

Views gained during the scrutiny process

As Sir Stephen Bubb said in his report:

“People with learning disabilities and/or autism and their families have an array of rights in law or Government policy – through human rights law, the Equalities Act, the NHS constitution, the Mental Health Act, the Care Act, the Mental Capacity Act, the UN Convention on the Right of Persons with Disabilities, and so on... [but] the lived experience of people with learning disabilities and/or autism and their families is too often very different. Too often they feel powerless, their rights unclear, misunderstood or ignored.”¹

1. Grounds for the referral

1.1 Middlesbrough Council requests that the Secretary of State for Health & Social Care considers our concerns about the decision made by South Tees Clinical Commissioning Group (CCG) and Hartlepool and Stockton (HaST) CCG on 1 February 2018 in respect of future respite provision following their consultation on *Transforming Care: Respite Opportunities and Short Breaks for People with Complex Needs and Learning Disabilities and/or Autism*.

1.2 The grounds for this referral are that we firmly believe the consultation was inadequate and that the CCGs proposed changes are not in the interests of the Health Service in our area. The reasons for the referral are as follows:-

- Misleading use / misinterpretation of the Transforming Care agenda
- Alternative health respite providers across Teesside unknown / untested
- Potential for major impact on carers / increased risk of family breakdown
- Potential for safeguarding issues and poor quality of care
- Potential for increased costs and reduction in added value
- Continued lack of clarity in respect of eligibility criteria and incomplete needs led assessment / resource allocation tool
- Lack of understanding around Bankfields and Aysgarth client base

1.3 Evidence to support our reasons for referral are laid out in detail below.

2. Context

2.1 South Tees CCG and Hartlepool and Stockton CCG serve a population of 600,000 across four local authority areas in Teesside. Findings² about the local population of people with Learning Disabilities (and their Carers) highlight that:-

- The North East has a disproportionately higher number of individuals with a Learning Disability than any other region in England. [Public Health England]

¹ Transforming Care for People with Learning Disabilities – Next Steps, January 2015, page 10.

² NHS ST CCG and NHS HaST CCG Report on proposed changes to respite opportunities and short breaks for adults (18+) with complex needs and learning disabilities and/or autism, January 2018 <http://www.hartlepoolandstocktonccg.nhs.uk/events/governing-body-in-common-meeting/>

- Three of the four Tees regions that are part of this Teeswide Project (Hartlepool, Middlesbrough and Redcar-Cleveland) have numbers higher than the national benchmark in relation to the all age population of people with a Learning Disability [Public Health England]
- There are more children and young people with severe or profound and multiple Learning Disabilities in the Tees Valley than the regional or national average. [Public Health England]
- As at 27th September 2017, there were 14 Children and Young People who would be due to turn 18 years in the next four years who have Learning Disabilities and complex needs who currently receive overnight respite services at Baysdale, Roseberry Park Hospital. [Tees Esk and Wear Valleys NHS Foundation Trust] and will require respite provision in the future.
- There is an ageing learning disability population, as it is estimated that the number of people aged 70+ who have Learning Disabilities and will be in receipt of social care services will be approximately double by 2030³.

2.3 In response to the above challenges the CCG's have proposed to commission flexible, community based respite provision, whilst maintaining the same respite facilities, extending the reach of the service and introducing more 'choice' into the system. The CCG's allocated 'financial envelope' to achieve this ambition is £1.5m (less than the cost of service delivery to the provider in 2017/18), and is undertaken in the name of the Transforming Care agenda.

2.4 We are of the strong view that this was not the intention of the Government's Transforming Care agenda, as respite is out with that agenda. Nor is the proposal a sustainable business model for either the current and/or future providers. In addition, insufficient evidence has been provided to scrutiny, despite repeated requests, to ensure that the CCGs proposal will provide safe and accessible health respite services for our local population. It is our firm view that the proposed solution fails to achieve its purpose. The parent/carers, Middlesbrough and Redcar and Cleveland MP's / local Councillors and both local authorities are of the view that the proposed solution will not meet the needs of current service users, plus projected demand, within the CCG's allocated £1.5m budget constraint for future delivery of the service. Those with lived experience of caring for a loved one with profound and severe learning disabilities across Teesside have repeatedly voiced their concerns throughout the consultation.

3. Explanation of the proposal

3.1 The *Respite Opportunities and Short Breaks for People with Complex Needs and Learning Disabilities and/or Autism* review is the process by which South Tees CCG and Hartlepool and Stockton CCG have sought to redesign the respite provision, funded by health, for people with learning disabilities, complex needs and autism across Teesside. At present this provision enables 90 families across the four local authorities to access between 33-40 nights bed based respite per year, at two respite centres - Bankfields and Aysgarth.

- Aysgarth Short Term Care Unit (6 beds) at 163 Durham Road, Stockton, TS19 0EA (as of 27th September 2017 this provision is accessed by 40 people).
- Unit 2 Bankfields Court (5 beds) at Normanby, Middlesbrough, TS6 0NO (as of 27th September 2017 this provision is accessed by 50 people).

³Learning Disabilities Observatory - People with learning disabilities in England 2015: Main report, Public Health England, November 2015 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/613182/PWLDIE_2015_main_report_NB090517.pdf

3.2 The facilities at Bankfields and Aysgarth, comprising of 11 bed based respite beds in total, serve a population of 600,000 and provide safe, accessible and sustainable respite opportunities for those with learning disabilities, complex needs and autism. Both centres are provided by Tees Esk and Wear Valley NHS Foundation Trust (TEWV) and have been delivered by the Trust for in excess of 30 years. In 2013 Bankfields benefited from a £5.3m renovation.

3.3 The key issues that led to the review and consideration of the development of services were as follows:

- Demand is growing
- The needs of people are becoming more complex
- There are potential gaps in services
- There is potential duplication of services
- National and local policies influence how services can be delivered
- Availability of choice needs to improve
- Access to and allocation of services needs to be effective
- Services need to be fair and equitable

3.4 Between December 2016 and February 2017 a pre-engagement exercise was carried out with members of the public, patients and carers about what respite meant to them. Seven possible scenarios for how respite, short break and day opportunities could be delivered in the future were developed.

3.5 The seven scenarios were then evaluated by the CCG's using an appraisal criteria. Five of the seven scenarios were discounted and two were taken forward to consultation. With both options, it was advised that there would be a new 'needs led' assessment an allocations process that would change how resources are allocated. With both options there would be the opportunity for people to have different types of respite / short breaks. Both options would need to be delivered within a £1.5 million budget.

3.6 A public consultation took place between 4 September and 10 November 2017 on the following options for service change:

Option 1 – people would not get bed based respite from 2 Bankfields Court and Aysgarth, but could get alternative bed based respite services elsewhere e.g. in another residential community setting or a hotel, with the appropriate support. Depending on the assessed needs and resource allocation, people will be able to access alternative community based activities with appropriate support, in addition to, or instead of, bed based provision. Different community bed based respite services are often less expensive than hospital bed based provision and service users' allocated resources may be able to go further.

Option 2 – some people could still go to 2 Bankfields Court and/or Aysgarth for bed based respite services, if this is how they chose to receive their respite. Depending on their assessed need and resource allocation they may have the opportunity to access alternative community based services in addition to or instead of bed based services. Because of the need for ongoing investment with the current NHS services there may be fewer opportunities for people to access alternative respite and short break opportunities.

3.7 The formal response from the Joint Health Scrutiny Committee, established specifically to consider the consultation, was submitted to South Tees CCG and HaST CCG on 11 January 2018, with specific views from each Council.

3.8 The view of the Joint Overview and Scrutiny Committee was that, it was not supportive of either of the options put forward and recommended that the CCGs should retain the current level of service provision at Bankfields and Aysgarth.⁴

3.9 On 1 February 2018, South Tees CCG and Hartlepool and Stockton (HaST) CCG held a Governing Body in Common meeting. At that meeting the decision was taken by South Tees CCG and HaST CCG that Option 2 be approved for implementation.⁵

3.10 Middlesbrough Council cannot support this decision and is of the view that the decision needs to be examined by the Independent Reconfiguration Panel. The decision is not in the interests of the Health Service in our area and nor is the Council satisfied that the consultation on the proposal was adequate. The evidence and supporting reasons for our referral are detailed below.

4.0 Evidence in support of the referral

Reason 1: Misleading use / misinterpretation of the Transforming Care agenda

4.1.1 Following the abuse scandal at Winterbourne View, the Department of Health committed to move people where appropriate, out of mental health hospitals into the community. In 2015 it launched the Transforming Care programme, which aims to reduce the number of beds for people with a learning disability in mental health hospitals by 35%-50% by 2019 and provide support for people to live in the community instead.

4.1.2 In April 2017 the House of Commons Committee on Public Accounts published their report entitled 'Local support for people with learning disabilities'. In evaluating the progress made to date in respect of the Transforming Care programme the Committee concluded that, more needs to be done to address barriers: money is not moving with the patient to pay for support in the community, too many people are not having care and treatment reviews and the uncertainty caused by the proposed changes to local housing allowance risks hampering the provision of accommodation in the community. The report highlights that, approximately 2,500 people with a learning disability are in mental health hospitals, some with secure facilities. These people are considered a danger to themselves or others and have behaviour that challenges services.⁶

4.1.3 Throughout all of the CCG's decision making documentation⁷ the Government's Transforming Care agenda is cited as a key driver for the review of respite services, emphasising the focus of that agenda as a reduced reliance on bed based provision and increased availability of community services.

4.1.4 Similarly, the CCG's have emphasised their consideration of the 'fifth test' (support for bed closures) as part of their overall assurance process. From the service users' and scrutiny members' perspectives, there has been a very strong message that it is a national government agenda that is driving the need to reduce the bed based respite care service and offer alternative community based choices. It is scrutiny's view that the references to Transforming Care have been misleading. The Transforming Care programme will, in fact, see more people

⁴Respite and Short Breaks Consultation Joint Health Scrutiny Committee Consultation Response, 11 January 2018, <http://www.egenda.stockton.gov.uk/aksstockton/images/att32945.pdf>

⁵ Governing Body In Common – Respite Services, 1 February 2018 CCG Decision Notice.

⁶ House of Commons Committee of Public Accounts, Local support for people with a learning disability, published on 26 April 2017.

⁷ NHS South Tees CCG and NHS Hartlepool and Stockton (HaST) CCG Governing Body In-Common, 1 February 2018, agenda and papers. <http://www.hartlepoolandstocktonccg.nhs.uk/events/governing-body-in-common-meeting/>

with learning disabilities and complex needs requiring support within local communities to reduce reliance on long term hospital inpatient admissions.

4.1.6 The report 'Building the Right Support' published by the LGA, ADASS and NHS England, in October 2015 outlines a national service model built around 9 key principles (p.25 and 26) for developing community services for people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition. Principle 4 states that:

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.

4.1.7 Parents and carers have advised that in all likelihood had the respite provision at Bankfields and Aysgarth not been available to them, some of those currently in receipt of the service would have been residing permanently in an inpatient setting. It is our view that the current offer at Bankfields and Aysgarth is helping to support carers across Teesside to care for their loved ones in the family home, thereby preventing prolonged inpatient stays. The options to close or reduce provision at these facilities appear contrary to the fundamental principles of the Transforming Care agenda.

Reason 2: Health respite providers across Tees unknown and untested

4.2.1 The CCG's have been unable or unwilling to elaborate on the detail of the 16 interested alternative providers they engaged with through soft market testing. Local Authority Commissioners have confirmed that there are currently no independent sector learning disability nursing facilities in Middlesbrough, Redcar and Cleveland, Stockton or Hartlepool. The private commissioned care sector has not been fully developed or tested to give assurance to Local Authorities or parent/carers that the sufficiently skilled workforce is out there to meet needs.

4.2.2 In contrast Bankfields and Aysgarth provide continuity of care by learning disability nurses for clients, some of whom have been receiving the service over a long period of time and have developed strong relationships with staff. Scrutiny fully recognises that there is a desire for greater flexibility and choice in local respite services, and recognition that children and young people coming through into adulthood do have different needs and expectations of the options that should be available. However, there is also a strong view that this should not be at the expense of current provision. The unique facilities at Bankfields and Aysgarth cannot be replicated or improved upon locally without significant financial investment.

4.2.3 Qualified staffing remains a key concern and at present all medication is administered by qualified nurses at Bankfields and Aysgarth. Staff have undertaken advanced qualifications in, for example, Autism and are experts/specialists in their field. As highlighted by the Chair of the UK Learning Disability Consultant Nurse Network in an article in the Nursing Times it is "important to emphasise the "unique contribution" of Learning Disability Nurses, which is their skill in providing specialist assessment and understanding of specific health risks a patient might have, based on their syndrome. Professionals that aren't trained to work with someone with a learning disability might say, 'that is just part of their learning disability, part of their behaviour', but actually there's an underlying physical health cause to that."⁸

⁸ The Nursing Times, May 2018 <https://www.nursingtimes.net/news/workforce/exclusive-learning-disability-nurse-shortage-needs-real-action/7024366.article>

4.2.4 In light of the above the local authority is of the view that the current level of specialism will not be replicated in the provision of flexible community respite. This has implications for the health and well-being of people with learning disabilities, as well as on the skills/experience of the health service locally. Parents / carers have also expressed clear concerns over the possibility of a 'downgrade' in service provision. The current service is recognised as providing a very high level of care, with the ability to meet the high level and complex needs of the clients. A significant benefit of the current facilities is the nurses / staff are dedicated to this level of provision. The term 'community based respite' has been used throughout the consultation documents and from the CCG's perspective Bankfields and Aysgarth are not regarded as 'community based respite' provision but as hospital bed based respite. In contrast the parent/carers view these specialist and highly regarded respite facilities as the definition of 'community based health respite'.

4.2.5 In England, the data reported in the Royal College of Nursing's UK labour market review 2017, shows that the number of Learning Disability Nurses fell by 18.4% between 2013 and 2017.⁹ The view has been expressed by professionals that 'unless this is rectified quickly the long-term consequence for the health and well-being of many people with learning disabilities could be catastrophic.' In addition the declining numbers will potentially hamper the aims of NHS England's Transforming Care policy, which aims to ensure that services are tailored to help more people with learning disabilities live in the community or at home rather than spend prolonged periods in hospital. The Council of Deans of Health report has also highlighted that some universities in England scrapped their spring 2018 intake of learning disability nursing students after courses were undersubscribed in 2017.¹⁰

4.2.6 Adult Social Care Commissioners have confirmed that previously there were two services that provided residential care for people with learning disabilities in Middlesbrough. Elmridge, a 42 bedded residential and nursing home and the Evergreens, which was a residential home with 29 beds within 3 bungalows on the same site. Evergreens closed in February 2016 and Elmridge in March 2016. With no other Learning Disability providers in Middlesbrough the older persons care home market was approached and asked if there was any interest in creating bespoke LD units. Dalby Court Residential Care Home created a 10 bed unit that is not exclusive and separate to the older persons' service. Windermere Grange developed a separate LD unit with 10 beds. As such there is limited LD residential provision and limited respite.

Reason 3: Potential for major impact on carers

4.3.1 From very early on in the process, it was clear that the CCG's preferred option was Option 1 which would have involved the closure of Bankfields and Aysgarth, both well established and highly valued services ('gold standard' in the words of the service users) in preference to a range of other, non-specified bed based respite options, available for a reduced number of nights for those service users who were deemed still eligible, once assessment criteria, that had not been determined, had been applied.

4.3.2 Option 2 provided for the existing services at Bankfields and Aysgarth to remain, but the CCG were clear that due to the higher cost of maintaining the existing service, the combined offer including the community-based provision would be less than in Option 1. However, the balance between spend on current and possible alternative provision has not been articulated.

⁹ The UK nursing labour market review 2017, Royal College of Nursing, December 2017

¹⁰ Council of Deans of Health, Learning disability nursing meeting report, 16 November 2017 <https://councilofdeans.org.uk/wp-content/uploads/2017/11/report-from-the-learning-disability-roundtable.pdf>

4.3.3 Parents and Carers have stated that they have already received a reduction in the number of night's respite they receive and the average allocation is currently 33 nights per year. This equates to 2.75 nights per month, any further reduction for the parent / carers is inconceivable. Owing to the demanding nature involved in providing 24/7 care to their loved ones, those in receipt of the service have advised that they often use this time to sleep. Many provide in excess of 100+ hours of care per week for their loved one. Irrespective of the form that alternative services may take, there has also been a clear view from parents / carers that community based services would simply not be suitable for many of the clients with high levels of complex needs.

4.3.4 As stated above, parents and carers advised that in all likelihood had the respite provision at Bankfields and Aysgarth not been available to them, some of those currently in receipt of the service would have been residing permanently in an inpatient setting. The respite service they receive allows them to recharge their batteries so that they can continue to provide the round the clock care required by their loved ones, at home, and within a community setting, for the rest of the year.

4.3.5 The prospect of a reduction in, or a removal of, this service has created an enormous amount of anxiety and concern amongst parents and carers. The uncertainty about the forms that alternative future provision may take have added to their anxiety levels, particularly where CCG illustrations have suggested that respite at home, or shared activities with parents, perhaps including an overnight stay in a caravan could be a suitable forms of respite.

4.3.6 In a communication to Teesside MPs, Councillors, Staff, NHS Managers, Public Health and Healthwatch, the unanimous view of the 90 parents and carers using the current Bankfields and Aysgarth facilities was clearly articulated – they feel the proposed alternatives will be **unsafe, dangerous and stressful** – parents need respite from the care, and need to be confident that the clinical health needs of their loved ones will be catered for. The current service supports parents and carers to enable them to look after their adult children at home, in the community, 325 days per year.

4.3.7 Between 1 April 2012 and 31 May 2016, there were 221 unplanned admissions to Bankfields and Aysgarth of which 89 were categorised as emergency. The top three reasons for these admissions all related to the ability of the carer:¹¹

- Carer unwell (including falls and post-operative recovery for carers)
- Carer/family breakdown (including family illness)
- Carer medical treatment or hospitalisation.

4.3.8 This demonstrates the vulnerability and fragility of even the existing arrangements; however this is simply a quantitative analysis of the situation. The emotional and mental impact is potentially much more significant. It is scrutiny's view (and a view also shared by Dr Brian Corbett) that a further reduction in respite services could have a catastrophic impact on the carer resulting in the need to secure long term inpatient beds for the adult children, at a much increased cost to health services. This view is in total contrast to the claims made in the CCG's Equality Impact Assessment which states:

¹¹ Case for Change, Respite Opportunities and Short Breaks for People with Complex Needs and Learning Disabilities or Autism, South Tees CCG and HaST CCG, presented to the Joint Committee on 14 December.
<http://www.egenda.stockton.gov.uk/aksstockton/images/att32456.pdf> (There were 115 unplanned admissions to the respite services from the Middlesbrough and Redcar and Cleveland localities, 39 of which were considered emergency admissions)

*'we anticipate that the services will have a positive impact on people who are carers as they will benefit from enhanced or improved services which may support them in their caring role.'*¹²

Reason 4: Potential for safeguarding issues and poor quality of care

4.4.1 The recent CQC inspection report for Bankfields and Aysgarth states that “there were two respite services where all of the patients were informal. Staff advised that they would always consider the use of the Mental Capacity Act 2005 and Deprivation of Liberty Safeguards in order to protect patients if they chose to leave. The service carried out ligature assessments and no ligature points had been noted. Where patients were at risk of harm they were under close observation. Where patients required the use of restraint there was a restraint care plan in place. Incident records were detailed and contained clear information about what led to the use of restraint, who had been involved and why it had been used.”¹³

4.4.2. Each individual in receipt of respite care at Bankfields and Aysgarth has a comprehensive file meticulously detailing their medical requirements. The current respite provision simply cannot not be replicated elsewhere. Examples of rescue medication, as required by many of those in receipt of respite at Bankfields and Aysgarth, as well as anti-anxiety and sedation medication were also provided to the panel. Bankfields and Aysgarth are clinical environments and those attending this provision have complex medical needs and are in need of this level of provision. The facilities at Bankfields and Aysgarth enable freedom of movement and fulfil Deprivation of Liberty Safeguards; these are first class respite facilities for people with learning disabilities, complex needs and autism in our area and we cannot afford for this provision to be reduced and/or replaced.

4.4.3. In response to a query from the Joint Scrutiny Committee the following details were provided in respect of the number of people with complex needs, learning disabilities and / or autism receiving respite and short breaks in other settings compared with Bankfields and Aysgarth. It is evident from the data provided that the other settings are well utilised by people from each of the local authority areas. The users of Aysgarth and Bankfields access these facilities, as the offer is a specialist clinical offer that is different to those provided in other settings.

Numbers of Clients per Local Authority / CCG People with similar complex needs / LD and/or Autism receiving respite + short breaks

Local Authority of Residence	Users of Aysgarth	Users of Bankfields	Other settings
Hartlepool (HaST)	2	0	96
Stockton (HaST)	38	0	147
Middlesbrough (South Tees)	0	35	168
Redcar & Cleveland (South Tees)	0	15	125

4.4.4 The infrastructure of both sites, including staffing, knowledge, expertise and training, as well as the provision of specialist equipment would prove difficult to recommission if either site were not to retain its current levels of funding. In 2016 Scarborough and Ryedale Clinical Commissioning Group put together a business proposal to develop and commission new

¹² Equality Impact Assessment, North of England Commissioning Support, August 2017, http://www.southteesccg.nhs.uk/wpcontent/uploads/2018/01/Equality_Impact_Assessment_LD_Respite-updated.pdf

¹³ CQC Report, Tees, Esk & Wear Valleys NHS Foundation Trust, May 2015 https://www.cqc.org.uk/sites/default/files/rx3_coreservice_wards_for_people_with_learningdisabilities_or_autism_tees_esk_wear_valleys_nhs_foundation_trust.pdf

respite services for Complex Care Learning Disability Respite clients. Having previously closed a facility in Pickering the CCG was “lobbied by a number of families who did access the Pickering service and wanted a replacement for it, which they hadn’t been able to source themselves and neither had the PCU from current providers.”¹⁴

4.4.5 The level of concern expressed by parents is understandable given that in February 2018 new research undertaken by Mencap suggested that a lack of training for health professionals could be contributing to the 1,200 avoidable deaths of people with a learning disability every year.¹⁵ The research highlighted that 38% of people with a learning disability die from avoidable causes, compared with 9% of the general population.

- **Almost a quarter (23%) of healthcare professionals have never attended training on meeting the needs of patients with a learning disability.**
- **Over 1 in 3 (37%) healthcare professionals think the quality of healthcare received by patients with a learning disability is worse than that received by patients without a learning disability.**
- **Almost half (45%) of healthcare professionals think that a lack of training on learning disability might be contributing to the avoidable deaths of people with a learning disability.**
- **59% think the issue of avoidable deaths does not receive enough attention from the NHS.**

4.4.6 Ten years on since Mencap published ‘Death by Indifference’ highlighting institutional discrimination leading to the deaths of six people whilst in the care of the NHS. The recent publication of the Learning Disability Mortality Review (LeDeR) in May 2018 has also highlighted the significant inequalities still faced by people with learning disabilities, raising significant concerns around their care. A total of 1,311 cases were passed for review between July 2016 and November 2017. 103 (8%) have been finished so far and of those, it was found that failings had taken place in one in eight deaths, from abuse to delays in treatment.¹⁶ Moving ‘respite’ provision away from Bankfields and Aysgarth is understandably a risk many parents are not willing to accept.

4.4.7 The potential for safeguarding risks is clear. As referenced previously in response to the closure of local LD residential facilities in Middlesbrough, Dalby Court Residential Care Home created some bespoke LD units (para 4.26 – para 4.27). Their recent CQC inspection report however, as published on 27 June 2018, only serves to strengthen concerns around the commissioning of alternative provision. The conclusion of the overall inspection report was ‘Requires Improvement’. At the inspection on 13 and 14 April 2018 the CQC found a breach of Regulation 18 (1) The Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 Staffing. This was because the CQC found that staffing levels were not always sufficient to meet people’s needs.

4.4.8 The report highlights, all of the care staff we spoke with expressed their concerns regarding staffing levels. Staff told us that they wanted to provide person centred care but had to focus on tasks to meet people's basic needs. One staff member told us, "I don't feel eight [staff] across the building is enough". Another staff member said, "Staff are stressed, if people are on their buzzers and you are dealing with someone two to one there is no one to go to the

¹⁴ Update Report for the Learning Disability Respite Unit proposals, Scarborough and Ryedale Clinical Commissioning Group, 25 January 2017, <http://www.scarboroughryedaleccg.nhs.uk/data/uploads/board-meetings/2017/25-january-2017/182.-update-report-for-the-learning-disability-respite-unit-proposals.pdf>

¹⁵ Treat me well Simple adjustments make a big difference – A campaign to transform how the NHS treats people with a learning disability, Mencap, February 2018, <https://www.mencap.org.uk/sites/default/files/201802/Treat%20me%20well%20campaign%20report%20FINAL%20DIGITAL.pdf>

¹⁶ The Learning Disabilities Mortality Review (LeDeR) Programme, Annual Report, University of Bristol, published May 2018 <https://www.hqip.org.uk/wp-content/uploads/2018/05/LeDeR-annual-report-2016-2017-Final-6.pdf>

other person." Another staff member told us, "When you are dealing with people two to one you are constantly hoping that people are okay in the conservatory." In addition, a fourth member of staff commented, "It's not very fair on the other residents having to wait. If they have a little accident it's degrading."¹⁷

4.4.9 On the days of the inspection one person using the service was displaying some behaviour requiring close observation and regular interventions from staff. This meant that one member of the staff team had to provide very close supervision to that person and was therefore often not available to meet the needs of other people.

Reason 5: Potential for increased health costs and reduction in added value

4.5.1 The cost associated with facilitating an out of area placement for the level of care required by those accessing health respite at Bankfields and Aysgarth is in excess of £2000 per week per individual. The annual cost therefore for an out of area placement for an individual with severe and profound learning disabilities is in the region of £104,000 per individual per year.

4.5.2 Those in receipt of bed based respite at Bankfields and Aysgarth reside at home, in the community, with their family 325 days per year. This represents a significant cost saving to the health service. Bed based respite for people with learning disabilities, complex needs and autism is also viewed by carers as the most important form of respite they receive. It is viewed as unique in its offer to meet the needs of the carer.

- If 10% of the 91 families (equating to 9 families) affected by the proposal were no longer able to support their loved one at home due to a reduction in / removal of the respite available at Bankfields and Aysgarth, the annual cost to the health service would be approximately £936,000
- If 20% of the 91 families affected by the proposal were no longer able to support their loved one at home, the annual cost to the health service would be £1.87m, a sum on its own, in excess of the total budget (£1.5m) currently sustaining 91 families.
- If 50% of the 91 families affected by the proposal were no longer able to support their loved one at home, the annual cost to the health service would be £4.7m.
- If all of the 91 families affected by the proposal were no longer able to support their loved one at home, the annual cost to the health service would be £9.5m.

4.5.3 In comparison to the figures above, the cost of the current respite support being provided to carers, who are making what would ordinarily be an unsustainable situation sustainable, is relatively small in comparison.

4.5.4 In addition to this, at present the CCG's are receiving added value for the service they are commissioning. By accessing respite provision at Bankfields and Aysgarth the individuals in receipt of the service are receiving regular clinical oversight, annual health checks and a prescription medication management service. This saves substantial time and resources for other parts of our local health system including GP's, pharmacies and A & E, as well as the acute sector.

4.5.5 This supports one of the key themes in the Five Year Forward View:-

¹⁷ Dalby Court, Residential Care Home Inspection Report, Care Quality Commission, June 2018
https://www.cqc.org.uk/sites/default/files/new_reports/INS2-2494711780.pdf

- The NHS will take decisive steps to break down the barriers in how care is provided between family doctors and hospitals, between physical and mental health, between health and social care.¹⁸

4.5.6 The proposed service changes appear much less capable of delivering this kind of added value. The menu of disparate respite options will create a fragmented service with limited continuity of care and loss of clinical / medical knowledge of the individual clients.

4.5.7 The CCG have consistently stated that there is no financial driver for the service review, they are not cutting services, and they are committed to keep a £1.5m budget. However, demand is growing. There are 14 young people who would be due to turn 18 in the next 4 years who have learning disabilities and complex needs who currently receive overnight respite services at Baysdale, Roseberry Park Hospital. The families of these young people are highly likely to need to access the respite services at Bankfields and Aysgarth as they reach adulthood. An increase in demand, with no increase in resource to meet that demand can only be accommodated by a reduction in the service.

It is scrutiny's view that the finite resource of £1.5m for future provision is inadequate to accommodate both current and projected demand.

4.5.8 The CCG's decision making report states clearly that the cost of delivering the services by the provider (Tees Esk and Wear Valleys NHS FT) is, in fact, in excess of the £1.5m budget. In 2017-18 a short term agreement was reached in respect of £220,000 cost pressure identified by the provider, meaning the actual cost of delivery of the service was £1,721,335.

4.5.9 Their 'do nothing' option indicated that coupled with a budget allocation of £100,000 for increased demand, the budget going forward would need to be £1,821,335 to deliver the same service. In both options 1 & 2, there is £150,000 contingency built into the £1.5m budget meaning that the actual difference between the projected cost of delivering the service under the Do Nothing option and the calculated cost under option 2 is £470,000. **The reality is that the CCG's are trying to support an increased number of people with complex needs using £470,000 less than the known current costs.** It is disingenuous for the CCG to claim that either option that was proposed as part of their consultation process did not have any financial drive behind it.

¹⁸ NHS England, Five Year Forward View, October 2014 <https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>

	Do Nothing	Option 1	Option 2
	£	£	£
Cost of current service	£1,501,335		
Cost pressure with current provider	£220,000		
Increase demand and patient needs assessments	£100,000		
Funding Available to new services		£1,501,335	£1,501,335
Utilised on :-			
- Bed Based Services (Residential beds)		£644,917	£765,947
- Bed Based Services (Shared Lives/adapted residential accomodation)		£99,000	£99,000
- Support in own home		£72,800	£36,400
- 1:1 or shared support to access community settings		£72,800	£36,400
- Holiday alternative accommodation		£196,000	£196,000
- Flexible community based leisure		£50,000	£50,000
- Flexible community based day services		£215,684	£167,454
Total cost of services	£1,821,335	£1,351,201	£1,351,201
(Cost pressure) / Contingency Reserve	-£320,000	£150,134	£150,134

4.5.10 The table above is taken from the CCG's report on proposed changes to respite opportunities and short breaks for adults (18+) with complex needs and learning disabilities and/or autism¹⁹ as presented to the Joint Governing Body in Common meeting on 1 February 2018.

The financial modelling detailed in that same document is also of concern to scrutiny members.

New package examples	
Current Package - 39 nights in NHS respite care	£18,330
Potential Alternative Package (for illustration purposes)	
14 nights in adapted accomodation (incl skilled support staff)	£6,222
7 nights support at home	£1,379
14 nights in bed based respite care	£6,202
14 days access to sessional activities (including skilled support)	£3,876
Total for 49 days respite including 35 overnights	£17,679
Current Package - 39 nights in NHS respite care	
£18,330	
Potential Alternative Package (for illustration purposes)	
18 nights in hotel accommodation (incl 1:1 support)	£10,332
6 nights support at home	£1,182
15 nights in bed based respite care	£6,645
Total for 39 days respite including 39 overnights	£18,159

4.5.11 The table gives an illustration suggesting that a current package of 39 nights = £18,330. This equates to £470 per night for bed based respite. In the potential alternative package example the bed based respite is costed at £443 per night. Although families have welcomed the continued use of TEWV as the service provider, as they have a high level of confidence in the service they provide it remains unclear to scrutiny how TEWV would be in a position to offer a lower unit price per night for bed based respite, whilst still retaining both facilities at

¹⁹ NHS ST CCG and NHS HaST CCG Report on proposed changes to respite opportunities and short breaks for adults (18+) with complex needs and learning disabilities and/or autism, January 2018 <http://www.hartlepoolandstocktonccg.nhs.uk/events/governing-body-in-common-meeting/>

Bankfields and Aysgarth. Particularly given that they were unable to deliver the existing contract arrangements within the allocated budget. In the minutes of the meeting in common, the CCG's Finance Director confirmed that the funding for respite is non recurrent which raises further concerns for scrutiny regarding the future sustainability of the service. The long term sustainability of respite provision at Bankfields and Aysgarth is entirely dependent on TEWW receiving the necessary funding.

4.5.13 It is scrutiny's strong view that the proposed service is undeliverable within the CCG's financial envelope of £1.5m and represents poor value for money in terms of meeting service users' needs. Choice is being funded where there is no clear demand for alternatives at the expense of a highly valued service delivering added value and mitigating the risk of carer breakdown, which would present a significant further cost pressure on the wider health and social care system.

Reason 6: Continued lack of clarity in respect of eligibility criteria and needs led assessment / allocation process yet to be finalised or approved

4.6.1 Whilst the assurances given by the CCGs now afford the opportunity for all of an 'individual's allocated resources to 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 CCG's are unable to provide any assurances relating to the minimum number of nights that will be available to families, as the assessment tool to determine the level of resource to be allocated had not yet been established. The inability of the CCGs to clarify the impact of their reconfiguration proposals, particularly on the individual families currently in receipt of the service is a serious flaw and undermines the value of other assurances given about access to the service.

4.6.2 Furthermore this has been a limiting factor in the quality of the consultation since consultees have been asked to make choices about options without any clear indication of the extent of the impact on them.

4.6.3 It is evident that for many of the families currently in receipt of respite at Bankfields and Aysgarth the consultation process initially gave the impression that additional respite opportunities would be provided. Whereas in fact the reality is that the changes proposed are at the expense of the current provision and those already in receipt of the service. Parents and carers have emphatically stated throughout that retention of the current service provision at Bankfields and Aysgarth is their preferred option. The Parent/Carer representatives have put together a short video (<https://vimeo.com/269297983>) featuring interviews with the families affected by the proposals.

Reason 7: Lack of understanding around Bankfields and Aysgarth client base

4.7.1 The CCG have argued they are required to commission services that provide equity and choice. From early on in the consultation process, there were strong concerns expressed from parents and carers that choices were being forced on them that they would be unable to access alternative provision due to the severe and profound nature of their adult children's learning disabilities and the complexity of their health needs, for example, care home environments may not be age appropriate. They felt very strongly that those choices would not provide respite in settings where parents and carers could be confident that the support staff were sufficiently trained to respond to the complex health needs of their adult children. There are also concerns about the quality of alternative provision and how this would be monitored.

4.7.2 The independent report on the consultation, commissioned by the CCG's, highlights the dissatisfaction with the consultation process and options. 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.

4.7.3 In response to the question how did respondents feel about the way in which they have been consulted with and the level of information provided. The independent report highlighted that 69% were dissatisfied.²⁰

4.7.4 Parents/Carers feel that the public consultation documentation was extremely misleading. The images used gave the impression that the individuals affected would regularly be able to participate in short break opportunities. The reality is that the level of complexity of need and the requirement for clinical oversight for many of those affected would make this extremely difficult. Many are non-verbal, are unable to take part in consultations or conversations, have specially adapted wheelchairs to support their bodies, wheelchairs designed and used to prevent their internal organs from being damaged, sleep systems for night time posture and require PEG/tube feeding.

4.7.5 An appendices document is attached, containing photographs of the current users of Bankfields and Aysgarth to illustrate the degree of difference in the health complexities faced by those using the services and the images used in the CCG's public consultation documents. The photographs also serve to demonstrate that the families in receipt of respite care at Bankfields and Aysgarth already go to great lengths to take their loved ones on holiday, despite their many health challenges, and the support they need from health is for 'respite' care in a safe, accessible environment with learning disability nurses present. Bankfield and Aysgarth should be viewed as flagship facilities to be replicated in all parts of the country.

5. Steps taken to reach agreement with South Tees CCG and Hartlepool and Stockton CCG on the proposals.

5.1 Middlesbrough and Redcar and Cleveland have looked in great detail at all aspects of the proposals and have done so over a series of formal meetings and informal evidence gathering sessions.

5.2 During the course of our meetings we have taken evidence from a wide variety of stakeholders including:

Local MPs

Bankfields and Aysgarth parent/carer representatives

Head of Policy and Public Affairs, Royal Mencap Society

Chief Officer, South Tees CCG

Chief Officer, Hartlepool and Stockton CCG

Assistant Director Mental Health Learning Disabilities and Transformation, STCCG

Senior Commissioning Support Officer – Learning Disabilities, NECS

Chief Executive, Tees, Esk and Wear Valley (TEWV) NHS Foundation Trust

Acting Chief Operating Officer, TEWV

Head of Learning Disability Services, TEWV

Director of Adult Social Care and Health Integration, Middlesbrough Council

Interim Corporate Director for Adult and Communities, Redcar & Cleveland Borough Council

²⁰ Independent report of the public consultation 4 September 2017 to 10 November 2017. Prepared by Consultant Researcher and Data Analyst, Jenny Harvey, December 2017, <http://www.southteesccg.nhs.uk/wp-content/uploads/2017/08/9915-NHS-Tees-Respite-Report-full.pdf>

Head of Specialist and Lifelong Services, Middlesbrough Council
Team Manager for Adult Social Care and Health Integration, Middlesbrough Council
Carer & Engagement Officer, Middlesbrough Council

5.3 A formal meeting of the South Tees Joint Health Scrutiny Committee was held on 25 April 2018 at which the CCG outlined the assurances that they were able to provide as their final negotiating position.

5.4 Whilst these assurances went some way to addressing Members' and service users' concerns, they did not fully resolve the situation to Members' satisfaction. That being the case, the joint committee recommended each Council to confirm its intention to refer the decision to the Secretary of State. Details of the assurances given by the CCG were contained in the presentation provided to the Joint Committee.²¹

5.5 Middlesbrough Council's Health Scrutiny Panel met on 18 May 2018 to determine the Council's position in relation to making a referral to the Secretary of State. The panel was unanimous in its decision to make a referral on this issue.

6. Conclusions

6.1 There appears to be no clear rationale for embarking on this course of action and the Government's Transforming Care agenda is being misinterpreted. The overriding aim of the Transforming Care agenda is to ensure people are supported to remain in the community and reduce unnecessary admissions to inpatient facilities. This review, however, is focused solely on a specific group of individuals who are already cared for by family at home.

6.2 Without the long term care provided by parents and carers affected by these proposals, the number of NHS England and CCG commissioned placements in inpatient beds in the North East would be greater. In addition, as inpatient beds are reduced in line with the Transforming Care agenda, the needs for respite / short break provision for people with the most profound and complex needs will increase. It is our view that the current level of bed based respite provision for people with learning disability, complex needs and autism across Teesside needs to be retained, as a minimum, if not expanded.

6.3 It is scrutiny's strong view that it was not the intention of the Government's Transforming Care agenda to reduce bed based respite provision, as respite is out with that agenda. Nor is the proposal a sustainable business model for either the current and/or future providers. In addition, insufficient evidence has been provided to scrutiny, despite repeated requests to ensure that the CCGs proposal will provide safe and accessible health respite services for our local population. It is our firm view that the proposed solution fails to achieve its purpose.

6.4 The parent/carers, Middlesbrough and Redcar and Cleveland MPs / local Councillors and both local authorities are of the view that the proposed solution will not meet the needs of current service users, plus projected demand, within the CCG's allocated £1.5m budget constraint for future delivery of the service. Those with lived experience of caring for a loved one with profound and severe learning disabilities across Teesside have repeatedly reiterated this as a concern throughout the consultation.

6.5 Scrutiny's view from the outset is that these proposals had been ill thought out and no consideration had been given to the impact on either the individuals concerned or the wider

²¹ CCGs presentation to South Tees Joint Health Scrutiny Committee, 25 April 2018 <http://it-mc-egenda.mbrodom.net:81/aksmiddlesbrough/users/SYSTEM/admin/kab14.pl?operation=SUBMIT&meet=1018&cmte=STH&grpid=SYSTEM&arc=14>

health service. Those in receipt of respite care at Bankfields and Aysgarth have no ability to communicate verbally, express any view on or comprehend these proposals. Parents / Carers have repeatedly stated that a decrease in respite provision, below a minimum of 30 nights for those with severe and profound needs, would result in increased admissions to residential care in a system that is already unable to cope. The proposals are not fit for purpose and reductions in respite provision at Bankfields and Aysgarth will result in increased pressures and costs to other parts of the health service. Middlesbrough Council cannot support this decision and is firmly of the view that the CCGs decision needs to be considered by the Independent Reconfiguration Panel.