

To Whom it May Concern

12 July 2018

We write in Support of Middlesbrough Council's referral to the Secretary of State for Health and Social Care concerning 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. The CCG decision followed their consultation entitled, *Transforming Care: Respite Opportunities and Short Breaks for People with Complex Needs and Learning Disabilities and/or Autism*.

It is clear to us that the changes proposed by the CCGs are not in the best interest of the National Health Service in the area which we serve and are not in the best interest of the carers who rely on the respite services central to the referral. It serves not for this letter to replicate all of the grounds within the referral, but we believe that the proposed changes are likely to have a major impact on carers and the sustainability of their role. In plain terms, we believe the proposed service changes will lead to an increased risk of family breakdown for families who have relied on these excellent services for many years, a poorer standard of care and an increase in safeguarding referrals. Also important, though secondary to the negative impact on already vulnerable individuals and their families, is our assessment that the proposed changes will lead to increased costs for the health and social care economy and a reduction in value for money. It is beyond us to understand how this can be in anyone's best interest.

Local Authorities are as familiar with service re-configuration as any organisation and appreciate that change may sometimes be necessary, but we believe that on this occasion there are shortcomings in the process and consultation that bring the result into question; 69% of respondents reported that they were "very dissatisfied" or "quite dissatisfied" with the way in which they had been consulted. The parents and carers feel that the CCGs misrepresented the proposed changes as the impression was given that the individuals affected would in future be able to participate regularly in residential short break respite, that more respite would be able rather than less. In practice however it appears that the high level of complexity of care displayed by most of the vulnerable adults means that a lack of respite opportunities with sufficient clinical oversight would mean an effective reduction in respite opportunities. The CCGs continue to maintain that the proposed changes would increase choice but there is little evidence that the market is able to meet the demand that the CCG envisages in terms of choice and opportunities for short breaks.

It is all too easy to underestimate the complexity of the individuals at the heart of this matter and to underestimate the skill and incredible determination of the carers in supporting their family members at home for so much of the year for so many years. As parents it is what we would always wish to do but the resilience required of this group of parents far exceeds the norm. The average respite allocation for the users of Aysgarth and Bankfields is 33 nights per year; the families provide this care for the other 332. The care plans at the units talk of individuals with a need for sedation, anti-anxiety medication, "rescue medication" and provisions found only in clinical settings. The families trust the existing provision and, if a practical absence of alternatives means the opportunity for residential respite is reduced, then the sustainability of care in some of these families is likely to come into question very quickly. If family situations begin to break down and residential placements become necessary then all hope or expectation of financial efficiencies will evaporate.

Bankfields and Aysgarth are trusted services that for many years have met the needs of a particularly complex group of vulnerable adults and their carers but tragically we believe that the promotion of "choice" in the manner proposed by the CCGs will lead to an effective reduction in the opportunity for respite for these very individuals. We believe that the proposed re-configuration is based on flawed process and flawed consultation and will not achieve its financial objectives.

We believe that the proposed reconfiguration will make the individuals that they are claimed to support significantly more vulnerable and for this reason we urge your consideration of the referral.

Yours faithfully



David Budd
Elected Mayor of Middlesbrough



Tony Parkinson
Chief Executive