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Healthwatch Hartlepool/Hartlepool Carers
Health Care Experience Consultation

Final Publication

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MISSION STATEMENT

"Healthwatch Hartlepool has been established in a way that is inclusive and enables involvement from all areas of the local community. We wish to involve those who are seldom heard."

Contents of the Report

1. Background and Methodology

1.1 In December 2017 the Healthwatch Development Officer met with representatives of Hartlepool Carers to discuss a range of health and social care related issues which impact upon the wellbeing of carers and the people they care for. Discussions touched upon a wide range of issues but it soon became apparent that there was a need to engage directly with carers to obtain first hand experiences of the effectiveness of local health services.

1.2 During our initial discussions a theme around Personal Health Budgets and Continuing Health Care had emerged. It was felt that carers were experiencing increasing difficulties and inconsistent application on the part of health professionals when applying for funding from both sources.

1.3 Consequently, it was agreed that a series of focus groups would be held, to which carers would be invited. The initial area of discussion at the meetings would focus on experiences of applying for Personal Budgets and Continuing Health Care, but it was agreed that there would also be opportunities to raise wider health related issues and experiences during the sessions.

1.4 Arrangements were then made to run five differently themed half day carer focus groups-
February 5th
Children and Young People (10am-12pm)
Transition and Adults (1pm – 3pm)
February 12th
Older People (10am -12pm)
Young Carers (8-11) (1pm – 3pm)
Young Carers (11-18) (1pm – 3pm)
The first three sessions were held at “The Place in the Park”, with the Young Carers sessions taking place at Hartlepool Carers offices on York Road.

1.5 The three sessions at the Place In the Park were attended by approximately 20 carers with a similar number of young carers attending the two sessions held at York Road.

1.6 Finally, it was agreed that a short report would be produced by Healthwatch Hartlepool which would outline key findings and make recommendations as appropriate. All information would be shared in full with key partner organisations including Hartlepool Borough Council but individual input and comments would be presented anonymously.

2. Findings

Continuing Health Care

2.1 NHS Continuing Healthcare is the name given to a package of care that is arranged and funded solely by the NHS for individuals who are not in hospital and have been assessed as having a primary health need.

2.2 There is a two stage process by which eligibility for NHS Continuing Healthcare is assessed. Firstly, the patient has an assessment with a health or social care professional using a screening tool called the Checklist Tool. If after completing this tool it looks like the individual may be eligible for NHS Continuing Healthcare, the second stage is a full assessment using a tool called the Decision Support Tool. Guidance states that the individual should be fully involved in the assessment and decision making processes. Their views about their care and support needs must be taken into account. If the individual is struggling to explain their views, or would like help doing this, a friend, relative or advocate can help.

2.3 A separate process of NHS Continuing Healthcare operates for children and young people. This applies when the child or young person has needs or challenging behaviour arising from disability, accident or illness that cannot be met by existing universal or specialist services alone.

2.4 Some children and young people (up to 18 years old) may have very complex health needs. These may be the result of congenital conditions, long-term or life-limiting or life-threatening conditions, disability, or the after effects of other serious illness or injury. Eligibility for such a package of health funded care is assessed following the same process to that illustrated in 2.1 above.

2.5 Feedback received from carers of both adults and children was remarkably similar regarding experiences of trying to access both types of Continuing Healthcare. Everyone who had been through either of the processes felt that it had been a complex, difficult and emotionally draining experience.
"It felt like the process and procedures took priority over the needs of my child"
"Everything was a fight, it felt like we had to battle for everything!"
"Services are not joined up, so you end up repeating things over and over again."

2.6 Carers with children reported that having a full diagnosis of the child's condition could be a major barrier to accessing support through Continuing Health Care.
"They haven't been able to come up with a diagnosis yet, but my child's care needs are still there and not being met."
"The system fails if a clear diagnosis is not in place. The whole process is diagnosis led and not patient centred"

2.7 Clear information on how both processes work, with clear explanations of eligibility criteria were said to be very hard to find.
"Information on Continuing Healthcare is hard to find and when you do find it, it's very unclear and difficult to understand."
"The whole process is very poorly explained and information that you have a right to is not always forthcoming."
"I am still unclear on what Continuing Health Care is. It was not explained well and appears to be inconsistently applied."

2.8 All carers reported inconsistencies in the interpretation of eligibility for Continuing Health Care that was received from different health professionals involved in the assessment process.
"Professionals do not appear to fully understand them (Continuing Health Care processes and eligibility criteria) and sometimes give contradictory advice"

“Input from social workers is very inconsistent, some cases are fast tracked and others aren’t but no explanation is given.”
“Staff need better training so they are able to fully understand and explain how the pathways and processes associated with Continuing Healthcare work.”

2.9 Many carers reported feeling that the process was finance driven and that it was becoming harder to access Continuing Health Care support.
“The system is dishonest, it pretends that it isn’t financially driven when in reality we all know that it is!”
“Carer experience is that applications are usually declined and criteria is getting tougher.”
“The person I care for has significant needs but still does not qualify for support.”

2.10 Experience of service delivery was reported to be inconsistent when dealing with transition from child to adult services.
“There were variations and inconsistencies in transition dates and although treatment was received through paediatric services it does not always mean services and support will continue into adulthood.”

Personal Health Budgets

2.11 A Personal Health Budget is an amount of money to support the identified healthcare and wellbeing needs of an individual, which is planned and agreed between an individual, or their representative and the local Clinical Commissioning Group (Hartlepool and Stockton CCG).

2.12 The aim of a Personal Health Budget is to give people with long term health conditions and disabilities more choice and control over the money spent on meeting their health and wellbeing needs. It may be used for a range of things to meet agreed health and wellbeing outcomes. This can include therapies, personal care and equipment within defined parameters.

2.13 Feedback received from carers largely reflected the experiences outlined above regarding Continuing Health Care. Once again carers generally reported the Personal Health Budget process to be both stressful and difficult to navigate.

"No one really knows about Personal Health Budgets, they aren't publicised and kept quiet"

"The process of applying for a budget is complicated and doesn't include cognition (Learning disability)."

The process for both (Personal Health Budgets and Continuing Health Care) is very complicated and feedback on decisions is poor or none existent."

2.14 Difficulties were reported in the way in which Personal Health Budgets are administered and the application process.

"The budget was driven by process and didn't accommodate the needs of the carer. This restricted what could be done and consequently the benefits were limited."

"I found the health budget to be inflexible and it didn't match up with individual and carer needs and circumstances, it wasn't person centred."

2.15 Some parent carers said that their personal knowledge and experience of the individuals condition was not fully taken on board.

"Carers are often not involved in the process and their knowledge and understanding of the persons condition and needs are not fully taken into account"

2.16 Certain types of rare condition, and conditions for which there was no full diagnosis were also seen as barriers to being able to access a Personal health Budget.

"People with rare conditions, where normal care provision doesn't fit could really benefit from having a Personal Health Budget but they are not made aware."

2.17 A more positive experience of the process was identified in cases in which support had been made available during the application process.

"The Personal Health Budget process has improved since a nurse at my GP practice became involved in the assessment process. This has led to better communication and a more informed process."

2.18 Several carers reported that the process was financially driven and that in recent years Budgets had been reduced despite needs either staying the same or increasing.
“Last year x received £1500 for a full year gym membership, but this year only assessed at £750 despite having a degenerative condition.”
“Everything is driven by money and they are always looking for ways to say no!”

2.19 The length of time it takes to get a decision on an application was also given as a reason why people choose not to apply for a Personal Health Budget.
“I know about them but didn’t bother to apply, too much hassle and too slow, I would rather self-fund.”
“From putting in my application it took three years to get it approved”
“I applied for a swimming pass over a year ago but have had no response, the waiting times and patient service are completely unacceptable.”

Continence Services

2.20 Carers highlighted several issues regarding support for continence issues. Carers of children with continence issues said that the service provision felt fragmented and unresponsive.
“It is difficult to get nappies from the Continence Service, School Nursing and the Continence Service seem to work separately”
“The service does not feel carer or people friendly and there is very little continuity”
“The service is now very adult focused, difficult to access and outcomes are poor”

2.21 Carers for both older people and children commented that very often they were provided with inappropriate products which failed.
“The range of products available is limited and do not always meet individual needs”
“Often the nappies you receive are not the right size and can’t be used which has led to a nappy black market.”

2.22 A consistent theme amongst those caring for older adults was the lack of availability of “pull ups”.

"The person I care for needs pull ups, anything else just doesn't work. They provide them in Durham, so why won't they provide them here?"
"The pads that we get are not always right and don't work. We need pull ups and can't understand why they don't provide them. Guess it will be money before the needs of the patient."

2.23 Several carers also said that they often experienced long waits for products and consequently they often end up buying a lot of products for the person they care for.
"We experience very long waits for pads and services."
"Lots and lots of problems. I have to buy a lot of products as the ones the person I care for needs are not available."

GP Services

2.24 All focus groups commented on GP services. Many carers felt that their GP was unaware or unappreciative of the needs of carers and consequently felt poorly supported.
"GP's appear to have a low level of understanding of carer needs, and cutting the Carer/GP liaison service is a big loss"
"As a carer I am often left feeling let down by my GP".
"GP's need to have a better understanding of the needs of carers and the role carers play in supporting someone."
"My experience of GP's hasn't been good. I have had problems with getting a diagnosis and prescribing."

2.25 Problems were highlighted around communication between the GP, the practice and the patient. Concerns were also raised about poor communication between practices and other health providers.
"Please communicate, explain decisions and talk to patients!"
"Communication between GP's and other health agencies can be problematic. My medication was changed in hospital but my GP didn't know."

2.26 The most frequently raised issue by all focus groups related to difficulties carers experienced in accessing appointments with their GP. Most carers are fully engaged in providing care to loved ones between 7.30am and 9.30am. Consequently, they find it extremely difficult contacting their GP practice between these hours to book appointments. When they are finally able to phone the practice, appointments have usually all been taken. This has a significant impact on the ability of carers to access primary care in a timely and convenient manner.

“It is really difficult getting an appointment at my surgery. It is hard to phone between 8am and 9am as it is a really busy time for me and you are just left on hold. When you finally get through all of the appointments are gone.”

“I have real difficulties getting an appointment to see a GP. You have to phone between 8am and 9am which is really hard to do for carers. By the time I get through all of the appointments are gone.”

“There needs to be better access to GP surgeries for carers.”

“I always have problems with appointments, last time it took 100 calls to get an appointment.”

“Care is not patient centred, and don’t get me started on the appointment system!”

2.27 Finally, concerns were raised about medication reviews, with several participants expressing concerns that they are cost driven, rather than for the benefit of the patient.

“Medication reviews are all about cost.”

“My GP has stopped prescribing some drugs which are an important part of my treatment. This is down to cost and not what is best for me.”

Hospital Services

2.28 Generally, carers were positive about experiences of care at Hartlepool and James Cook Hospitals.

“Really good experience of Urgent care at Hartlepool Hospital, it is an excellent service.”

“We have used Orthopaedics, Phlebotomy and Haematology at Hartlepool Hospital, they are all excellent and the staff very caring.”

“The volunteers at James Cook provide a wonderful service.”

2.29 However some concerns were expressed about North Tees Hospital and the care received by patients with a learning disability.

“Patient experience in hospital can be poor, particularly North Tees. A course of antibiotics was missed, I was cold and waited four hours to be taken to the toilet. But they don’t have enough staff.”

“Hospital experience for people with learning disability is not so good, understanding and empathy from some staff can be poor. Also, being on a ward can be a scary experience.”

2.30 Difficulties getting to and from hospital appointments at North Tees and James Cook were highlighted by all groups particularly by those carers who relied on public transport.

“I have to go to North Tees for check-ups every few months. It costs me a fortune for a taxi or takes ages by bus and I have to get someone to stay with him while I am away.”

Community Services

2.31 Concerns were expressed about some aspects of wheelchair services. Several people stated that the person was expected to fit around the wheelchair, and the size, mobility and needs of the individual were not properly considered.

“I had a difficult experience with wheelchair services, they weren’t very helpful. Patient and carer needs are made to fit around big contract services rather than being about the individual.”

“They didn’t have the correct understanding of the needs of the wheelchair user. I had to pick a wheelchair from internet pictures.”

“With a wheelchair you have to get it right, otherwise it is a waste of money and it has a big impact on the quality of life of the person in the wheelchair and their carer.

2.32 Several carers raised concerns about physiotherapy and in particular services for children. It was reported that in some instances parents were paying privately for physiotherapy services for children as school based services were not meeting individual needs.

“Children in main stream schools are getting a poor inadequate service and often needs are not being fully identified and met. Families often end up having to pay for private physiotherapy services for their child.”

“The service is not working for many children, it is under resourced and health plans often do not fully meet the needs of children.”

Mental Health

2.33 Carer mental health was raised in the discussions of all focus groups. Caring can be a physically and emotionally draining experience and have a massive impact on the health and wellbeing of the carer.
"Being a carer has a big impact emotionally and psychologically and can have a big impact on your mental wellbeing".
"Caring for someone 24/7 can leave you feeling drained, emotionally and physically, you have to live it to really understand."
"I have felt stressed and depressed but caring for my child must come first."

2.34 Overall, carer experience of mental health support services was mixed. Some reported positive and supportive inputs which had been helpful, others felt that they had wasted their time and had not benefited from their uptake of services.
"I went for one session at MIND, the counsellor was not very good and I did not find the experience helpful. I did not go back."
"Crisis support is inconsistent, you get a mixed response."

2.35 Concerns were raised about Children and Adolescent Mental Health services (CAMHS). A recurrent theme across all focus groups was the time it takes to access CAMHS services and difficulties accessing sensory assessments. Consequently, there was a really strong feeling that all too often support was not made available at an early stage and consequently small manageable problems often became bigger and much harder to address.
"It takes too long to access CAMHS and once you do it is too complicated."
"My child had major difficulties accessing a sensory assessment. This had a massive knock on effect for the whole family. Eventually they did get a diagnosis of autism, but there is a lot of missed diagnosis and under diagnosis which has massive implications for children and carers."

2.36 Many carers felt that the peer support they received through Hartlepool Carers was far more effective than the support that was available from other mental health specific organisations.

"Hartlepool Carers gives me an opportunity to share how I am feeling with people who understand."
"Being a carer can be really stressful, if you don't care for someone yourself, you don't really understand. At Hartlepool Carers there are people who have been through what you are experiencing and understand how you are feeling."

3. Conclusions

3.1 Carer experience of Personal Health Budgets and Continuing Health Care is generally not positive and can be extremely stressful and cause considerable anxiety for the applicant and carer. In both areas understanding and interpretation of criteria is vague and can vary depending on the personal knowledge and awareness of the health professional spoken to. Clear, easy to understand information appears to be hard to find and both processes appear to focus primarily on cost rather than the needs of the individual.

3.2 Carers of both adults and children are experiencing significant difficulties in accessing suitable continence products from the Continence Service. Consequently, those who rely on the products are suffering both in terms of dignity and wellbeing, and carers are having to access appropriate products elsewhere at significant cost to themselves.

3.3 Carers across the town are experiencing major difficulties accessing GP appointments. Appointment systems at many surgeries are based around patients phoning the practice between the hours of 8am and 10am which for many carers is one of their busiest and most intense periods of the day.

3.4 Experience of hospital services was generally quite positive although some concerns were raised regarding the experiences of patients with a learning disability and transport.

3.5 The individual needs of the cared for person and carer are not always being fully addressed in the areas of wheelchair services and children's physiotherapy. Consequently, the wheelchair provided may be inappropriate or the physiotherapy package inadequate in order to address identified need.

3.6 A significant number of people were unaware of complaints/compliments procedures and where to find instruction on what to do. This indicates that on some occasions new care service users are not being told about where to find them, or that current methods of passing on information are failing in some cases.

3.7 Mental health is a significant issue for carers and those they care for. Access to timely mental health interventions appears to be problematic both for adults and children. Consequently, this has led to low levels of confidence in mental health service providers amongst some carers and some unmet/undiagnosed mental health care needs amongst both carers and those they care for.

4. Recommendations

Continuing Health Care

4.1 That as a matter of urgency, the processes and procedures associated with applications for Continuing Health Care for both children and adults is reviewed with a view to making the process more transparent, consistent in application and understandable to those who apply for it.

4.2 All staff involved in facilitating Continuing Health Care applications should be trained to a consistent level of awareness and understanding and joint training/development of health and social care professionals should be considered to maximise consistency in approach and interpretation.

4.3 A specific review of transitional arrangements should be undertaken in order to ensure consistency of approach to transition from children to adult CHC arrangements and that parents and carers are kept fully informed and involved at all stages during this time.

4.4 In all cases, the needs of the individual and not financial implications must be the key focus in applications for Continuing Health Care.

Personal Health Budgets

4.5 As a matter of urgency, the process and procedures associated with applications for Personal Health Budgets should be reviewed with a view to ensuring transparency and consistency in application.

4.6 Hartlepool and Stockton CCG should look to raise awareness of the purpose and availability of Personal Health Budgets amongst patient groups in Hartlepool who may potentially benefit from accessing a Personal Health Budget.

4.7 All staff involved in facilitating Personal Health Budget applications should be trained to a consistent level of awareness and understanding and joint training/development of health and social care professionals should be considered to maximise consistency in approach and interpretation.

4.8 Efforts are made to ensure that applications for Personal Health Budgets are turned around in a timely manner and that at all stages applicants are kept informed of progress in clear, concise and understandable language.

Continence Services

4.9 The Continence Service undertakes a full consultation with service users and carers regarding the appropriateness of current service provision and product types which are available and that the outcomes of the consultation are acted upon and implemented at the earliest opportunity.

GP Services

4.10 As a matter of urgency, GP practices across Hartlepool consult with carers and carer organisations to identify ways by which carer access to GP appointments can be improved.

4.11 GP practices provide detailed information to patients and carers which describes the various ways in which GP appointments can be booked, including on-line and via the 111 service.

4.12 Hartlepool and Stockton CCG give serious consideration to ways in which awareness of carer needs and circumstances can be improved in GP practices within Hartlepool including the reintroduction of a Carer/GP Liaison officer.

Hospital Services

4.13 North Tees and Hartlepool Foundation Trust should engage with Hartlepool Carers to ensure that carers are fully aware of shuttle bus times, the volunteer driver scheme, subsidised taxi scheme and reduced cost hospital carparking availability.

Mental Health

4.14 Efforts should be made to ensure that funding streams are secured to enable Hartlepool Carers to provide support to carers in the areas of mental wellbeing and resilience on a permanent basis.

4.15 Mental health service providers including CAMHS and TEWV should examine ways of working more closely with Hartlepool Carers to ensure that mental health services are responsive to the specific needs of carers in a timely and effective manner.

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