumed respite care prevents or delays a breakdown in the family home resulting in a move into residential care, then all intensities of respite care that we have illustrated were cost-saving. Therefore, even if we assumed equivalency of QALYs for respite vs. standard care, respite care is cost-effective on the basis that it is cost-saving to the public sector. In these scenarios we assumed a baseline probability of placement breakdown to be 21.5% for children and 10% for adults and that respite care is 1% effective in reducing the likelihood of a placement breakdown. Importantly, respite care remained cost-saving even when we undertook sensitivity analysis and assumed: the baseline probability of breakdown is 1%, when we used the upper estimates of unit costs to calculate respite care, and when we used lower estimates of residential care costs.

The limitations of our analysis are that the data are based on assumptions and are not based on evidence from effectiveness studies.

However, in the absence of data, this analysis is potentially useful in that it helps to 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.

- We emphasise to the Guideline Committee that we advise extreme caution in drawing conclusions about cost-effectiveness of respite care from these analyses. 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, are not robust, and their validity cannot be confirmed.

More research is needed to understand the intensities and costs of respite care that is currently provided to children and adults with intellectual

disabilities and behaviour that challenges. More research is also needed to understand the effectiveness and cost-effectiveness of these services.

In the absence of research, anecdotal evidence suggests that provision of respite care is varied and that the amount of respite care provided is insufficient.

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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