

**Joint Strategic Review of Short Breaks in Surrey
Independent Analysis of Public Consultation
Final Report for Surrey County Council**

**Produced by Qualitative Data Analysis Services (QDAS)
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Background and introduction:

In May 2014, Surrey County Council (SCC) in partnership with NHS Guildford and Waverley Clinical Commissioning Group (CCG) undertook a Joint Strategic Review of Short Breaks for children with disabilities in Surrey during 2013. In February 2014 SCC Cabinet and Surrey CCG Boards agreed for a public consultation to be carried out. This took the form of an online survey open to the public and a series of consultation meetings with interested groups, including parents and carers of children with disabilities, and professionals working with them. The consultation was undertaken in order to understand whether current service provision for children with disabilities is meeting their needs. There was a particular focus on options for the future of Applewood (SCC) and Beeches (NHS) provision.

Qualitative Data Analysis Services (QDAS), a consortium of experts in qualitative analysis, was commissioned by the SCC and NHS Guildford and Waverley CCG to analyse the data collected via the online survey and the ten public consultation meetings regarding Applewood and Beeches facilities. QDAS were asked to act as independent consultants and have no allegiance or relation to any of the groups or individuals with interest in the outcomes of SCC decisions. To maintain this neutral standing, QDAS did not read or review any materials regarding the facilities or issues involved beyond the data provided. The following report therefore summarizes QDAS findings derived from the survey and consultations without regard to any additional existing material. QDAS cannot and will not make any suggestions or recommendations based on the future of short break services in Surrey; only reporting on what is present in the consultation data.

Method:

Data amounted to 274 responses to the online survey and meeting notes from ten public consultations. The notes were taken during the meetings by SCC staff who were also in attendance. They are therefore summaries of meeting content rather than verbatim (i.e. word-for-word) transcripts. To organise and manage the data, QDAS implemented the use of the qualitative data analysis program, NVivo. Once the data were imported, general frequencies from the survey were tabulated, and open responses from the survey and the meeting notes were thematically coded. Themes were generated using grounded theory, a qualitative methodology which involves a researcher reviewing the text and creating an appropriate word or phrase to assign to (tag) segments of content. The process is iterative, and themes (codes) grow and change as additional data are reviewed. By the end of the analysis, 54 unique codes were identified (see Appendix for a full list of these codes).

Two of these themes, "value to families" and "access", were present in each document. An additional 19 appeared in more than half the documents, showing relevance and general applicability. However, it's not so much which discrete codes exist, but how those are represented and create impact overall which is important.

Summary of results:

The vast majority of respondents (mostly parents/family) to survey and within meeting minutes is insistent that both Applewood and Beeches remain open. There is much resistance to change for a multitude of reasons including consistency of routine and familiarity of the facilities and staff for clients, ease of transport with facilities located conveniently, and the value of safe overnight respite to families. Many describe their overnight respite option as a "lifeline" and their only option for ever having a sense of normalcy at home, for parents and particularly for siblings. Family carers explain that having an overnight without the young person at home is both restful and restorative, enabling them to put out the energy required to care for the young person integrated within the family unit the majority of the time and for the long-term. Both facilities are described as their child's "home away from home"; families are generally pleased with the care their child receives, indicating that staff are seen as an extended family, and stating how much their child enjoys their stays. Many are pleased with the independence aspect of nights away and how having overnights with friends at the facilities is similar to the sleepovers being had by age-matched peers. Families are adamant that closing either facility will only cost SCC more since they will end up having to put their child in full residential care, something which they have so far been able to avoid. They reject the idea that having carers come to their house will be equivalent to having the young person on overnight respite out of the house. There is also disbelief that SCC would choose to close Applewood, a relatively new, costly, and purpose-built facility.

Meanwhile, there is considerable frustration and confusion about the process of accessing facilities and care in general. Issues include learning about options and facilities in the first place, attaining referrals, being told different things by different people in terms of minimum age or other eligibility for respite, ability to make it through the assessment process, and the sometimes lengthy delays before respite can be attained as well as having it cancelled at short notice. "Everything is a fight", said one respondent, and many families just aren't up for it.

Family carer perspectives and opinions are sometimes in conflict with those of SCC and NHS Guildford and Waverley CCG. Although the SCC indicates that the needs of young people accessing Applewood and Beeches are similar, families feel that there are differences that would make combining Applewood and Beechwood clients challenging. Beeches seems to have younger clients generally than Applewood, for example. Already families have experienced the inability for certain children to be accommodated when other specific children are having an overnight. There is also concern about the lack of nursing staff onsite as well as the number of awake staff. SCC indicates there is plenty of capacity available and that the facilities are not being used to their potential, but families are not experiencing the same, and feel that closing either facility will only put further strain on families already at a breaking point.

A significant subset (48) of survey respondents' comments focused on Ruth House as part of the educational programme for Freemantles' school students. Specifically, these respondents report reading the Joint Strategic Review paper and having concerns about the future of the Residential Learning Program (RLP). They strongly state that RLP and

short breaks are two different services which both need to be maintained. As such, they believe the current consultation is misleading. They state that it has not properly involved Ruth House families or pupils who would be affected, and does not indicate how decisions regarding the future of Applewood and Beeches will impact Ruth House clients. They are convinced that the outcome of the current review is distorted and inaccurate as they await a response from their challenge to the changes proposed by the SCC. (See Appendix for additional information.)

Research Questions:

SCC and NHS Guildford and Waverley CCG asked QDAS to specifically consider four questions. These questions and our best answers to them based on the data provided are as follows:

1. *Which options presented do parents, professionals and the children themselves feel would achieve the best outcomes for children, young people and their families?*

The survey asked the following question:

Which of the following option(s) do you think would best meet the needs of children and young people with disabilities and their families in East Surrey?

Options	Detail
a) Either select TWO options, one Applewood (A) and one Beeches (B) option	A1: Applewood remains open and Surrey County Council develops an improved in-house service.
	A2: Surrey County Council closes Applewood and makes alternative provision for children and young people who use the service.
	A3: Surrey County Council outsources the management of Applewood, to a private or voluntary organisation.
	B1: Beeches remains open and responsibility for future commissioning and funding of the service transfers to Surrey County Council.
	B2: NHS decommissions Beeches, funding is reallocated to meet the health needs of children and young people with disabilities in the community. Care packages for children using the service transfer to alternative providers.
b) Or choose combined option	C1: Decommission both Beeches and Applewood and develop a new service based on Applewood or an alternative site.
c) Or state your own idea	Other (please state)
d) Or don't know	Don't know

* Please select an option for Beeches and an option for Applewood or a combined option or state your own option below
Multiple choice checkboxes

Table a) Responses to survey options for what would best meet the needs of children and young people with disabilities and their families in East Surrey

	No. of responses
A1: Applewood remains open and Surrey County Council develops an improved in-house service	199
A2: Surrey County Council closes Applewood and makes alternative provision for children and young people who use the service	4
A3: Surrey County Council outsources the management of Applewood, to a private voluntary organization	5
B1: Beeches remains open and responsibility for future commissioning and funding of the service transfers to Surrey County Council	161
B2: NHS decommissions Beeches, funding is reallocated to meet the health needs of children and young people with disabilities in the community. Care packages for children using the service transfer to alternative providers	12
C1: Decommission both Beeches and Applewood and develop a new service on Applewood or alternative site	10
Other	46
Don't know	6

It should be noted that although respondents were instructed to choose their preferred option for Applewood and Beeches, some chose as many as three options, and others chose only one option; hence the total number of responses (Table A)) totals 443 not 274 (the total number of survey responses submitted).

Therefore percentage calculations on the basis of this question are nonsensical. Overall, as indicated above, the vast majority of participants in the survey (and consultations) hold strong opinions that both services must remain open to best serve the population, as the A1 and B1 options have far more responses than all other options combined.

In the survey, 149 respondents identified themselves as parents/family; 46 identified themselves as professionals; 7 identified themselves as children; 72 identified themselves as having an "other" interest. For those in the latter category, most (44) identified themselves as a friend of a family or disabled child,

several were godparents, and a few had mixed or different interests altogether, such as former professional. See Table #1 in Appendix.

2. Why do parents, staff and other professionals feel that their chosen option will achieve the best outcomes for children and young people?

Participants generally state that their chosen option best suits the children and young people by maintaining the health of the family unit. The children and young people are able to stay integrated within the family and community while parents and siblings are able to utilize overnights to recoup sleep and spend time with each other without worrying about disruption by, inclusion of, or safety of the young person. This ability to have a few hours of "a normal life" in intervals is crucial to the family's overall health and well-being, particularly in situations where there may only be one carer. Because they are able to have this break, the family carers are able to maintain the effort required for longer term care of the young person.

Consistency and routine also come up frequently, as participants discuss how long (years, in some cases) it has taken for young people to become accustomed to a facility and the staff. There is considerable anxiety about having to live through that settling-in process again if the situation were to change.

Geographic convenience is another major factor in the opinions held by the participants. Most find it easy to have the young person attend overnights at their chosen facility, and some worry about the time and logistics it would take to transport the children to a different location.

3. How would the closing of either of these services impact on the outcomes for children and young people and their families?

Because this question was not asked directly, a respondent would have to volunteer information about how they perceive the closure of Applewood or Beeches would affect a child, young person, or their family. Additionally, since both services are currently in operation, any discussion of closure and follow-on effects is necessarily speculation on the part of the respondent.

That said, participants most frequently mention the possibility of having to resort to full-time residential care for the young person if they were unable to attain regular overnight care due to the closure of one or more facilities. They feel that this option is highly undesirable due to the break-up of the family unit and the cost required (to be shouldered by the SCC and tax-payers, potentially). "Our family would collapse," said one respondent considering closure of a facility.

4. What kind of support do children, young people and their families value? Are there any other modes of support suggested that could help meet the need of families accessing overnight respite?

Again, these questions were not asked of participants in the survey or during public consultations, so information that is relevant would have been indirectly volunteered. Children and young people, families, and professionals all respond that short breaks out of the home are essential. They appreciate facilities that feel home-like, however, rather than institutional. Additionally, it is important that the facility be able to accommodate the young people with appropriate staffing to provide safe care overnight. The fact that Applewood was purpose-built came up frequently. Many participants indicated they or their children appreciated the opportunity to have overnights with peers, with some comparing these to sleepovers their age-matched peers or siblings enjoy with friends.

The (in)ability to access information about available services was an oft-repeated theme. Some were frustrated that there does not appear to be a centralised resource where families can learn about their options, particularly as professionals (social workers and others) working with families appear to not be fully informed either, both with regard to the existence of the facilities in the first place as well as their entrance requirements. There is continued confusion about what the entrance requirements actually are, both in terms of age restrictions and health needs.

Some participants offered suggestions for improvement or other alternatives. The most frequent suggestion was to ensure facilities were being used at capacity and open every day of the week, seen as a possibility if information about the services were more easily available and referrals appropriately made. Some also suggested investing in staff training, and others asked if a charity could run a facility or if it could be operated as a co-operative partnership. Several people suggested a different use of current space or a different location altogether.

One suggestion for overnight alternatives, having a carer come into the family's home to take care of the child, was soundly rejected by all participants who mentioned it. They feel that this option does not provide equivalent respite to having the young person out of the house. Instead, they feel that the additional individual in the home is disruptive and intrusive, adding to chaos and upset rather than enabling the peace of a restful night.

APPENDIX

Table #1 – Responses by Interest (self-identified by respondent)

Interest	# of Respondents	# of Responses for Each Option							Don't Know
		A1	A2	A3	B1	B2	C1	Other	
Child or young person with a disability in Surrey	7	6	0	0	5	0	0	1	0
Family of a child with a disability in Surrey	149	98	1	5	82	4	3	33	4
Other (please specify)	72	56	2	0	47	2	5	8	1
Professional who works with disability services	46	39	1	0	27	6	2	4	1
<i>Grand Total</i>	<i>274</i>	<i>199</i>	<i>4</i>	<i>5</i>	<i>161</i>	<i>12</i>	<i>10</i>	<i>46</i>	<i>6</i>

Codes/Themes:

Two themes came up in all eleven source documents - value to families and access. 21 codes were in six or more of the eleven source documents.

Table #2 - The ten most common codes from the survey and the consultations

Survey	Consultations
Demand or need for facilities	Value to families
Value to families	Demand or need for facilities
Respite	Access
Ruth House	Monetary value
Monetary value	_Beeches
Consistency	Capacity
_Beeches	Sleep or overnight
Geographic location	_Applewood
Staffing	Respite
_Applewood	Facility, knowledge of

Table #3 – Codes by documents

Codes	Survey	Applewood	Beeches	Brooklands	Clifton Hill	CLDT	E. Surrey Mencap	Manor Mead	Portesbury	SPAN	Woodlands
A : _Applewood	31	8	3	3	2	0	3	0	0	1	2
B : _Beeches	35	4	7	7	1	1	5	3	0	1	2
C : Ability to experience 'a normal life at home'	30	0	2	1	0	0	0	0	0	0	0
D : Access	12	3	8	12	2	3	1	3	2	1	6
E : Age-appropriate developmental milestones	1	0	0	1	0	0	0	1	0	0	0
F : Capacity	18	3	6	1	4	2	4	2	0	3	4
G : Choice needed	8	1	0	0	1	1	0	1	0	0	0
H : Clients, older	5	1	0	0	0	2	2	0	0	0	0
I : Clients, range of needs	11	2	3	0	3	0	1	1	0	1	1
J : Clients, younger	8	0	1	2	1	2	2	1	1	2	1
K : Comparing facilities and client needs	9	3	4	0	0	0	1	1	0	0	0
L : Consistency, familiarity, routine, or issues with change	53	2	0	0	0	0	5	0	2	1	1
M : Demand or need for facilities	141	6	2	15	4	4	5	4	0	2	4
N : Difficult home lives	7	0	0	1	0	0	1	0	0	0	1
O : Difficulty asking for help	0	0	0	5	0	0	0	0	0	0	0
P : Early intervention	3	0	0	1	0	0	0	0	1	0	0
Q : Enjoyment of stay	15	0	0	0	0	0	0	0	0	0	0
R : Everything is a fight	6	0	0	2	0	1	0	1	0	1	2
S : Expertise or resource	7	0	0	1	0	1	0	0	0	0	0
T : Facilities, age of	14	0	0	0	0	0	0	0	0	0	1
U : Facility, knowledge of	17	1	0	7	3	2	1	2	2	1	2
V : Facility, leasing	0	0	1	0	0	1	1	1	0	0	1
W : Facility, purpose built	11	1	0	0	1	1	0	0	0	0	0
X : Facility, size of	10	1	0	0	0	0	0	0	0	0	0
Y : Fairness of client opportunity	2	3	3	4	2	2	0	0	0	0	1
Z : Future care and coping	29	1	1	1	2	1	1	0	1	0	0

AA : Geographic location or advantage	34	1	2	2	2	2	1	0	1	0	1
AB : Health needs	4	1	4	6	1	2	1	2	0	0	1
AC : Independence	10	0	1	0	0	0	0	1	0	0	0
AD : Institutional in nature	1	0	1	0	0	0	0	0	0	0	0
AE : Integrated in family and community	16	0	0	0	0	1	0	1	2	0	0
AF : Knowledge of document	0	2	0	0	1	1	0	0	0	0	0
AG : Monetary value	71	8	5	3	6	1	6	3	0	0	2
AH : Other facilities or providers	17	1	1	4	1	0	3	0	1	1	2
AI : Putting SCC needs before clients'	8	0	1	0	3	0	0	0	0	0	1
AJ : Reliability and trust	18	0	0	0	0	0	0	0	0	0	0
AK : Respite	92	0	1	3	3	3	0	3	3	2	3
AL : Ruth House	84	0	0	0	0	0	0	0	0	2	0
AM : Safety	15	0	2	0	1	0	0	0	0	0	0
AN : SCC responsibility for appropriate care	10	2	1	0	0	1	0	1	1	0	0
AO : Services at another's home	2	0	0	0	1	0	0	0	0	0	0
AP : Services at client's home	9	0	1	0	0	0	0	0	0	0	0
AQ : Services in community	1	0	0	0	0	0	0	0	0	0	0
AR : Services in-house	2	0	0	0	0	1	0	0	0	0	0
AS : Skills acquisition	3	0	0	0	0	0	0	1	0	0	0
AT : Sleep or overnight	22	1	4	7	3	3	1	3	1	0	3
AU : Social or relational aspects	16	0	0	0	0	0	0	0	0	0	0
AV : Social worker	1	0	0	16	0	1	0	0	2	1	0
AW : Staffing	33	4	4	0	3	1	1	0	0	0	4
AX : Stress or problems	23	0	0	1	0	0	1	0	0	0	0
AY : Suggestions for changes or improvement	20	2	0	4	1	1	0	0	1	0	2
AZ : Support	24	0	0	4	1	1	1	0	0	1	0
BA : Time	13	1	0	1	0	1	0	0	0	0	2
BB : Value to families	141	1	3	16	6	2	10	5	5	1	6

Table #4 - List of all codes (alphabetical order)

_Applewood
_Beeches
Ability to experience 'a normal life at home'
Access
Age-appropriate developmental milestones
Capacity
Choice needed
Clients, older
Clients, range of needs
Clients, younger
Comparing facilities and client needs
Consistency, familiarity, routine, or issues with change
Demand or need for facilities
Difficult home lives
Difficulty asking for help
Early intervention
Enjoyment of stay
Everything is a fight
Expertise or resource
Facilities, age of
Facility, knowledge of
Facility, leasing
Facility, purpose built
Facility, size of
Fairness of client opportunity
Future care and coping
Geographic location or advantage
Health needs
Independence
Institutional in nature
Integrated in family and community
Knowledge of document
Monetary value
Other facilities or providers
Putting SCC needs before clients'
Reliability and trust
Respite
Ruth House
Safety
SCC responsibility for appropriate care
Services at another's home
Services at client's home

Services in community
Services in-house
Skills acquisition
Sleep or overnight
Social or relational aspects
Social worker
Staffing
Stress or problems
Suggestions for changes or improvement
Support
Time
Value to families

Outliers/Data issues:

Ruth House. Of the survey data, 48 responses are entirely focused on Ruth House. Given the nearly identical and lengthy phrasing, our best guess is that a "suggested response" was circulated within a community. We have not done additional analysis on these responses other than to mark them as related to Ruth House because the focus of this report is on Applewood and Beeches. The gist, however, is that the Joint Review misrepresents Ruth House, that the options provided are not fully transparent since there isn't indication of how Ruth House will be impacted by changes for Applewood and/or Beeches, and that families who make use of Freemantles and Ruth House have not been appropriately consulted. The respondents are very upset. All the comments relating to Ruth House are provided in a separate document.