

## Queries Raised by Aysgarth Parents Focus Group and CCG responses

Original queries (in bold) and CCG response are below.

---

7 November 2017

Thank you for participating in the on-going consultation about respite opportunities for people with complex needs, learning disabilities and/or autism.

Both Hartlepool and Stockton CCG and South Tees CCG recognise the important benefits to both people using services and their families and carers and the tremendous community benefit carers provide when looking after people with complex needs. Respite provision for people with learning disabilities and complex needs should provide both a high quality experience for the person whilst giving a well-deserved break to carers and families. As such, the CCG's are committed to retaining the full £1.5m financial envelope for this provision and are consulting on how best to provide this.

However, it is also recognised that there are people and families across the area who cannot access current services, or for whom current services are not appropriate, plus young people reaching adulthood in the coming years for whom respite services would unlikely be available, which is driving the need for a review of how services are provided.

At present, £1.5m is allocated to providing respite services for around 100 people. Through work engaging service providers, the CCG's believe that they can continue to provide respite provision based upon the needs of people and families whichever option is taken forward, including bed-based provision, rather than on the limited basis it is currently provided to a limited number of families. Using a solely medical model is considerably more expensive per person per day/night than community options which may actually be more appropriate for some people and it is anticipated that more people will be able to access respite services in either model.

It is recognised that there are concerns from some people and we are continuing to work to address those concerns and queries through consultation events and by publication of "Frequently Asked Questions" provided both to people who request answers and published on the CCG websites with regular updates as questions are raised. This feedback and the answers provided will be included in that. Providing reassurance to people who are concerned by the on-going review and future options is a key aim and staff are working daily to speak to people and outline the reality of what future options can provide.

Allocation of respite provision will, in future, be based upon assessed need. Once the decision is made on which option is being taken forward, the assessment and allocation process will determine spend from the £1.5m allocation based upon what is needed and how respite can be provided on a more personalised basis, including both day time activities and overnight breaks. Using alternative provision may mean that people will receive more respite opportunities and stays as the money available can go further.

It is recognised that unmet respite needs can place pressure on local authorities which is why local authority representatives from each area and social care staff are involved in the project and contributing to development. It is anticipated that this programme of work will actually ease current and future pressure on local authorities caused by unmet needs.

NHS England have been involved in the programme of work and are supporting progress. It is believed that current funding levels, spent in a different way, will meet the needs of people and families. The

programme is being overseen by a Local Authority led Overview and Scrutiny Committee and the consultation exercise has been co-designed with partners from North of England Commissioning Support, Inclusion North and other VCS groups. As such, people and carers can be assured that the process is transparent, fair and open.

People working on the programme from health and social care have nothing but the interests of the people at heart and it would be reassuring for them to receive messages of support and encouragement to help provide the best opportunities for respite care that we can for the people of Teesside.

## **AYSGARTH PARENTS FOCUS GROUP – POINTS/QUERIES RAISED FROM THE PUBLIC CONSULTATION BROCHURE**

**1. PAGE 4- PAR 2 – LESS RELIANT ON SERVICES THAT ARE PROVIDED WITHIN HOSPITAL, MAKING SURE THERE ARE GOOD SERVICES AVAILABLE IN THE COMMUNITY – Aysgarth is not hospital based, and has an excellent mark/award with many of its professional techniques/methods adopted by other provisions.**

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.

**2. PAGE 4- PAR 3 – MORE EFFECTIVE WAY TO ENSURE THAT THE NEEDS OF INDIVIDUALS ARE MET SAFELY AND IN A WAY THAT MEETS THE WIDE RANGING AND PERSONALISED OUTCOMES FOR INDIVIDUALS AND THEIR FAMILIES AND CARERS. SOME SERVICES NEED TO BE TAILORED TO THE NEEDS AND CHALLENGES OF INDIVIDUALS – Aysgarth meets the wide ranging needs of the individuals that attend and gives a satisfactory outcome to parents and carers of a safe secure provision that gives them valuable overnight respite that is not provided anywhere else.**

It is recognised that a high proportion of the people who access the services and their families are satisfied with the service, notwithstanding the recommendations and ideas for future development for services. It is also recognised that there are individuals in the community who have needs which are not met who need access to services for people with complex needs who cannot access the existing services. There have also been examples from people who have attended our consultation sessions where the bed based services have not been appropriate to meet the needs of their family members.

**3. PAGE 4 PAR 5 – ISSUES THAT LED TO THE REVIEW:**

**DEMAND IS GROWING – More money needs to be input, expand the excellent graded provision at Aysgarth that is currently working well! Rarely can the same amount of money be used to accommodate twice as many people.**

The CCG has the responsibility to review services on an ongoing basis and to develop services that are cost effective, sustainable and meet the needs of the current and future populations. The CCG has been working with providers to help develop the market and ensure that provision of respite can meet needs within the current financial envelope.

**4. THE NEEDS OF PEOPLE ARE BECOMING MORE COMPLEX – So why target a provision that provides essential overnight respite for the most complex of adults by reducing bed spaces.**

It is recognised that there are individuals in the community who have needs which are not met who need access to services for people with complex needs who cannot access the existing services. There have also been examples from people who have attended our consultation sessions where the bed based services have not been appropriate to meet the needs of their family members.

## **5. THERE ARE POTENTIAL GAPS IN SERVICES – Can you give examples?**

It is recognised that there are individuals in the community who have needs which are not met who need access to services for people with complex needs who cannot access the existing services. There have also been examples from people who have attended our consultation sessions where the bed based services have not been appropriate to meet the needs of their family members. The intention of this is to support us to bridge the gap between health and social care services to support the delivery of a wide range of services to meet the wide range of service needs. Currently the offer that is available is a singular offer of a bed based setting which is not appropriate for everyone with complex health needs. There is over reliance on a single provider with a finite offer of 11 beds. The initial engagement exercise identified the need for more choice for people with complex needs.

## **6. THERE IS POTENTIAL DUPLICATION OF SERVICES- Can you give examples of this currently?**

It is known that there are individuals who access overnight respite within the NHS settings and who access day services simultaneously, which is costly and not an efficient use of resources. In terms of breakdown this equates to the following:

7 nights overnight respite at NHS setting - £3990

5 days day services access - £400

Transport to and from day services - £500

Using the £1.5m available more wisely is intended to increase opportunities for people to receive the respite breaks and activities they need.

## **7. NATIONAL AND LOCAL POLICIES INFLUENCE HOW SERVICES CAN BE DELIVERED – Can you name the policies and how they influence delivery of service?**

This information is available in more detail in the Case for Change

<http://www.hartlepoolandstocktonccg.nhs.uk/wp-content/uploads/2017/10/Case-for-Change.pdf>

The main driver is Transforming Care, information is available at:

<https://www.england.nhs.uk/learning-disabilities/care/>

## **8. AVAILABILITY OF CHOICE NEEDS TO IMPROVE – Can-not do this on the same budget, nor is it fair to remove one option of choice to provide others.**

Initial market engagement activities in Jan/Feb 17 and more recently in November 2017 identified indicative costs of providing support to individuals in a personalised way and the initial indications are that money spent within community settings and services goes further than in hospital/clinical settings.

There is a need to explore alternative ways to meet people's respite needs with the identified budget allocation available. The CCGs have a responsibility to ensure that money is spent in the most effective way and to ensure value for money for the local communities.

## **9. ACCESS TO AND ALLOCATION OF SERVICES NEEDS TO BE EFFECTIVE – Services are, and have always been allocated on assessed needs of individuals, and in their best interest how can this be changed?**

The current system of allocation does not allocate provision on a needs-led basis, there is an initial eligibility threshold however everyone irrespective of their needs or the needs of their carers are allocated the same amount of overnight stays. CCGs have worked alongside the Trust to develop an assessment tool that considers the eligible health needs of the individual and also the needs of their family carer(s) to enable resources to be allocated directly in response to the needs of individuals.

**10. NEEDS TO BE FAIR AND EQUITABLE – it is not fair to remove essential bed based respite to provide alternatives that do not meet the needs of these very vulnerable individuals – why are their needs not considered fair?**

Bed-based respite will still be available in both options. There has been detailed analysis undertaken in relation to the needs of the people who currently access the service, those Children and Young People who are aged 14+ and who currently access short break opportunities. This analysis has looked at how many people have different types of needs, and specific diagnosis or needs that often occur together and other relevant aspects in relation to the needs and risks for individuals.

The assessment and allocations process is still being developed, there are plans in place to embed the process across services to ensure fairness and equity. The tool has been developed by the CCG, Tees Esk and Wear Valleys NHS Foundation Trust and also the Local Authorities. There is a group of individuals from all organisations involved who are further developing and refining the tool. In addition there are plans to scrutinise and review the allocations process with the involvement of advocacy groups and also parent carer representatives.

There are two main elements to the assessment and allocations process which considers the health respite needs of the individual and the circumstances and respite needs of the carer.

The assessment tool will result in a banding and subsequent resource allocation which will be responsive to the identified needs for each individual and their family allowing for people to choose respite opportunities and options that suit their need.

The “eligible health needs” element considers the person’s needs in relation to day to day living for example personal hygiene and dressing, nutritional needs and support, keeping themselves and others safe, supporting behaviours and other specific personal needs.

The “carer circumstances and needs” element considers what services are currently being received, the informal network of support that exists within the family and also the impact of the caring role on the person’s wellbeing and ability to work or enjoy family life. The principles of this part are centred around the provisions of the Care Act 2015.

**11. PAGE 5 PAR 1,2,3 – Aysgarth does provide emergency care and support, as most parents will testify, however it only has limited capacity which is already over-subscribed with many clients not receiving their care plan quota. Again this suggests that expansion of the provision not reducing the number of beds is the answer. How are you going to provide emergency cover in the community, sending clients to strange unfamiliar and inappropriate provisions?**

Part of the work that has been done as part of the project has looked in detail at the emergency admissions into NHS bed based settings. The predominant reason for emergency admission is carer breakdown, carer illness or illness of the person that is cared for.

With a wider range of options and available services, emergency situations would be more readily accommodated and would reduce impact on other families planned bookings. At the moment there is reliance on a finite resource of 11 beds where emergency provision is made available when possible however this often impacts upon planned stays for the individuals who already have booked respite. The feedback from the initial engagement highlighted that this was important for the future and was a way that respite could be improved for the future.

**12. PAGE 5 PAR 4 – DUPLICATION OF BED BASED RESPITE AND DAY SERVICES? How can a person be in two places at once? Bed based is overnight and day services through the day how can these be duplicated when at different times, and if clients already have day care how can they use the alternative respite provisions you are proposing in the community many of which occur during the day? Who determines the individual’s personal outcomes and what will help achieve them?**

The CCG pays for bed-based accommodation for people and separate day services that some of the same people will also use. This can occur together. It relates to payments being made for people to be in two places at once not to someone physically being in two places at once.

Personal outcomes and what will help individuals to achieve them will be developed by care managers or other relevant professionals alongside the individuals and their families. The CCGs are working with Local Authority colleagues in relation to this.

**13. PAGE 5 PAR 6 – HAVING SOME BED BASED RESPITE SERVICES IS IMPORTANT – Having Bed based respite is not just important, it is ESSENTIAL to the social emotional and mental wellbeing of both the vulnerable adults but especially the parents/carers. It gives them down time to recoup and get their strength back. Reducing this provision WILL, (not potentially) impact on their ability to cope and manage to care for their adults, potentially creating an even bigger burden, more expense on the system.**

The prevention agenda is recognised by CCGs and an understanding that it is important to get service access and availability right to support people and their families and to support people to remain in their own homes and family environments for as long as possible.

Both options that are taken forward include the provision of a bed based offer in recognition of this need.

**14. PAGE 5 PAR 11 – MORE CHOICE, BETTER FACILITIES, PERSON AT THE CENTRE OF THEIR OWN SUPPORT – Bring the choices in Situ to Aysgarth so that a number of clients can access them at once rather than each client going out separately into the community, which many struggle with anyway. Consider their limitations and be flexible with how you can meet these individual's needs to provide variety with cost effectiveness of economy of scale.**

A high proportion of individuals who access the NHS bed based settings also access day service provision over five days each week. In addition to this staff at the NHS bed based setting provide opportunities for individuals who remain at the setting to do a variety of different activities. Part of the review and the development work should support each individual who has respite needs to be able to pursue activities of their interest within or outside of buildings based settings. This is included within the range of flexible community based respite opportunities part of the consultation.

**15. PAGE 6 – Lots of non-committal words within your examples of variety of respite provision “could look like in the future” “potentially from trained and/or qualified staff.” It has already been brought to your attention that staff needs more training as detailed paragraph 12, page5, and with the shortages that currently exist within the health sector how do you propose to guarantee the availability of medical staff?**

There has been detailed analysis undertaken in relation to the needs of the people who currently access the service, those Children and Young People who are aged 14+ and who currently access short break opportunities. This analysis has looked at how many people have different types of needs, and specific diagnosis or needs that often occur together and other relevant aspects in relation to the needs and risks for individuals.

Work is on-going with Local Authority partners in relation to the support that will be required for individuals to manage any changes in a safe and supported way and will complete formal risk assessments as part of future care and support planning processes.

Any provider of services that is commissioned by the CCGs will be required to sign up to the NHS Standard Contract, as such there are checks and balances in place to ensure that service providers deliver good quality and safe services. The CCG would not commission a service that wasn't safe. Anyone who bids for the service through the procurement would have to evidence this.

In relation to purchase of services from non NHS providers, as with any service commissioned by the CCGs, there will be a contractual relationship in place which will ensure that Providers continue to provide services under the terms of the agreements.

It is vital for the CCG to commission services that safely and effectively meet the needs of individuals. Vagueness of alternative respite provisions suggested “residential/nursing/care home setting” where would this be?

This consultation is being undertaken at a formative stage and as such no formal procurement has taken place as the findings of the consultation will influence service design and future delivery of services. Market engagement has been undertaken in January and February 2017 and more recently in November 2017 and part of this has been able to identify up to 19 providers who are interested in working with the CCGs to deliver respite services in the future

In the event that Option 1 is selected and taken forward, the CCG will commission services within CQC registered settings to provide bed based provision as part of the respite opportunities as well as a wider offer of alternative accommodation such as short break and other holiday options.

If Option 2 is selected and taken forward, the bed based aspect of the respite opportunities service will be delivered by the current provider from the current service settings, in addition to a wider offer of alternative accommodation such as short break and other holiday options.

**16. “Flexible community based leisure & activity options” – has anyone truly looked at the logistics, cost, organisation involved in providing individual person-centered respite provision like this for 200no vulnerable complex needs individuals – how can this possibly be any cheaper?**

Market engagement has been undertaken in January and February 2017 and more recently in November 2017 and part of this has been able to identify up to 19 providers who are interested in working with the CCGs to deliver respite services in the future.

Initial market engagement activities in Jan/Feb 17 and more recently in November 2017 identify indicative costs of providing support to individuals in a personalised way and the initial indications are that money spent within community settings and services goes further than in hospital/clinical settings.

There has been oversight of the patterns of usage for the individuals who currently access the service and there has been financial modelling undertaken based on the indicative costing information obtained through the initial market engagement exercise.

Part of the work ongoing is to ensure that logistics, including transport and travel arrangements to personalise respite services, are appropriately provided.

**17. “Flexible respite provision,” “Flexibility” can sometimes be good, but more often bad to complex needs adults, leaving them feeling anxious, agitated not able to enjoy their respite because they are not aware of what is expected of them, unfamiliar environments and people who do not understand them and their very complex needs, mannerisms, diet etc.,. CONTINUITY, FAMILIARITY, SECURITY, are key words that help support our adults through their day to day life and enable them to have some enjoyment and fulfilment. Is this not the individual’s outcomes you are seeking?**

Flexibility does not necessarily mean that things will constantly change. It just means that services provided will be designed around a person’s needs, long term and/or short term. The initial engagement exercises undertaken in January and February 2017 indicated that in the future there is a need for services to be more responsive and flexible and able to meet the changing needs of individuals and also their family and carer circumstances.

The concerns highlighted here and the need for people to have continuity, familiarity and security are of paramount importance to the CCGs. Personal outcomes and what will help individuals to achieve them will be developed by care managers or other relevant professionals alongside the individuals and their families. The CCGs are working with Local Authority colleagues in relation to this.

**18. 1:1 support – what about the very challenging individuals that need in excess of 3:1 or even 4:1 to access the community? How cost effective is this? Is this not another good reason to bring some of the alternative respite provision in house to Aysgarth where multiple clients can benefit within one visit, within a comfortable environment where they are calm and settled and able to participate, rather than anxious and agitated due to strange environments, noises, sensory overload etc?**

There has been detailed analysis undertaken in relation to the needs of the people who currently access the service, those Children and Young People who are aged 14+ and who currently access short break opportunities which has extended to understanding the levels of 1:1, 2:1 and 3:1 support needs and also the needs in relation to transfers and moving and handling requirements. This analysis has also looked at how many people have different types of needs, and specific diagnosis or needs that often occur together and other relevant aspects in relation to the needs and risks for individuals.

Work is on-going with Local Authority partners in relation to the support that will be required for individuals to manage any changes in a safe and supported way and will complete formal risk assessments as part of future care and support planning processes.

Part of the review and the development work should support each individual who has respite needs to be able to pursue activities of their interest within or outside of buildings based settings with the right level (and number) of appropriate support staff. This is included within the range of flexible community based respite opportunities and clinically led outreach support provision as part of the consultation.

**19. Changing the assessment and allocation process! Should this not be carried out by an independent organisation? Not anyone linked to the health authorities carrying out the consultation to ensure fair and un-bias consideration with no pre-meditated outcomes?**

The assessment and allocations process is still being developed, there are plans in place to embed the process across services to ensure fairness and equity. The tool has been developed by the CCG, Tees Esk and Wear Valleys NHS Foundation Trust and also the Local Authorities. There is a group of individuals from all organisations involved who are further developing and refining the tool. In addition there are plans to scrutinise and review the allocations process with the involvement of advocacy groups and also parent carer representatives.

There are two main elements to the assessment and allocations process which considers the health respite needs of the individual and the circumstances and respite needs of the carer.

The assessment tool will result in a banding and subsequent resource allocation which will be responsive to the identified needs for each individual and their family.

The eligible health needs element considers the person's needs in relation to day to day living for example personal hygiene and dressing, nutritional needs and support, keeping themselves and others safe, supporting behaviours and other specific personal needs.

The Carer circumstances and needs element considers what services are currently being received, the informal network of support that exists within the family and also the impact of the caring role on the person's wellbeing and ability to work or enjoy family life. The principles of this part are centred around the provisions of the Care Act 2015.

**20. PAGE 8 PAR 2- NEARLY HALF OF THE PEOPLE WHO USE BED BASED RESPITE AT BANKFIELD COURT OR AYSGARTH, ALSO USE DAY SERVICES 5 DAYS A WEEK – What is the**

**problem with this? This is not duplication because they happen at different times of the day, and is this not part of the choice of the individual?**

Services that are provided or commissioned directly by Stockton Borough Council are not included in this consultation. In some cases people with complex health needs access these services through Continuing Healthcare or Jointly Funded package arrangements. The flexible community services that are discussed as part of this consultation relate to opportunities that CCGs would like to make available to people with Learning Disabilities and complex health needs in the future, making sure that services can meet the needs of the individuals.

See also the answer above relating to **PAGE 5 PAR 4 – DUPLICATION OF BED BASED RESPITE AND DAY SERVICES**  
**PAGE 8 PAR 4 – AS PART OF THIS CONSULTATION ONE OF THE OPTIONS WILL RESULT IN THE BEDS AT BANKFIELDS OR AYSGARTh BEING REDUCED – How can this be a fair and democratic public consultation, with the views of the parents/carers and vulnerable adults taken into account, when the most damaging outcome to all concerned has already been decided by the trusts???**

The findings of the initial engagement identified that the care provided within NHS settings was excellent and carers were confident and comfortable although identified that improvements to facilities needed to be made.

The initial engagement also identified that there needed to be more choice and flexibility for people with Learning Disabilities and complex needs.

Retention, modernisation and extension of existing services would still result in a finite resource of an identified number of beds. This does not allow for the option of a choice of alternative options or increased capacity. There would be cost implications in doing this which would not result in the development of future proof services.

**21. I feel that this is not a consultation about improving respite provision – making it person centered. This consultation is being used as a smoke screen to enable the NHS to try and get twice as many bucks for their money. It is a cut back by stealth, by targeting the most vulnerable adults, who they feel have no voice or opinions to object or make themselves heard. If it was truly person centered they would not be looking at reducing or even closing the only bed based provision that is currently meeting the needs of these most complex of adults. Aysgarth offers person centered provision, it offers emergency cover. The NHS needs to acknowledge that any which way; they are not going to be able to meet the needs of 200 individuals with the budget of 100 individuals!! They need to be looking at what is working! What is providing excellent bed based respite provision and look to expand not reduce or close it. It is widely acknowledged within the medical world that sleep deprivation can impact on many illnesses and an individual's ability to cope adequately, so why are they looking to reduce this most needed of respite provision and “potentially” put many more families into crisis never mind improving respite provision.**

The project to date has undertaken significant analysis of the current and future groups of people who access (or who may need to access) respite services in the future.

As at 31<sup>st</sup> August 2016 there were 9 Children and Young People who will rise 18 in the next four years who currently access bed based short break respite services at Baysdale and who are likely to need similar types of support into their adulthood and would be likely to be referred to 2, Bankfields Court or Aysgarth.

There are 28 Children and Young People who are known to Local Authority Transitions Teams and special school nursing who are due to turn 18 in the next four years and who are likely to have significant complex needs and/or behaviour perceived as challenging and who will have respite needs.



There are a further 523 Children and Young People aged 14+ on Tees who are known to Local Authority Children's Teams who may have respite needs into the future.

In addition, there may be a group of individuals who may also need to receive community based respite support following inpatient discharge under the Transforming Care programme in coming months.

There are also people who either did not qualify for the current service, or for whom the current services are unsuitable, and people who may not have applied for health respite provision but who under the future programme, may do so. Information has been collected from Local Authorities to identify that there are individuals in current social care provision whose needs are difficult to meet. Complete information about this will not be apparent until services are developed and people are given the opportunity to request access to a wider range of respite services for people with complex needs.

The CCG and Local Authorities will continue to provide services that are compliant with all relevant legislation. The CCG recognises its obligations to the local population and also to carers themselves under the Care Act. The findings of the initial engagement activities earlier in 2017 highlighted the importance of providing bed based respite care as an option for future respite provision. This has been reflected in the options that have been brought forward for consultation.

This is a genuine consultation which is being undertaken at a formative stage and is happening so that the Tees Clinical Commissioning Groups can hear what people think about the CCGs proposals about how respite for people with Learning Disabilities and complex needs is provided. Talking to people about our ideas for the future will help the CCGs to improve respite services to better meet the needs of people with learning disabilities and complex needs, their families and carers. The CCGs are reviewing the services that are provided by the NHS and has found that there are many complexities in providing respite. Talking to people involved will help everyone understand the needs and the challenges.

**22. One last thing! Where within the questionnaires did any one single parent or carer suggest that bed based respite would be better for them or their adult if it was reduced or removed?? So why has the NHS consultation board proposed this as their key way of improving respite provisions, based on information received from parents and carers??? I think there is genuinely a need for an increase and variety of respite provisions within the Tees Valley but not at the expense of existing ones. I feel that the original questionnaires that were used to compile these consultation proposals were misleading in what they were proposing to offer. I'm sure that many people who completed the survey were not aware, as I wasn't that if they asked for more of one thing it would be at the expense of another. Opinions in this consultation brochure have been manipulated to determine a pre-set outcome for the NHS, and this is why like so many other points mentioned above I feel this consultation document is flawed and does not fairly represent what the adults with complex needs, their parents, carers and families feel they need to meet their best interests.**

The findings from the initial engagement activities in January and February 2017 did not indicate that parent/carers were suggesting reduced or removed NHS bed based provision. The feedback from them was that their experiences of the NHS bed based provision in the main was overwhelmingly positive. 60% of the respondents to the questionnaire identified improvements such as; more flexibility, improved facilities, more staff, more respite time, more choices for people with complex needs, responsive services, improved transport, emergency provision that does not impact on planned bookings.

The information from individuals and families was gathered and used to identify priorities for the service going forward and the scenarios have been evaluated against the criteria which was directly informed by the feedback from the initial engagement. Further details about this can be found on page 10.