

Appendix 5a

Letter to Alex Cunningham MP, Member for Stockton North, and Cllr Bob Cook, Leader of Stockton Council

These letters were also endorsed by 29 parents of adults with severe complex needs and/or autism who currently attend Aysgarth bed based overnight respite provision.

Mr Alex Cunningham MP

Business Centre
70 Brunswick Street
Stockton on Tees
TS18 1DW

Dear Alex,

I am writing to make you aware of my concerns regarding a Public Consultation that is underway currently regarding respite opportunities and short breaks for people with complex needs and learning disabilities and/or Autism. Commissioned by Hartlepool and Stockton Clinical Commissioning Group along with South Tees Clinical Commissioning Group, there have been 4 public consultation meetings between 18th -30th September in Stockton, Middlesbrough, Redcar, and Hartlepool. The meetings were held to give parents, carers, and individuals the opportunity to voice their opinions, raise their concerns regarding current, versus alternative respite provision. Current respite provision is Aysgarth Respite Centre, Durham Road, Stockton and Banksfield Court Respite Centre, Middlesbrough. Between the two provisions approx. 100 individuals use these centres. We were told that the cost per bed per night was £500, a figure that was not substantiated by any data or costings.

Initially we were told that our opinions were to be used to formulate outcomes. An explanation of funding and short fall was given which raised many questions but very few answers given. My understanding was that there were twice as many individuals needing respite provision than were currently being provided for (200 and increasing versus currently 100)

We were directed to 2 options that we were asked to vote on, 1 being closure of both provisions with the respite being provided for individuals to access activities out in the community or "a range of bed based respite services at private respite centres", however no actual examples, or names of respite providers could be offered at this point in time! Yet the commissioning group were in effect asking us to vote "Blind" for an option that had no detail behind it yet had massive impact on our young adult's lives and social, emotional and mental wellbeing!! 2nd option was to continue to buy bed based respite provision at Aysgarth and Bankfields Court, however there would be less opportunity to buy flexible community based respite services because of the costs per bed of £500 per individual per night at Aysgarth and Bankfields. This figure was queried by many people and no substantive costings could be given in deed Dan was very glib in his blasé attitude that someone somewhere had done the maths but not him as he had only been in post since April!!! There were private respite providers there plus professionals from the education sector who all found this £500 figure very hard to justify as all were saying that £200-£300 bed per night was the figures they could deliver the service at or was delivered at within the education sector.

Many people were very unhappy at the options that were being proposed (which included local councillors, education professionals, parents and carers and Staff from the two provisions). Indeed I

had to question whether any of these people that were making these life changing decisions for our young adults had ever even been to the respite centres or knew of the extreme calibre of disability and medical challenges these centres provided respite for? They seemed to be idealising options to solve a problem, not looking at what was needed for adults with profound combined mental, learning, and medical disabilities.

By the end of the meeting an exasperated Dan stated that “the bottom line was the budget was not going to increase of 1.5 million pounds, and they had twice as many individuals to provide respite for, so you do the maths!!”

My concerns are:

-This public consultation is just a paper exercise, and decisions have already been made by stealth. It appears to me that the most vulnerable of society have been targeted because of their inability to make themselves heard, understood, and dispute any outcome.

-Not enough information was available for any person to make a fair and informed judgement whether the alternative option could provide appropriate medical/respite provision for the type of adults to access.

-Many of the young adults that attend Aysgarth and Banksfield are at the extreme end of ability, suffer extreme anxieties and challenging behaviours and simply do not, or cannot cope with accessing the community. To make them do so would be severely detrimental to their whole wellbeing.

-There is very much an identified need for bed based respite with medical provision

-Although many of these individuals have been given an option to voice their opinions with simplified brochures, they are still not able to read, understand any of the literature and certainly not the implications on their lives. These people are some of society's most vulnerable, if they are shipped out here, there and everywhere, how and who is going to manage the safeguarding of them in so many different places and environments?

- Many of these adults have strict dietary limitations, (Diabetic, Gluten, Dairy, Soya free diets). Currently Aysgarth and Bankfields cater for the varied diets per individual. How could this be managed out in the community? And I speak from experience.

- Logistically to offer individualised community based respite provisions, that include up to 4-1 staffing out in the community which some of these young adults require, entrance costs to activities, transport costs, medical support, staffing to cover sickness at short notice, dietary restrictions etc. etc. is nightmarish to organise, and cannot be cost effective in making savings. It has chaos and disaster written all over it.

- Actually many of these adults already attend day time provisions. After a day out of their home they do not want to have to go out again, but are happy to go to the bed based respite provisions, where they know the environment, they know what to expect, and what is expected of them. They are comfortable and are made comfortable, welcomed and treated like an extended family member. They can relax and feel safe. All their complex needs are known, understood and met by familiar staff under the security of one roof, and safeguarding is tight. Surely what the commissioning group are looking to offer duplicates what the adults are already receiving?? And that most certainly is not a cost effective way of using the budget, plus how do they propose for the adults to be in two places at once??

- Why are we not looking to the saying” if it's not broken don't fix it??” Actually should we not be looking to expand on what we have? Why not look to economies of scale to save costs, and also bring some of the community based respite into the base of Aysgarth and Bankfields.

The bottom line here is that Aysgarth and Bankfields meet the needs well of the profoundly disabled adults that they cater for. The problem is not with the respite provision, it is with the NHS looking to make savings and choosing the most vulnerable of society's people. People who they think will put up least resistance when they pull their life rug from under them. Offering a decision to parents, carers and disabled adults that carries no weight.

- THIS IS A SERVICE THAT IS NEEDED and if the numbers are increasing then the NHS have to look at cost cutting elsewhere to meet the increase in demand. It's not as if they have not been aware for a number of years of the growing demand of children coming through the system that were going to become adults, so why has there been no forward planning to accommodate this demand rather than trying to take away a respite provision that has been assessed and identified as a need for each individual that uses it currently?

- Finally the impact that all of the change proposed above will have on the parents and carers of the adults affected by this consultation. We have 30 days a year that we can rely on respite for us. 30 nights out of 364 that we know we can make an arrangement and stick to it. That we can relax knowing our children are safe, secure and happy. This is a vital life line that allows us to have a snippet of normality in our lives. It allows us to do things that most other nights it's impossible, like visit family that live away, or socialise with friends, or watch what we want on the T.V., or have a bath without having to bathe someone else first to name just a few. The impact of the above mentioned and preferred changes by the NHS Trust (to close down Aysgarth and Bankfields) will inflict more and more stress on the parents and carers and on our ability to cope and support our adults. This could indirectly have financial impact on the NHS too. Who will look after our adults if we are not able to?

Letter to Cllr Bob Cook, Leader of Stockton Council

I am contacting you all regarding the above mentioned Public Consultation that is currently underway and closes on 10th November 2017. I have grave concerns regarding how this consultation is being steered, and the massive negative impact this is likely to have on both my son and my own social, emotional and mental wellbeing.

I am a mother and full time carer of a young adult (19yrs old) who currently accesses bed based respite provision at Aysgarth, Durham Road Stockton, which is one of the two respite provisions that are currently under review with this consultation. The other being Bankfields Court in Middlesbrough.

I have emailed a detailed letter to Alex Cunningham MP, a copy of which is attached to this email which further expands many of my concerns, however I am looking to make contact with all councillors that may be able to support their constituents concerns and possibly offer insight, support, observe this process which I feel is going to have such a detrimental impact on some of the most profoundly disabled and vulnerable adults within the locality.

All of the adults that attend Aysgarth have a combination of complex health, learning, mental health, physical, social, sensory disabilities and often specific dietary requirements. many are unable to understand this consultation or express their views or anxieties in anything other than the most basic behaviours.

In brief the consultation is looking to provide respite for twice as many clients (200 instead of 100) with only the same budget of 1.5 million pounds. Their objective is to offer alternative respite provision (short breaks, community based respite) and reduce the number of beds available for the bed based respite.

Due to the complexity of disabilities, combined with medical needs this alternative is on the whole unsuitable for most of the adults that access Aysgarth currently, an opinion that has been strongly advocated by parents/carers/staff/social services, and educational professionals at the meetings held already. However it seems from my point of view that it is falling on deaf ears, and the NHS are not aware of the client group that they are making life changing decisions about. So much so that at a meeting on the 25th October it was stated that people were not understanding what was being proposed and that closure of one or the other of the provisions (Aysgarth or Bankfields) was pretty much definite. How can this be stated at this point in time when the consultation is still underway?? where do our opinions come into consideration within the decision making process? and how is this taking into account the best interests of these most vulnerable of societies adults?

Many of these adults can not cope with change on a daily/weekly basis, and many need specialist feeding, medication apparatus, and intense self help and personal hygiene support which cannot be provided out in the community. How can safeguarding be secure with these very vulnerable adults out in the community? and what happens if there is a medical emergency out in the community? Aysgarth and Bankfields provide a safe secure service that is in demand in excess of its capacity according to NHS so why are they looking to reduce it? I fear that cut backs are being levelled at these individuals because they don't have a voice themselves to stand up and be heard, and I am extremely worried about this essential provision of overnight respite for carers and how this will impact on both family and disabled adults standard of living and mental well being if it is removed or reduced. What about the knock on affects on social care if carers/parents cannot cope with the added burden placed on them by reducing medical bed based respite provision.

As you can see this is already creating much anxiety to myself and other parents, and I am looking to make councillors aware of this crisis that is pending and request that some input from yourselves be forthcoming as a matter of urgency.

Yours Sincerely Sharon Davison