Councillor Eddie Dryden
Chair, Health Scrutiny Panel
Middlesbrough Council
PO Box 503
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8th August 2018

The Right Honourable Matt Hancock MP
Secretary of State for Health and Social Care
39 Victoria Street
Westminster
London
SW1H 0EU

Dear Secretary of State,

REFERRAL TO SECRETARY OF STATE FOR HEALTH AND SOCIAL CARE
Respite care services for adults with complex needs
and learning disabilities and/or autism
Middlesbrough Council Health Scrutiny Panel

On 18 May 2018, the Health Scrutiny Panel ("the Panel") of Middlesbrough Council ("the Council") resolved to refer a proposal to you on *Respite opportunities and short breaks for adults (18+) with complex needs and learning disabilities and/or autism*.

This letter and associated documentation, constitutes "the proposal"), which is made by the Council pursuant to regulation 23(9)(c) of the Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013 ("the Regulations").

Explanation of the proposal to which the Report relates ("the Proposal")

1. The Proposal has been jointly adopted by NHS Hartlepool and Stockton-on-Tees Clinical Commissioning Group and NHS South Tees Clinical Commissioning Group (together, "the CCGs")

2. The Proposal relates to the provision of respite services ("the Services") for adults, resident in the areas of the Council and Redcar and Cleveland, Stockton-on-Tees and Hartlepool local authorities (collectively, "the Area"), who have complex needs and learning disabilities and/or autism ("Service Users").

3. Currently, the Services are provided to Service Users within the Council's area through the provision of:

(1) bed-based services at two built facilities ("the Bed-Based Services") operated by Tees Esk and Wear Valleys NHS Foundation Trust ("the Trust"), namely:

(a) Aysgarth Short Term Care Unit (6 beds) at 163 Durham Road, Stockton-on-Tees TS19 0EA ("Aysgarth");

(b) Unit 2, Bankfields Court (5 beds) at Normanby, Middlesbrough TS6 0NO ("Bankfields");

(2) weekday services ("the Day Services") operating at The Orchard in Middlesbrough, Kilton View in Brotton and Allensway in Stockton-on-Tees, provided jointly by the Trust and local authorities including the Council.

4. The Bed-Based Services and Day Services operate in conjunction with each other to meet the needs of Service Users within Teesside (made up of the Council's area and the areas of Redcar and Cleveland, Stockton-on-Tees and Hartlepool councils). The Bed-Based Services operate an open referral system operated under an assessment tool (described by the CCGs as a "demand-led" process). Emergency provision is accommodated within the Bed-Based Services.

5. As at 27 September 2017, 40 Service Users were accessing Aysgarth and 50 Service Users were accessing Bankfields [7/356]. 35 of the 50 Service Users accessing Bankfields are resident in the Council's area.

6. The current Bed-Based Services allow c.90 Service Users in the Area to access between on average c.33 nights respite care per year. When not accessing the Services, these users reside in the community and are typically cared for by family members.

7. The recurring costs to the CCGs of the current Bed-Based Services is said to be £1,501,365 [10/450].

8. Between December 2016 and February 2017, the CCGs carried out a pre-engagement exercise on the basis of a document *Our Needs and Responsibilities: Respite Services for People with Learning Disabilities and Complex Needs* [7/395-401] ("the Needs and Responsibilities Document").

9. 7 scenarios [5/65] were canvassed during that exercise of which 5 were discounted following the application of appraisal criteria. In a formal consultation exercise running from 4 September 2017 to 10 November 2017, 2 scenarios were given as options [5/97]:

Option 1: *Buy a range of Bed Based Respite services to replace the existing Bed Based Respite services. Change the assessment and allocations process, making it more needs led. Buy flexible community based respite services. Buy clinically led outreach support services.*

Option 2: *Continue to buy Bed Based Respite services at 2 Bankfields Court and Aysgarth. Change the assessment and allocation process, making it more needs led. Buy flexible community based respite services.*

**maintaining services at 2 Bankfields Court and Aysgarth means there will be flexible community based services as in Option 1 but they will be limited due to the funding needed to maintain the existing service.*

10. Both the consultation documentation for the Proposal ("the Consultation Documentation") and the decision-making report of January 2018 ("the Decision-Making Report") provided that provided that "both options will be delivered within the existing £1.5 million budget" [5/67]; see also the Decision-Making Report [10/427]. In a FAQ document the following question was posed and answered [6/131]:

    Q: *The financial envelope is remaining the same, how is Option 2 affordable when you will still be paying £1.5 million for the beds in Aysgarth and 2 Bankfields?*

    A: *Depending on the outcomes of the consultation and analysis of the feedback, it could be that fewer beds are purchased within current settings and the financial resources will be used to provide people with a broader range of options to choose from which can more flexibly meet their respite needs. Different community based alternatives are often less expensive than hospital bed based provision and peoples allocated resources may be able to go further and enable them to achieve improved personal outcomes.*

11. A joint overview and scrutiny committee was established by the Council, Hartlepool Borough Council, Redcar and Cleveland Borough Council and Stockton Council ("the Affected Councils"), and the CCGs sought to consult with it.

12. **On 1 February 2018, at governing body meetings of the CCGs in common, it was resolved to adopt Option 2** [10/553-556] (i.e. the Proposal) ("the Decision")**.**

<u>Summary of the evidence considered</u>

13. A chronology of events is enclosed marked "Appendix 1".

14. A bundle of documents is enclosed marked "Appendix 2". References in this letter to numbers in square brackets are references to tabs and page numbers of that bundle.

15. In broad overview:

    (1) The Tees Valley Health Scrutiny Joint Committee ("TVHSJC") was informed of the pre-engagement exercise at its meeting of 21 October 2016 [Tab 1].

(2) The pre-engagement exercise was conducted between December 2016 and February 2017 with an update being provided to the TVHSJC on 26 January 2017 [Tab 2]. Pre-engagement documentation was not provided until after the event ("Case for Change") submitted to the Joint Health Scrutiny Committee ("JHSC") for its meeting on 14 December 2017 [7/174]).

(3) Feedback was provided to the TVHSJC in April [Tab 3] and July 2017 [Tab 4], although the communications and engagement report [19/698-893] was not provided to that Committee.

(4) Formal consultation was delayed as a result of the snap election. It was also determined that as the options did not affect Darlington BC's area, a joint committee of affected local authorities should be formed.

(5) That committee, the JHSC, met for the first time on 11 October 2017 [Tab 5], by which point formal consultation had been on foot for over a month. Consultation Documentation was provided to the JHSC at that meeting.

(6) The JHSC met two more times during consultation, on 20 November [Tab 6] and 14 December [Tab 7]. Concerns were fed back to the CCGs at both those meetings. Parent representatives attended the November meeting. The recommendation of the JHSC made at the December meeting was that it did not support either Option 1 or Option 2, and recommended that the CCGs retain the current level of Bed-Based Services [7/411].

(7) The Council's position, reached at a meeting of the Panel on 19 December 2017, was in line with that of the JHSC. The Council formally responded on 11 January 2018 [417-420]. The position of other local authorities was similar [466].

(8) The executives in common of the CCGs met on 18 January 2018 and resolved to recommend Option 2, which recommendation was taken up by the CCGs' Governing Body In Common at a meeting on 1 February 2018 [Tab 10], that body being provided with the Decision-Making Report.

(9) The Decision was reviewed by the JHSC on 5 February 2018 [Tab 11[. Assurances were sought and a presentation was made to the JHSC at a meeting on 19 March 2018 [Tab 14]. The power to report to yourself was not delegated and so the matter came back to the Panel for determination.

16. In addition to the reports and appended evidence considered at meetings, the Panel has also had regard to the further documentation in tab 18 of the Bundle, the CCG documentation not provided to meetings at tabs 19 and 20, and the material referenced in this letter.

Grounds for the Report

17. The Report is made on the grounds that:

    (1) the Council considers that the Proposal would not be in the interests of the health service in its area.

The writer is of the view that it is necessary to cite a second ground:

    (2) the Council is not satisfied that the consultation on the Proposal was adequate.

The reasons for making the Report

18. The reasons for making the Report ("the Reasons") are, in summary:

    (1) The reliance placed on the Transforming Care agenda was irrational.

    (2) The consultation and the Decision disclosed a lack of understanding of the needs of the Service Users accessing the Bed-Based Services.

    (3) The proposed changes to the assessment and allocations process have not been defined with sufficient clarity and completeness.

    (4) There was no or no adequate data on "community based alternatives" within the Area.

    (5) The Proposal, if adopted, gives rise to unacceptable risks of adverse impact on the well-being of Service Users' family units, including to carers and Service Users themselves.

    (6) The Proposal, if adopted, gives rise to unacceptable safeguarding risks to Service Users if the Proposal is adopted.

    (7) The Proposal is not financially justifiable on any rational basis.

19. The Reasons are expanded upon below, together with the evidence in support of those Reasons.

(1) Reliance on the Transforming Care agenda

20. The provision of respite care for persons with complex medical needs constitutes the provision of health services: *R (on the application of T & others)* v. *London Borough of Haringey* [2005] EWHC 2235 (Admin) per Ousley J. at §§65-67, followed in *R (on the application of Juttla and others) v. Hertfordshire Valleys Clinical Commissioning Group* [2018] EWHC 267 (Admin) per Mostyn J. at §11.

21. Any substantial variation in the provision of existing respite care therefore may not be made without consultation pursuant to the 2013 Regulations: *Juttla.*

22. Contrary to a suggestion made by the CCGs at a meeting of the JHSC on 19 March 2018 [14/629], it is submitted that the CCGs have a statutory duty to provide the Bed-Based Services. The Bed-Based Services are health services (*Juttla*) which are necessary for the reasonable requirements of the Service Users and therefore the CCGs have a duty to arrange for the provision of the same pursuant to s.3 of the National Health Services Act 2006. Provision of the Bed-Based Services are not some option within the gift of the CCGs that could be yielded to the implementation of an alternative policy-based agenda at their election (c.f. Decision-Making Report, at para 9.0 [10/459]). The Panel is concerned to note that the CCGs financial cover of respite services is said to be non-recurrent [10/549].

23. As the title of the CCGs' Consultation Documentation indicates, significant emphasis was placed by the CCGs on the "wider Transforming Care agenda" at all stages of the process. It was (FAQ 101) "the main driver" [6/138].

24. The 2015 Transforming Care programme seeks to achieve a shift away from inpatient care to care in community settings for people with learning disabilities and/or autism (with a target of a 35-50% reduction by 2019), together with giving those persons and their families more choice and a stronger say in their own or their families' care. It provides for a strong emphasis on personalised care and support planning, personal budgets and personal health budgets.

25. The tone of the Consultation Documentation and the Decision-Making Report was that provision of the Bed-Based Services was somehow contrary to the Transforming Care agenda.

26. At the meeting of the TVHSJC on 20 July 2017 the CCGs were minuted [4/47] as stating that:

> *Transforming Care focussed on moving beds from hospital settings and providing respite and beds in a different way and model, for example, an overnight stay in a Premier Inn with care still being provided by Health Care Assistants.*

27. The Consultation narrative document stated [5/60]:

> *This Consultation is in line with the national and regional 'Transforming Care' agenda, looking at how people with learning disabilities and their families and carers can use a bigger range of different types of services, closer to where they live. Importantly there should be less reliance on services that are provided within hospital, making sure there are good services available in the community.*

28. A stakeholder briefing provided to the JHSC at its meeting on 11 October 2017 [5/97] said:

> *The most significant change being proposed is to bed-based services. Currently, patients access services at 2 Bankfields Court in Middlesbrough, or Aysgarth in Stockton-on-Tees for their bed-based respite needs.*
>
> *Currently, £1.5 million per year is spent on providing these services. The CCGs want to spend this money differently and in line with national direction, would like to move bed-based facilities away from a hospital setting as this isn't always the most appropriate place for service users and does not provide the best value for money.*

29. The Case for Change Document presented to the JHSC on 14 December 2017 stated [7/382]:

> *The focus of this national agenda is to ensure that people are supported to remain in the community and to reduce the unnecessary admission to inpatient facilities. A large part of this is to co-design and implement an effective, responsive, proactive, resilient and flexible community model of services and support to facilitate timely discharge and prevent admission to inpatient facilities. This is also supported by the principles that are outlined within the October 15 NHS England publication 'Building the Right Support'.* [sic]
>
> *Transforming Care includes a strong emphasis on reduced reliance on bed based inpatient provision and the availability of community services within local communities, personalised care and support planning, personal budgets and to put people at the centre of their care to enable maximum choice and control about how needs are met.*

30. That document concluded, inter alia [7/393]:

> *Re-design will enable the delivery of the aims of Transforming Care agenda and support the Local Authority and CCG obligations to carers under the Care Act.*

31. In the "FAQs" it was stated in question 16 [6/118]:

> *Transforming Care is a programme that is happening across the country, to reduce people's reliance on hospital provision and to make available a robust community infrastructure. This will support people to remain in or return to their own communities and home settings.*
>
> *Research has been undertaken in relation to models that are in other areas of the country. The situations vary, however in most instances, respite is commissioned for people with complex needs through the Local Authority commissioning arrangements through continuing healthcare funding streams or directly from continuing healthcare commissioning arrangements.*

The situation in Tees is that this provision currently sits outside of any of these arrangements.

32. The FAQs made 17 references to reducing reliance on hospital provision under the Transforming Care agenda (Qs 12, 16, 20, 222, 25, 38, 46, 78, 80, 83, 88, 95, 98, 102 and Qs 1, 8 and 16 raised by Asygarth Parents Focus Group).

33. The "need to move away from hospital based bed care" under the Transforming Care programme was described as a "key message" in a presentation by the CCGs to the JHSC on 19 March 2018 [14/605].

34. It is, in fact, a trite proposition that the Service Users of the Bed-Based Services are being cared for in the community.

35. The provision to those users of the Bed-Based Services for the purposes of respite is not inimical to community care. On the contrary, it supports it.

36. See, for example:

    (1) LGA, ADASS, NHS England's Building the right support (October 2015)[1] service model principle 4:

    > *People with a learning disability and/or autism should be supported to live in the community with support from and for their families/carers as well as paid support and care staff – with training made available for families/carers, support and respite for families/carers, alternative short term accommodation for people to use briefly in a time of crisis, and paid care and support staff trained and experienced in supporting people who display behaviour that challenges.*

    (2) Committee of Public Accounts' Local support for people with a learning disability HC 1038 (24 April 2017)[2] evidence of Dan Scorer (Q1) ("key services that families rely on, such as respite services") and Ray James (Q112-113) ("Respite is one of the things we hear most frequently from parent carers about its value and risk in relation to that").

    (3) The evidence of parents and carers of Service Users that had the Bed-Based Services not been available to them, some of those would be residing permanently in an inpatient setting.

37. That being so, the emphasis placed in the CCGs' documentation (including the Consultation Documentation) on reducing inpatient and hospital provision was inappropriate and misleading.

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[1] https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf
[2] https://publications.parliament.uk/pa/cm201617/cmselect/cmpubacc/1038/1038.pdf

38. In contrast to the bulk of the content of the Consultation Document, the CCGs did in the Decision-Making Report (para 5.5 [10/449]) accept that the Bed-Based Services were outwith Transforming Care bed reduction goals: a surprising (albeit correct) concession given the previous reliance on that goal and the explicit description of the Bed-Based Services as hospital facilities (see e.g. FAQ 95 [6/137]):

> *Q: The consultation narrative states that there needs to be less reliance on services in hospital, making more use of services in the community. How does this relate to Aysgarth?*
>
> *A: Although it is acknowledged that there is a homely environment in the NHS respite services, it is actually a hospital facility and is delivered within a clinical model. In addition it is paid for at the same rate as a treatment and assessment bed however does not deliver a treatment and assessment service. Under either new model, there will be a focus on providing high quality, personalised services that meet the needs of people and families*

39. Despite this concession, reliance was nonetheless placed by the CCGs on the satisfaction of the new (April 2017)[3] fifth reconfiguration test to allow for service closure. Whilst reliance was also placed on this by NHS England in its final assurance letter [10/468], it was, with respect, reliance that was misplaced. The fifth reconfiguration test focuses on significant hospital bed closures and looks for, inter alia, sufficient alternative provision (such as increased community services). The test is inapplicable here, because the respite beds are, of themselves, alternative provision; they are not the hospital beds that are sought to be reduced.

40. In essence, the Transforming Care bed reduction goal has been used by the CCGs to build a case for reducing what is a necessary ancillary provision if that goal is to be achieved and supported.

41. Insofar as it implements that case, the Proposal is not in the interests of the health service in the Council's area.

(2) Lack of understanding of needs of Service Users accessing Bed-Based Services

42. The Bed-Based Services are currently accessed by approximately 90 Service Users with highly complex needs who require clinical oversight. They include persons at the extreme end of the autism spectrum, with coexisting complex health needs including profound and multiple disabilities, complex epilepsy, mental health conditions and challenging behaviour. They include adults with profound and multiple learning disabilities who have additional health needs. Many are non-verbal, are unable to take part in consultations or conversations, have specially adapted wheelchairs to support their bodies, and/or to prevent their internal organs from being damaged, have sleep

[3] https://www.england.nhs.uk/2017/03/new-patient-care-test/

systems for night time posture and require PEG/tube feeding. To access Bed-Based Services, Service Users are assessed against criteria that they require 24-hour access to nursing interventions (Panel's letter of 11 January 2018 [9/417-420]). A thumbnail sketch of typical user needs is provided in the letter from the parents of Service Users of November 2017 [18/660-661]

43. It is common ground [6/141, 6/157, 7/244, 7/249, 18/660] that Bankfields and Aysgarth provide excellent care and that parents and carers are confident that those in their care are medically and emotionally provided for in those facilities in a safe setting. Within the Council's area, Bankfields recently underwent an extensive refurbishment to improve its clinical offer to Service Users. A further asset for the Service Users is the lifetime of knowledge of the person being cared for within the Bed-Based Services [6/167, 27/17].

44. From early on in the exercise, strong concerns were expressed by parents and carers that the severity and profound nature of Service Users' learning disabilities and/or autism, and the complexity of their health needs was simply not recognised in the pre-engagement and consultation process [18/659-660]. References in consultation to provision of respite in chalet, caravans and bed & breakfast accommodation gave rise to real concern amongst the carers and parents of Service Users that there had been a failure to comprehend their very significant and specialist needs (see e.g. letter of Andy McDonald MP [7/407], letter from parents [18/659-660]).

45. The independent report of the public consultation prepared by Jenny Harvey in December 2017 ("the Harvey Report") [7/177-355] identified these concerns [7/217]:

> *Family members and carers, as well as other stakeholders, criticised the consultation process specifically commenting upon the lack of knowledge and experience of decision makers in caring for those with complex needs, the perceived ambiguity and lack of detail in the options which makes it difficult for people to make an informed choice, as well as the lack of voice which has been given to service users.*

46. Further particularity is provided at paragraph 9.6 of the Harvey Report [7/245], including:

> *A number of family carers who submitted individual responses raised concerns about the lack of genuine experience and knowledge of decision makers about the extreme calibre of disability and medical challenges that Aysgarth and 2 Bankfields Court provide care for.*

47. A significant majority of respondents (69%) were "very dissatisfied" or "quite dissatisfied" with the way in which they had been consulted [7/229].

48. The nub of the issue is perhaps identified in a CCG comment minuted at the meeting of the JHSC on 20 November 2017 [6/165-166]:

Councillor – How long had the £1.5 million budget been in place? Will that amount change? If there were more people identified, as needing services, wouldn't spend per head reduce, if the finances remained the same?

CCG Response – Would need to check on how long the budget had been £1.5. The rationale for change was not about money. Every year the CCGs go through spend areas and assess them. The current medical model was expensive and it was known, through talking to providers, that we could provide more opportunities for respite and overnight stays for people and have a better allocation process, so that people who couldn't access respite could do. It was felt that the £1.5 million could be spent in a better, more appropriate way, so that more people could access services and help.

49. A stated goal of the Proposal is to widen the net that the £1.5 million reaches (see Case for Change Document - "demand is growing" - "there are potential gaps" - "availability of choice needs to improve" [7/366-367]). The Consultation Documentation appears to have been produced with this wide net in mind, without paying due regard to the particular and specialised health needs of those actually in receipt of the existing service, those who would (inevitably) be the most likely to be affected by any change.

50. In a presentation to the JHSC of 19 March 2018, the CCGs placed significant reliance (describing them as "key messages") on their statutory duties "to ensure equity as well as equality" and "to offer choice" [14/605] whilst making no reference to their statutory duty under s.3 of the 2006 Act to commission health services, including hospital accommodation, other accommodation for the purpose of any service provided under the Act and such other services or facilities for the prevention of illness, the care of persons suffering from illness and the after-care of persons who have suffered from illness as the CCGs consider are appropriate as part of the health service.

51. The point about the Bed-Based Services being a health service is made succinctly in the parents' letter of November 2017, paragraph 6 [18/660]. It does not appear to have been grasped by the CCGs.

52. In essence, the Proposal appears to have been predicated on the perceived need to deliver equity and equality and to offer choice to a wide class of potential users without paying any demonstrably sufficient regard to the actual needs of the existing Service Users and the long history of the Bed-Based Services in satisfying those needs.

53. Given the (relatively) small number of Service Users by contrast to the Area's population, and the (relatively) small number of bed provision by contrast to the global bed provision in the Area (see [18/660]) (which of itself is indicative of the particularly complex and severe needs of those Users) then a more appropriate consultation/investigation might have focused on those particular Service Users and their individual needs, how they were being met by the Bed-Based Services, and how a different provision might affect them. Indeed, the particular vulnerabilities of those

Service Users cried out for a more detailed consultation and review. A more focused consultation of this nature might well have led to the conclusion that provision of the Bed-Based Services, rather than being "expensive", was the most appropriate way of supporting the care of the Service Users in the community.

54. The Panel's firm view, however, is that the "voice of the carer" was not fully taken into account during the consultation (see its letter of 11 January 2018 at [9/419]). The attendance of in excess of 40 family carers and their sons and daughters at a meeting of the Joint OSC in November 2017 was testament to the fact that many felt their concerns had not been listened to and their voices had not been heard.

55. In this regard, the detail provided by the CCGs as to the third reconfiguration test (i.e. clear clinical evidence) appears somewhat sparse - see:

    (1) the Decision-Making Report at [10/449] (which largely consists of internal updating and detailed future steps for implementation) and

    (2) the summaries in the presentation made to the JHSC on 19 March 2018 at [14/616-617], which in essence consist of support for the aspiration of increasing choice.

56. What is absent is any clinical appraisal of the effect of removal of any degree of Bed-Based Services and/or their replacement with services from an unknown alternative provider or providers.

(3) Lack of clarity on proposed changes to assessment and allocations process

57. Under the Proposal, the assessment and allocation process will be changed, "making it more needs led".

58. No clarity has been provided as to what this entails. The Decision-Making Report provides a needs grid [10/451] which says nothing of substance. The section of the presentation made to the JHSC on 19 March 2018 relating to this topic [14/619-623] is indicative of the vague and aspirational nature of the proposal consulted upon. Graphics of children of different heights standing on boxes to watch a baseball match provides little assistance to the Panel in assessing the extent to which vital respite care is going to be affected by the Proposal.

59. The Case for Change stated that a "predetermined assessment and allocations criteria is proposed which is based around a notional resource allocation based on the respite needs of the individual and their parent or family carer" [7/381]. In the Decision-Making Report it was said the "proposed assessment and allocation tool … has not yet been finalised. Financial modelling will continue as the assessment tool is further developed" [10/452]. The model had not been finalised by the time of the meeting of the JHSC on 19 March 2018 [14/601]. No further particulars of the model were provided to the South Tees Joint Health Scrutiny Committee ("STJHSC") on 25 April 2018 [16/639-646].

60. Some indication of the modelling exercise can be discerned from the sensitivity analysis reported at paragraph 5.6 of the Decision-Making Report, where it is stated [10/453]:

> *The new assessment and allocation model is based on the needs of both the service user and their carers. The tool generates a financial allocation to service users which can be used to purchase a mix of bed based and non-bed based services. The mix of services cannot exceed their allocation. Sensitivity analysis has been run in the event that every service user decides to utilise their full allocation on bed based services. This model generates a bed based requirement of 1,610 bed days for South Tees CCG and 1,255 bed days for Hartlepool & Stockton-on-Tees CCG, both of which are within the current bed capacity available and within the allocated funding given by the new tool.*

61. This is a total of 2,865 bed days, a slight reduction on the current provision (average of 33 nights per year x 90 Service Users) of c.2,970.

62. However, troublingly, the assurance sought from the CCGs that those currently in receipt of 33 nights respite at Bankfields would still have that option available to them with the current level of clinical oversight [16/641] was not given at the meeting on 25 April 2018. It is plain the model was still a work in progress on that point. The lack of the specific assurance sought plainly undermines the reliance that can be put on the "worst case" scenario in the Decision-Making Report. The STJHSC members were of the view that the CCGs inability to clarify the impact of the Proposal, particularly on the individual families of the Service Users currently in receipt of the Bed-Based Services was a serious flaw which undermined the value of other assurances given about access [17/649]. The parents of Service Users were similarly concerned of the lack of particularity in the assurances given [18/689].

63. It is hard to see how intelligent consideration and response of the Proposal can be made at any stage when the assessment and allocation tool has yet to be finalised, as recognised by the STJHSC [17/649] and parents [18/689]. Such detail as has been drip-fed in the course of the process is not supported by assurances in the dispute resolution process undertaken pursuant to the Regulations.

<u>(4) Lack of information on community-based alternatives</u>

64. FAQ 74 provided [6/131]:

> *Q: Before the consultation ends can we look at the alternatives?*
>
> *A: Unfortunately the CCGs would only be able to identify providers following completion of the procurement exercise, and procurement cannot commence until consultation is concluded. There will be no opportunity to enable individuals and their families to view the alternatives before they are formally commissioned.*

65. At the first meeting of the JHSC on 11 October 2017 the issue was raised. As per the minutes [5/101]:

> *Members requested more details on the nature of the alternative providers of bed based provision as outlined in Option 1.*
>
> *As part of preliminary work, sixteen possible providers from the local area had expressed an interest in working with the CCGs to provide a range of respite opportunities. Due to commercial confidentiality the NHS were not in a position to outline the identity of the organisations. Options could involve a variety of services, including Shared Lives approaches. It was noted that a variety of local authority respite and short break services had been developed over recent years, and provided a demonstration of the type of services that could be developed for clients with health needs.*
>
> *Members noted that further information on the types of alternatives should be provided. It was important that examples of alternatives were made clearer to the services users and their families and carers, so that they were able to make a fully informed response to the proposals.*

66. The JHSC's suggestion has not been taken up. No further information on alternatives has been provided.

67. Any consideration of alternatives necessarily involves taking the existing provision as a base-line. Insofar as that is concerned, the Panel's view echoes that of many consultees: that the current Bed-Based Services are a "gold standard" which could not be replicated elsewhere [11/566]. This is not just the result of the facilities and the staff who operate them; it is also the product of many years' experience of the individual Service Users personal characteristics [6/167] (nearly 50% of Service Users have been accessing the Bed-Based Services at either Aysgarth or Bankfields for in excess of 5 years [7/371, 372]. There appears to have been no adequate attempt in the decision-making process to consider what might be the cost (financial, emotional and clinical) of disrupting this well-established and trusted source of the Bed-Based Services with services from various untried and untested providers in the market (see the concerns summarised at [7/219, 227]).

68. It appears to the Panel that disproportionate emphasis has been placed by the CCGs on the policy aspiration of choice at the expense of according due weight to the significant benefits of continuity (see FAQ 71 [6/130], Supplemental FAQ 17 [9/155], Decision-Making Report [10/445, 459]) in an arena where health services are provided to a small group of highly vulnerable persons over many years.

69. In any event, in common with other stakeholders [7/250-251, 19/843], the Panel is not satisfied that any suitable alternatives exist in the local market. The Bed-Based Services is a valuable resource of expert and specialist nursing care which is unlikely to be available to such a degree and extent elsewhere. There is a national downward

trend in the availability of learning disability nurses[4]. Learning disability nurses have been recognised[5] as making a unique contribution in their skill in providing specialist assessment and understanding of specific health risks a patient might have, based on their syndrome, in situations where someone without that training may wrongly discount symptoms of underlying physical issues as being merely behaviour associated with learning disability.

70. Adult Social Care commissioners have indicated that there were previously 2 facilities in the independent sector that provided residential care for persons with learning disabilities in the Council's area. They were:

    (1) Elmridge (42 bedded nursing and residential home) - closed in March 2016;

    (2) Evergreens (29 bedded residential home with 3 bungalows) – closed in February 2016.

71. Enquiries of the care home market have been made to gauge interest in providing bespoke learning disability units. Dalby Court Residential Care Home, operated by Sanctuary Care, has created a 10 bed unit but this is not exclusive or separate from the older persons' service. Dalby Court was recently assessed by the CQC as "requires improvement"[6]. The report spoke of pressures caused by under-staffing. Windermere Grange (St Martins Care) has also developed a 10 bed unit. Such specialist learning disability provision is therefore limited.

72. The Panel further notes that no information on the balance between the spend on the current Bed-Based Services and "community based" services has yet been provided.

(5) Adverse impact on Service Users' family units and carers

73. The Bed-Based Services are a necessary ancillary to the care in the community of the Service Users. Service Users are typically cared for by family members, who, owing to the challenging nature of the needs of Service Users, generally provide round-the-clock assistance. Many carers are providing in excess of 100 hours per week. Respite care, as well as being a health service to the Service Users, has, as the name suggests, the benefit of providing respite to carers of the Service Users.

74. It is a trite proposition that respite enables carers to take a rest from the challenge of providing care, and to recharge so care can continue when the respite period is over - if evidence were needed see, for example, the findings of the engagement report (at [3/24]):

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[4] Royal College of Nursing's The UK nursing labour market review 2017 shows an 18.4% decline from 2013 to 2017 in the qualified workforce in England for the work area learning disabilities/difficulties https://www.rcn.org.uk/professional-development/publications/pub-006625.

[5] Nursing Times 8 May 2018 https://www.nursingtimes.net/news/workforce/exclusive-learning-disability-nurse-shortage-needs-real-action/7024366.article

[6] https://www.cqc.org.uk/sites/default/files/new_reports/INS2-2494711780.pdf

Words and phrases such as "break", "relax", "peace of mind", "safe place", "rest", "time out", "recharge", "anti stress" were particularly common in relation to the responses from Carers about what respite means to them.

75. For respite care to achieve this underlying and important purpose, it is crucial that it is effective in permitting carers to take full advantage of the respite period. The exercise is counter-productive if, during the respite period, carers have no confidence or peace of mind that those they care for are being properly cared for (c.f. the current position - "carers are confident that their sons and daughters are medically and emotionally cared for and are safe from any risk of abuse" [9/418]) or are called upon to deal with situations arising at the respite facility where service providers, unfamiliar with the service user, require assistance from the permanent carer).

76. The Bed-Based Services accommodate unplanned admissions, including emergency admissions - so, for instance, where the Service User is admitted where the carer falls ill, where there has been a family bereavement, and so on [7/370-371]. The ability of the Bed-Based Services to make such accommodations is an important safety-net for the provision of care in the community. In a period of just over 4 years, there were 221 unplanned admissions to the Bed-Based Services of which 89 were categorised as emergency: a very small proportion of total admissions.

77. The recommendations of the CCG's executive in common, approved in the Decision, included a recommendation to "fulfil plans to separate crisis and respite arrangements to address current levels of unplanned admissions to respite beds" [10/460]. This element of the Proposal does not appear to have formed part of the public consultation, and the Panel is most troubled at the suggestion that at times of crisis, when the bank of experience and knowledge of the Bed-Based Services is most likely to be called on, the suggestion is that those services are not to be used.

78. The Panel is very concerned that disruption to the release valve of planned respite and the safety-net of unplanned respite could have a catastrophic impact on the carers of the Service Users (see, for instance, the letter of Dr Brian Corbett [18/691-693]). The analysis on the impact on carers conducted by the CCG is, with respect, somewhat superficial in scope and over-optimistic [20/913].

(6) Unacceptable safeguarding risks

79. The Panel is of the view that the Proposal in its current form presents unacceptable safeguarding risks to Service Users.

80. The excellence of the Bed-Based Services is not in doubt.

81. As detailed in Reason (4) the detail of alternative providers is inadequate / non-existent. The presence of safeguarding risks to persons with learning disabilities is

well-known and well-documented[7]. The Panel is extremely concerned that the Proposal is to remove the conduct of the care of some of the most vulnerable members of the community from those who have providing it for many years into the hands of unknown providers.

(7) Financial justification

82. The Panel is concerned that the CCG's approach has been to look at the £1.5m p.a. currently spent on the Bed-Based Services as a fund potentially available for distribution to a wider class of persons in the interests of choice (and, as appears below, as an expense in respect of which savings can be made).

83. The point has already been made (see paragraph 22 above) that the Panel's view is that the Bed-Based Services are health services which the CCGs have a statutory duty to provide to the Service Users.

84. The Panel is further concerned that there appears to have been a failure to properly appreciate that, in facilitating care in the community for the Service Users by the provision of respite services, very significant value for money is being obtained by contrast to the next most likely alternative, namely inpatient care for Service Users whose family carers would be unable to cope (see e.g. [7/238, 341]) without the safety valve and safety net of known and trusted respite care. The Panel strongly suspects that in spending c.£1.5m p.a. on the Bed-Based Services, the CCGs save many millions of pounds on the next most likely alternative.

85. There is further the point that the Bed-Based Services provide significant added value to CCGs. Through those Services, Service Users are receiving regular clinical oversight, annual health checks and a prescription medication management service. This saves substantial time and resources for other parts of the health service, including GP's, pharmacies and A&E, as well as the acute sector. It supports the "breaking down barrier" theme in the Five Year Forward Review [1/1]. A change to disparate respite options is likely to create a fragmented service that will be less capable of delivering this kind of added value.

86. The dedicated facilities currently provided constitute a valuable, constantly developing source of specialist skills and expertise - a cost saving at a time when specialism in this field is in short supply (see paragraph 69 above). The Panel is concerned that the financial modelling fails to take a sufficiently long term provision having regard to this fact.

87. Demand will increase as young people attain the age of majority (future need data is at [35-36]). The Panel is troubled that no consideration has been given to a budgetary increase to accommodate rising demand for respite services.

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[7] Mencap suggest a lack of training for health professionals could be contributing to 1,200 avoidable deaths of people with learning difficulties every year: https://www.mencap.org.uk/sites/default/files/2018-07/2017.005.01%20Campaign%20report%20digital.pdf

88. The Panel's view is that that a finite resource of £1.5m is inadequate to accommodate both current and projected demand.

89. Insofar as current demand is concerned, the Panel notes that the Trust have stated that the cost of the Bed-Based Services is in excess of the agreed block funding [10/450] and that a short term agreement has been reached with respect of funding for 2017-2018 (shown as £220,000 "cost pressure") in the Decision-Making Document [10/451].

90. Turning to projected demand, the CCG's The "do nothing" model at [10/451] identifies an additional £100,000 allocation (which the Panel considers to be modest) for increased demand to give a total cost of services of £1,821,335 (factoring in the true current cost of the Bed-Based Services).

91. The Panel is concerned to note that the contrasting costs under options 1 and 2 are said [10/451] to include a £150,134 contingency.

92. The Proposal is therefore to deliver a wider range of services to more users at a saving over continuation of the existing service of £470,134 p.a. The Panel is most concerned that it was not made clear in the course of consultation that the aim was to deliver the Proposal at a cost not just "within" (see paragraph 10 above) but significantly *under* existing budget.

93. The Panel notes that illustrative costings shown in the Decision-Making Document at [10/452] show a cost per night in the existing Bed-Based Services of £470, and a cost in "bed based respite care" of £443 per night. The Panel is unclear how the CCGs propose to retain the Bed-Based Services and in addition deliver alternative community based series at this rate, not least given the inability to deliver the Bed-Based Services within existing budget.

Steps the Council has taken to try to reach agreement with the CCGs in relation to the Proposal

94. Following the adoption of the proposal on 1 February 2018 the JHSC and the Council have made concerted efforts to impress their concerns upon the CCGs and to reach agreement thereon. As set out in the attached chronology, there have been 2 meetings of the JHSC, at the second of which the CCGs made a presentation; the CCGs have also presented to the South Tees Scrutiny Joint Committee on 25 April 2018, and the Panel has considered the matter at various separate meetings.

95. Whilst assurances have been received from the CCGs and the Trust [648], significant areas of concern remain.

96. In particular, whilst the CCGs' assurances state that all the allocated resources can be used for bed based respite at the current facilities and families will no longer be required to choose an alternative respite service from a menu of options, the CCGs were unable to provide any assurances relating to the minimum number of nights that

would be available to families as the assessment tool to determine the level of resource to be allocated had not yet been established.

97. As stated above (paragraph 62), members of the Panel felt that the inability of the CCGs to clarify the impact of their reconfiguration proposals, particularly on the individual families currently in receipt of the service was a serious flaw and undermined the value of other assurances given about access to the service. They also felt it was a limiting factor in the quality of the consultation since consultees had been asked to make choices about options without any clear indication of the extent of the impact on them. The Panel is very concerned that the cost savings that emerge in the Decision-Making Document were not adequately identified and consulted upon. The panel is not satisfied that the "gunning principles" in particular principles 2 and 4 have been adhered to. The panel is further concerned that the Equality Impact Assessment produced is insufficient, and is at odds with the information provided.

Conclusion

98. I make this report to you pursuant to the Regulations, and, in view of the ongoing anxiety and uncertainty that the Proposal has caused the dedicated families and carers of the 91 Service Users, I respectfully ask that you arrange for it to be given anxious consideration at the earliest opportunity.

Yours sincerely,

Councillor Eddie Dryden
Chair of Middlesbrough Council's Health Scrutiny Panel