

Substance Misuse and Mental Health

in the Borough of Darlington

Accessing and using local services



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Please note: Following on from Healthwatch Darlington's engagement and research which was conducted in August 2018 providers and commissioners such as; Tees, Esk and Wear Valley NHS Foundation Trust have been given the opportunity to share their own comments and feedback. These comments can be found on pages 27, 28 and 29.

Introduction

Who are Healthwatch Darlington?

Healthwatch Darlington is a charitable company limited by guarantee which makes us a totally independent organisation. We help local patients, service users and their families to get the best out of their health and social care services in the Borough. We listen to the voices of service users and use their real-life experiences to influence and improve the delivery and design of services.

- Healthwatch Darlington is representative of diverse communities.
- Healthwatch Darlington's vision and mission focuses our work on what needs to be achieved to improve Health and Social Care services for local people.

What we do:

- Enable local voices to influence the delivery of local Health and Social Care services
- Use local volunteers to gather views and experiences from local people
- Involve and engage local people, putting YOU at the heart of Health and Social Care service decision making
- Enable local people to make informed choices about their own, their families and friends' Health and Social Care
- Influence the way services are planned, designed, commissioned and delivered
- Have strong relationships with Health and Social Care providers as a critical friend using community views to influence and improve planning and delivery of services
- Provide information, advice and support about local services and signpost to them

We are independent and we make Health and Social care providers answerable to the people who use their services.



Why have we explored substance misuse and mental health?

Healthwatch Darlington identified areas of priority and improvement based on local service user feedback and this has influenced our action plan for 2018/19. One area of services identified was mental health services and the voices of service users in recovery from drug and alcohol addiction was brought to our attention throughout our recent 'What's Important to you survey?'. We listened and spoke to local service users from the Recovery and Wellbeing service which sits under a regional charity called NECA.



Methodology

The project used a mixed methodology approach. We believe that for this particular research that it was important to collect largely qualitative data with some quantitative. With this in mind we conducted targeted focus groups and four case studies. We worked closely with NECA targeting service users that were in recovery giving them an opportunity to share their experiences.

Our team along with some of our volunteer Health Connectors visited NECA and facilitated a focus group. We used structured questions to guide the group into discussion.

We identified four individuals who were willing to share their real-life patient experience as part of our case study research. Each case study appointment was one and a half hour's long and was conducted by one Healthwatch Darlington member of staff and one volunteer Health Connector. We used structured questions to guide us but allowed for the discussions to progress naturally. We conducted these with sensitivity and each individual has signed a confidentiality agreement and given consent to their information being shared.

We have worked with service users to develop recommendations and their views along with our research has helped to underpin the recommendations based within this report.

Who are NECA?



NECA is a registered Charity whose key focus is to improve the lives of individuals and communities throughout the region. For over 40 years NECA have supported and enabled thousands of individuals to sustain long term Recovery from substances and gambling misuse. They provide a range of health and wellbeing services, acknowledging that wider health determinates can have a significant impact on individual recovery.

The local Recovery and Wellbeing service in the Borough of Darlington currently support 536 service users.

Tees, Esk and Wear Valley NHS Trust



Tees, Esk and Wear Valleys NHS Foundation Trust (TEWV) delivers NHS inpatient and community mental health, autism and learning disability services for people living in County Durham and Darlington, the Tees Valley and most of North Yorkshire. Their specialist services support people living elsewhere in the country, particularly other parts of the North East, Yorkshire and north and west Cumbria.

Within each of the three local areas they have four clinical directorates:

- adult mental health and substance misuse services
- mental health services for older people
- children and young people's services
- learning disability services

This report centres around local services provided by the Trust and are featured within our findings. Throughout our research and engagement, services regularly highlighted were Improving Access to Physiological Therapies (IAPT) known locally as Talking Changes, Darlington Mental Health Crisis and Intensive Home Treatment Team and West Park Hospital.

IAPT (Talking Changes):

Provide free and confidential talking therapies through a progressive model of care to anyone over the age of 16 years old living in County Durham and Darlington who experience a common mental health problem such as depression, generalised anxiety, specific phobias, panic, obsessive compulsive disorder or post-traumatic stress disorder for example.

Context and Background

Darlington Mental Health Crisis and Intensive Home Treatment Team:

They operate 24/7 and provide specialist assessment for people aged 18 years and older who need urgent mental health care. We assess and identify your needs, including mental health, physical health, social care, any risks to you or others, your strengths and hopes for recovery.

West Park Hospital:

Is a local hospital and the Tees, Esk and Wear Valley NHS Foundation Trust's (TEWV) HQ based in Darlington providing inpatient wards and community services for adults and older people.

Mission and Priorities:

The Trusts mission is to improve people's lives by minimising the impact of mental ill health or a learning disability.

One of their goals is to provide excellent services working with the individual users of our services and their carers to promote recovery and wellbeing. This means that they make a positive difference to the lives of service users and carers by:

- supporting individuals to achieve their personal recovery goals
- delivering safe and effective care (at the right place and right time) that meets individual needs
- fully engaging people in the development and delivery of their individual care plans
- ensuring everyone has a positive experience of our services
- providing high quality, accessible information to help service users manage their own health and care.

TEWV's business plan summary 2018/19 - 2020/21 can be accessed via their website:

https://www.tewv.nhs.uk/content/uploads/2018/08/short-summary.pdf

The plan sets out the Trust's plans to improve the quality and efficiency of the services delivery over the next three years (1st April 2018 - 31st March 2021) and to deliver their mission and vision.

One of the quality account improvement priorities is set out in the business plan which covers "Develop a Trust-wide approach to dual diagnosis which ensures that people with substance misuse issues can access appropriate and effective mental health services." with an aim to finish this by March 2019.

Context and Background

Mental Disorder and co-existing Substance Misuse Clinical Link Pathway (CLiP):

The Trust aims to develop a clinical pathway for dual diagnosis that is compliant with national guidance by NICE and the UK guidelines on clinical management of drug misuse and dependence (Orange Book). It aims to replace the clinical aspect of the Trust's policy and procedure **Care and Management of Dual Diagnosis.** The latest UK guidelines on clinical management of drug misuse and dependence can be found via the gov.uk website:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/673978/clinical_guidelines_2017.pdf

Within the latest UK guidelines, it mentions the importance that individuals are not turned away from either drug and alcohol treatment services or mental health services due to their co-existing illness but rather that services should be perceived by the service user as supportive.

Different service models are used in caring for patients with dual diagnosis. Collaborative is when both mental health and substance misuse service communicate closely, support each other and work with co-ordinated or joint care plan. The Trust mentions within the Clinical Link Pathway document that they have always favoured a collaborative model even if it has been difficult to implement collaboration into practice.

Care and Management of Dual Diagnosis Policy:

The current policy in place at the Trust details that standards of practice and processes that are to be followed when caring for individuals with concurrent mental health and/or learning disability and substance misuse needs. The purpose of the policy is to comply with Care Quality Commission (CQC) standards and local/national guidelines, all staff are aware of the care and management of dual diagnosis and it also sets out the standard for joint working and liaison between both mental health and substance misuse services.

Some of the key objectives within the policy include:

- Service users are not to be discriminated against due to their mental health needs being perceived as drug or alcohol induced.
- Receive care based on their needs, provided by the service (or services) best placed to suit those needs.
- Have an appropriate care co-ordinator or lead professional allocated;
- Receive care delivered in a collaborative manner from a care plan if multiple providers are involved;
- Are cared for by staff in mainstream substance misuse and mental health services who are competent and capable of responding to dual diagnosis needs.

Context and Background



Public Health Guide for commissioner and providers

Better care for people with co-occurring mental health and alcohol/drug use conditions:

Public Health England with the support from NHS England developed this guide to address disparity. This is in line with commitments set out in the national Mental Health Crisis Care Concordat action plan and to help implement key recommendations in the Five Year Forward View For Mental Health. This guide was developed with the aim to inform the commissioning and provision of effective care for people with co-occurring mental health and alcohol/drug use conditions. It aims to support local areas to commission timely and effective responses for people with cooccurring conditions.

Two key principles:

- Commissioner and providers of mental health and alcohol and drug use services have a joint responsibility to meet the needs of individuals with co-occurring conditions by working together to reach shared solutions.
- Providers in drug and alcohol, mental health and other services have an opendoor policy for individuals with co-occurring conditions and make every contact count. Treatment for any of the co-occurring conditions is through every contact.

NHS England and local Clinical Commissioning Group's (CCG's) have a duty to reduce inequalities between patients in access to health services and the outcomes achieved. In 2014 and in response to evidence of significant gaps and variations in quality and availability of care, signatories to the Crisis Care Concordat partners agreed a national action plan which include a specific focus on improving crisis care for people with mental health issues and co-occurring alcohol/drug use. It is through this plan Public Health England committed to developing this guidance with NHS England.

The Five Year Forward View for mental health sets out a series of recommendations to the NHS and Government to achieve parity of esteem between mental and physical health, placing a particular focus on tackling inequalities.

You can read more about this guidance via:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/att achment data/file/625809/Co-

occurring_mental_health_and_alcohol_drug_use_conditions.pdf

Healthwatch Darlington priorities

Healthwatch Darlington conducted a survey earlier in the year called 'What's Important to you?'. This gave patients and their families living in Darlington an opportunity to tell us what they think we as a local Healthwatch organisation should be looking at within the Borough of Darlington. We wanted to find out what was considered priority for people in the local area and which Health and Social care services mattered to them the most.

We sent the survey out via our weekly E-bulletin and through our social media platforms. Our Health Connector volunteers visited venues across Darlington such as Darlington Memorial Hospital, Darlington College and the Dolphin Centre. They engaged with service users and encouraged them to take part in our survey. We received 172 responses to our survey which was fantastic. After engagement the data was analysed, and then presented to our Board of Directors who decided on our action plan for 2018/19.

The views of local service users and their families were very much at the heart of our decision making for 2018/19.

Findings

We asked people living in Darlington a mixture of questions so we could identify where they would like to see Healthwatch Darlington in the community, which communication platforms would they like us to use and which Health and Social Care services would they like us to look at for 2018/19.

45% of 172
told us Mental
Health was
priority!

14% of people
within our survey
told us Substance
Misuse was an
area that needed
some attention!

Improving Access Psychological Therapies (IAPT) Focus Group

Healthwatch Darlington conducted ten focus groups across Darlington on behalf of Darlington Clinical Commissioning Group throughout April and May 2018. We gave participants the opportunity to explore the proposed model and care pathways for the service Improving Access Psychological Therapies (IAPT) better known locally as Talking Changes.

One of these focus groups was with NECA service users. There were eight participants within the group and they all shared their views and opinions on the new model. This highlighted many concerns amongst the group that have been very relevant to Healthwatch Darlington's engagement and research for this report.

Findings

- Some individuals have experienced barriers accessing more complex therapies as they are told they most stop using drugs or alcohol. They feel this is a barrier. One individual said he does not drink alcohol 90% of the time and the other 10% is when he relapses. Despite this he still can't access further treatment. He has been told it isn't enough. Individuals within the group told us that many clients within the Recovery and Wellbeing service use drugs and alcohol to mask their mental health. Their mental health has always been there even before addiction.
- The group were very concerned that drug and alcohol addicts were not mentioned at all within the proposed model and care pathways for IAPT (Talking Changes).
- The group discussed how important it was for service users to have a team of professionals to look at the combined process to address the issues they face and link substance misuse with physiological.
- The group have highlighted concerns regarding the mental health crisis team and feel the service is under pressure and they don't always meet the needs of all patients. A few individuals have mentioned they have tried to call and no one answers the phone. The group also feel that the crisis team can slow down a patient receiving mental health support due to the pressures the service is under.
- The group have highlighted that other life factors can have an impact on how they access services. For example: no phone, no fixed abode or a low income. These factors need to be considered for every patient to avoid early discharge from services if they are unable to make it to an appointment.
- The group raised concerns about referral systems, information and signposting. There has been particular mention about communication between services and they believe they do not work together.

- The group believe there is not enough support during the waiting period for mental health support. During the wait the group said they would like more support. The group said they would like to be signposted to other services for support. Another suggestion was the option to go to a support group whilst waiting.
- The group raised strong concerns around the waiting times for mental health services.

"We try to call the Mental Health Crisis Team and no one answers the phone!"

"We want more support during the waiting period for mental health support!"



Important update: Since Healthwatch Darlington conducted research and engagement work during August 2018 further information has now been updated. A new service specification for Improving Access to Phycological Therapies (IAPT) has been developed which now includes consideration of dual-diagnosis patients (service users in recovery from a drug or alcohol addiction.)

Substance Misuse Focus Group

Following on from our first visit to NECA we decided to return to give services users an opportunity to share their experiences when using local mental health services. We decided to hold another focus group which was attended by nine different service users and two professionals. This was the perfect opportunity for Healthwatch Darlington to begin to understand the many barriers that service users were facing when accessing services.

- The group all agreed that they believe that their mental health and substance addiction needs to be addressed with a collaborative approach.
- The group told Healthwatch Darlington they face many barriers trying to access mental health services especially when they need complex therapies. They told us they are often passed around services which has left them with no faith in the system. They feel like there is no a light at the end of the tunnel to recover which makes them feel worse and impacts their mental health further. They don't feel listened too as service users and feel they are treated differently.
- The group told us they feel the mental health crisis team is under pressure and they don't get much help from this service. A member of the group told Healthwatch Darlington they felt that they were only noticed by the mental health crisis team when they tried to take their own life. The group said that the crisis team don't always answer the phone which is worrying.
- The group did tell Healthwatch Darlington that they feel the police service have improved in the way they deal with an individual who is having a mental health crisis. This is positive, and we were happy to hear this.
- The group agreed that life factors beyond their control can sometimes have an impact on how they engage with services. As mentioned previously this could be a range of factors from no fixed abode to a low income. They told us there are **not enough options for non-internet and phone users**. The group feel that staff members within mental health services need to make more of an effort to check on patients. They said it would make a difference if they tried to contact them if they miss an appointment before resorting to early discharge.
- The group have regularly told us throughout the focus group that they are not given enough information, they are not communicated with effectively and that they have concerns about referral and signposting systems.

- The group had mixed responses about the support they felt they got from their GP surgery. Some believed if they asked for a double appointment they were only given 10 minutes where as some thought if they received a full double appointment it was for 20 minutes. The group told us that making an appointment was stressful and they always end up seeing a different GP which means they have to start at the beginning of their patient story each time.
- The group told us that there is no support during the waiting period for mental health services and they have never been offered any.
- The group told us that they are regularly signposted or referred back to NECA by mental health services. The group get excellent support from NECA but unfortunately NECA cannot offer mental health support.
- The group told us it would be beneficial for the facilities and services at NECA to be expanded so that they can get the mental health support they need in one place. If NECA could expand and hold Self-Management and Recovery Training (SMART) groups for mental health as well as drug and alcohol addiction this would offer them extra and much needed support for their mental health. SMART groups are all about self-management and checking in on each other giving clients a chance to offload. They also look at resources and training which could help clients to understand their own mental health better enabling them to self-manage.
- Some of the group told Healthwatch Darlington that the local charity who offers floating support to vulnerable individuals called the 700 Club were really good at supporting individuals and that they respond and support service users within two weeks.
- During the focus group 7 out of 9 told us that they had decisions made about their care and treatment without their input. They feel that their rights have been taken away at some points during their experience.
- 5 in the group told us they did not have a mental health care plan or they were not aware they could be involved with this.



Healthwatch Darlington conducted person centred case study interviews with four different clients who use the Recovery and Wellbeing service at NECA. We looked at the patient story in-depth and pulled out important key points and looked at 'What was missing' from their patient experience.

Case Study - Sarah



Sarah's mental health issues began in 1997 when she was living in Essex. At that point in time she was married with two children aged 18 months and 5 months. She was depressed and used alcohol as a coping strategy. The health visitor did check up on her and she was diagnosed with post-natal depression, but received no treatment for this. Her marriage broke up and she did not know how to cope with two babies on her own. Social workers were eventually involved when she could no longer safely look after the children. At one point she tried to bath the babies whilst drunk. At that time she had a choice of calling her husband to take the children or have them taken into care. They were put into the care of their father and Sarah subsequently lost custody of them completely.

She was admitted into a psychiatric ward for two weeks but had no support from staff or family. When she went home on leave the house was empty, she had nothing to occupy her and could not cope so she turned to alcohol again. On her return to the hospital she told the psychiatrist what she had done and so the hospital discharged her from their care.

Sarah attended a drug and alcohol center for a short time and received support from a psychotherapist who used art as a therapy, but Sarah found it was 'awful'. She was able to get her own home and a job as a care worker but lost the job due to her alcoholism. She was admitted to a rehabilitation unit but did not recover from the alcoholism; she was allowed out but took advantage of the free time to drink alcohol. She was in the rehab center for two years and lost her home. On discharge she lived at a MIND hostel for a period of time where she was fine during the day when staff were around and there were lots of activities going on. But after 5pm when staff left and she was on her own she turned to alcohol again. In 2001 she attended NECA for acupuncture to try to stop the alcohol dependency, but it was not successful.

For 15 years she did not need support from mental health services because she had been prescribed medication and had recovered. She has had support from Mental Health services for the last year and has been sober for two and a half months.

Sarah now lives on her own and has a job, however she is experiencing a cycle of going on sick leave approximately every four months. Her manager does not understand mental health and so she receives no support or suggestions of adjustments that could be made at work to help her. She has now agreed to resign from work as an alternative to being sacked.

Her GP referred her to West Park Hospital as she was depressed and suicidal; the Crisis Team visited her at home daily for a few months. Her GP then got her an appointment with a psychiatrist and she now has a care co-ordinator whom she sees once a month at West Park Hospital.

Sarah feels the Crisis Team and the Trust have a terrible attitude to alcoholism; she recently told her care co-ordinator that she had been sober for two months and the co-ordinator 'did not bat an eyelid'. Sarah obviously felt this was a great achievement for her and some recognition would have benefitted her greatly. She just felt that the co-ordinator did not care which was added to by the fact that she was 30 minutes late for her appointment with Sarah.

Previously she had asked for an increase in medication as she felt that now she was not relying on alcohol, she needed an increase in her medication. Her co-ordinator advised her that they would need to ring her GP and they would call her back when they had done so. As they did not ring her back, Sarah called them and was told they was on annual leave, so she called her GP surgery. The surgery told her she would need to ring West Park. West Park said go to the GP. Sarah has now been waiting for over a month to have her medication increased and feels that she is struggling a lot.

She now feels she doesn't know what she is doing with no job and no support from her care co-ordinator.

Summary of key points:

- Services are never accessible and professionals never call back.
- A pattern has emerged of cancelled appointments by professionals.
- Sarah feels like a number, as professionals demonstrate no sign that they actually care.
- Not treated with dignity and respect.

- As an in-patient at West Park it was awful; Sarah was left with no support, no group sessions, no one-to-one sessions with staff and was lucky to get five minutes discussion. She basically felt all she was there for was a rest.
- Sarah's care plan is over a year old and there has been no mention of it being updated.
- Sarah had no input to her care plan as her care co-ordinator compiled it and she is not totally happy with it.
- Services are overstretched and staff do not fully appreciate they they are dealing with the lives of very vulnerable people.
- Sarah did not feel she had a say when she was sectioned. She was fine with the decision but had no involvement in the decision.
- Sarah feels the services that are provided contribute to a deterioration in service users' mental health because professionals don't listen and don't actually do anything to help.
- NECA are marvelous; Sarah feels that they really care and that she matters. She sees her key worker once a week. She attends SMART meeting's, self-management groups and recovery training for two hours a week. She gets the chance to tell the group how she feels, what kind of a week she has had and has been shown coping techniques.
- If Sarah had a relapse she would call her co-ordinator, go to an AA
 meeting or go into NECA but NECA is not open all the time or on
 weekends. It would be ideal if it was open for some evenings and
 for some times at the weekends.
- Sarah likes having the time to go for walks, go to AA meetings and go to NECA as these are the things that help her.

What was missing?

- Better understanding of substance misuse and more tolerance of alcoholism. Too often when professionals find out service users are still drinking they just discharge them from services.
- Information about services and how to use services.
- Communication between care professionals and service users.

Case Study - Chris



Chris has lived with mental health problems for most of his life, but things spiralled out of control 20 years ago at the young age of 21 years old. Chris told us that the implications of negative experiences from his childhood have had a massive impact on his mental health and this has led to where he is today. Chris has been diagnosed with numerous mental health conditions over the years including Dysthymia (Chronic depression), Obsessive Compulsive Disorder (OCD) and Post Traumatic Stress Disorder (PTSD).

One day Chris decided to drink a beer which immediately made his mental health symptoms feel better. So he decided to have another one and another one. This started to become a regular occurrence and before long he was drinking beer and cider daily. Chris believes this helped, he turned to drinking as a way to cope and to self-medicate. Fast forward 20 years and Chris is currently still trying to receive help and support from mental health services. Fortunately for Chris he sought help for his alcoholism and he has now been a recovering alcoholic for 10 years. He does admit stopping alcohol has made his mental health worse, but he is desperate for help to stabilise his mental health problems as he currently feels suicidal.

Chris lives with complex PTSD and on a day to day basis, this effects his life drastically. He is unable to get out of the house often as he experiences panic attacks, he does have a dog which helps on some days. Chris also exercises six days a week which is a massive help. Chris experiences black outs and has harmed himself during these episodes. Chris showed Healthwatch Darlington some very upsetting photos of scratches on his body which happened during a recent black out, he can't remember or recall anything about this black out. Over the years Chris has lost friends and has been unable to maintain friendships with people who drink alcohol. He gets help from his parents but unfortunately, they don't speak to him about his mental health problems, so to this day he only has one friend he can talk to for support.

Chris has tried to seek help and was referred to West Park Hospital which sits under Tees, Esk and Wear Valley NHS Foundation Trust (TEWV) by his GP. He has had a mental health care plan in the past but doesn't recall having any input. He was assigned a community psychiatrist nurse (CPN).

Unfortunately, he has now been discharged from the service due to an incident at an appointment. Chris only recalls being seen on a few occasions and this was over a 2 and half month period. He said they never returned his calls. At the most recent appointment he was desperate to discuss his withdrawal symptoms after a relapse. He had lost one stone in weight due to sensation of not being able to swallow. During this month Chris struggled to eat food. He wanted to discuss this with his CPN but got the feeling she was not listening. Chris mentioned she began discussing his future discharge plans which he found very upsetting as he was in not a position to even be thinking about discharge. He eventually let his frustration get the best of him and he threw a water bottle across the room and left the appointment. He was sent a letter shortly after telling him he has been discharged from the service because of the incident.

Chris had asked to find out why and was eventually called to a meeting with a manager and the CPN in question. Chris was told he was not discharged because of the incident and the CPN repeatedly denied this was the reason. Chris told Healthwatch Darlington that he presented them with the letter which was quickly brushed off as a mistake. He has tried to seek help from Talking Changes who have turned him away as they believe he is too erratic for the service. Chris has approached Mind in the past but unfortunately has been told his complex PTSD needs to be addressed before they can help him. On this present-day Chris has still got no help from mental health services and feels completely on his own. Fortunately, Chris does get support from NECA but this is limited.

Chris also told Healthwatch Darlington about an experience with the mental health crisis team. He had a break down in his GP surgery after considerable financial stress. He was very upset and crying. The crisis team were called out and visited him at his home address. He recalls a big gentleman being very inconsiderate about his financial situation. He told Healthwatch Darlington he felt belittled by the man and that he didn't understand. This actually made him feel worse. He told Healthwatch Darlington if he experienced another mental health crisis he would not ring them again. We asked Chris who he would ring and he said no one.

Chris is desperate to get the help he needs so he can recover and one day return to employment. Chris finds it embarrassing living like this and has got to a point where he has no hope.

Summary of key points:

- Chris used alcohol to self medicate to help his mental health
- Chris has been a recovering alcoholic for over 10 years but does not get support for his mental health
- Chris does not feel listened to by health care professionals and feels phone calls are often not returned.
- Chris feels he has had little input into his own care plan.
- Chris has had numerous diagnosis's made about his mental health, one of them being complex PTSD. This is not being addressed by mental health services.
- Chris has had very little support from West Park, he feels the staff members don't listen to him and feels he has been let down by them.
- Chris has been discharged early from services.
- Chris has felt belittled by staff members within the Crisis Team.
- Chris is passed around services, but no one is willing to help him.
- If Chris has a mental health crisis he would turn to no one for help.
- NECA support Chris but he knows this is limited.

What was missing:

- Services with the resources and capacity to deal with complex PTSD.
- Understanding and staff awareness at West Park of the difficulties recovering alcoholics face when in recovery and coping with mental health problems.
- Involvement in his own care plan.
- Compassion and understanding from Crisis team staff members.
- Support and follow up calls from staff members at West Park.
- Information about services that can help him.
- NECA not having the resources to support clients with mental health.

Case Study - Daniel



Daniel was abused at the age of 16 years old and this has had a massive impact on his mental health. Daniel believes this is the reason he began drinking alcohol and it has covered his mental health issues over the years. Daniel has stopped drinking alcohol and has been a recovering alcoholic for 3 years now. He feels this has made his mental health worse and he hates not being able to drink. He also has a lot of self-hatred for his feelings and during our conversations with Daniel he did get quite emotional and upset.

Daniel still suffers daily with his mental health and on his worst day he doesn't leave the house. He is very anxious and this along with paranoia means he feels that the back room in his property is the most unsecure room in the house. He will often stay in this room for security reasons. He feels depressed and, in the past, has had daily suicidal thoughts. Daniel however does have support from his partner but even his partner feels his mental health is never addressed. They are both very frustrated with services as no one is willing to help Daniel. He is unaware of any support being offered to his partner as a carer.

Daniel finished counselling last year which did help him but counselling sessions are limited on the NHS. He has had referrals to West Park hospital but feels they have never been able to support him. He has got the impression from staff members that he just 'needs to pull him self together'. He was due to receive a report from West Park Hospital following on from his care and treatment but this never happened. He has no care co-ordinator and doesn't think he has ever had a mental health care plan. He wants to receive more counselling but has to wait for this. Daniel believes people with addictions are not treated very well and that they are just a number on a bit of paper. He feels regular contact from a health professional throughout has treatment would have been more helpful. Danial has had decisions regularly made without his input as he won't speak out when he thinks differently. He will often just agree when in reality he really isn't happy with decisions. He feels it would be better having a mental health care health care professional that can recognise that in him. Daniel said NECA has been his most consistent support.

At present Daniel has no mental health support from services. He thinks his GP would help and refer him to services, but he doesn't know where as he has been passed around services that often. Daniel does admit if his mental health is poor this results in him missing GP appointments. He doesn't feel he would want to go to his GP often as he has felt dismissed by them in the past when he was drinking alcohol.

Daniel said he wouldn't ring the crisis team for support as he feels they would not believe him. He does have a lack of trust in services which means he has minimal engagement.

Daniel is desperate to get the support he needs from mental health services.

Summary of key points:

- Daniel has no support from mental health services at present.
- Daniel feels dismissed by staff at West Park and has not had good support from this service.
- Daniel struggles to receive enough mental health support to help him recover. Counselling sessions are limited.
- Daniel finds it hard to engage with staff members and mental health services because of his anxiety and paranoia but this is not recognised.
- Daniel feels individuals with an addiction are often treated disfavourably within mental health services.
- Daniel thinks he has no mental health care plan in place and often has been uninvolved in decisions regarding his care and treatment.
- Daniel doesn't have much trust in mental health services such as the crisis team.

What was missing:

- Consistent communication and support from mental health care.professionals for individuals who struggle to engage.
- Regular counselling sessions which benefit patients.
- A mental health care plan.
- Compassion and understanding from mental health staff members.

Case Study - Craig



Craig attended the meeting with his partner and carer Ailsa; she supports Craig with everything and was able to give a lot of information regarding Craig's situation. However Craig obviously felt comfortable enough to provide us with information himself.

Craig has had a troubled childhood which included having soft drinks being spiked with drugs by his dad and was an addict from five years old. Due to childhood trauma and his past exposure to drugs as a child, he has been an addict for 21 years. He was bullied at school and this caused him to respond by getting angry and lashing out.

About four or five years ago he tried to stop taking amphetamines and that was when he started have problems with his mental health. He suffers with depression, anxiety and paranoia. For three years now he has been using cannabis and wants to stop using it.

His GP has referred him to West Park Hospital for treatment for his mental health issues but they refuse to see him until he is off the drugs, but he cannot stop these as it stabilises his mental health symptoms. Craig feels it is extremely difficult for him to open up about his feelings and his symptoms as his emotions will explode and his mental health will deteriorate massively. He needs to be in a safe environment and is able stay at home by himself as he feels safe. However he never goes out without Ailsa to support him and keep him under control should he get paranoid and get upset. The only person he will listen to and trust is Ailsa.

Ailsa gets no support as his carer; she is reluctant to consider help as Craig feels like a burden and she would not want to 'abandon' him. They almost broke up six years ago but they are steady now. She does get Carers' Allowance and Craig is applying for Personal Independence Payments (PIP). He has some friends who visit them at home and has support from some friends and family but his mental health has affected relationships with people and many have now turned their backs on him.

Craig does not sleep well and can go for days and weeks without being able to sleep. He experiences night terrors and will wake up crying. His GP will not prescribe medication for his insomnia and Craig feels that he just does not listen to him regarding this. He can have blackouts and experiences schizophrenia. Once he woke up from a blackout at the window with an axe in his hand and he had people in his flat at the time.

Craig is desperate to have formal help for his mental health problems but feels that health professionals are just not interested because of his drug use.

Summary of key points:

- Craig has been to West Park three times but has received no help. NECA once
 phoned West Park Hospital to tell them that Craig was in need of help but
 they would not listen.
- Twice Craig has gone to Darlington Memorial Hospital where staff called out the Crisis Team but they just say the same things; that he needs to address his drug use first.
- Craig's GP practice cannot support him and he feels they just don't know how to handle his health concerns. He feels that GPs are not trained to deal with mental health problems and addictions.
- Craig has no mental health care plan and he would not know his rights with regard to his mental health and treatment.
- Craig feels that his depression, paranoia and anxiety need addressing but they never have been. He has never had an opportunity to deal with it.
- Craig has lost hope in the system as he feels that they are completely clueless and he is fed up with rejection. He feels no one is listening and so his situation is hopeless.
- Craig feels he needs someone to listen, someone to help him to deal with things, someone he can call when he needs to.
- Craig is worried that he will scare off counsellors when he starts to talk about his past. He has had experiences in the past with health professionals who have turned their backs on him which he believes is because they could not cope with his traumatic past.
- Craig wants to work but has never had a job because of his drug abuse and health. He has found that the Department of Work and Pensions and Citizens Advice Bureau have been brilliant pointing him in the right direction for support.
- At a recent incident Craig found that one police officer was great and really listened and understood the situation.
- Craig is on the violent patient list and when an ambulance was called a police officer was sent as well for no reason and this really agitated him.

- Craig now feels that the problems are caused by himself. He is scared to have
 a referral back to West Park because he is on the brink of never going back
 again as he feels that if he did and they turned him away again then he would
 commit suicide.
- NECA have been helping him for 10-15 years.

What was Missing?

- Craig feels that if he and Ailsa got help, someone who would really listen to them and they were actually given a care plan then he would be ecstatic.
- He would want someone whom he could see on an individual basis regularly. Someone who could deal with complexities and not 'flip out.'
- NECA should have trained mental health workers.
- There needs to be professionals trained to help patients with mental health problems who also use drugs.

Thank you

Healthwatch Darlington really appreciate the time given by all of the NECA service users who shared with us their real life patient story.



Conclusion

Throughout this report Healthwatch Darlington have focused on the real-life experiences of service users living with an addiction and addicts who are in recovery. We have focused on mental health services and their ability to navigate and use these services in the Borough of Darlington.

The qualitative and quantitative data provided by local service users has helped shape our recommendations alongside the consideration of local, regional and national policy framework.

Healthwatch Darlington identified a number of concerns about local NHS services being delivered by Tees, Esk and Wear Valley NHS Foundation Trust. The services identified have been: Improving Access to Physiological Therapies, West Park Hospital and Darlington Mental Health Crisis Team.

The most important concern that has emerged from this work has been the lack of support that service user's are receiving from local mental health services. There seems to be a number of barriers in the way when accessing care and treatment especially more complex therapies which is usually for the most vulnerable patients. Service users are regularly experiencing early discharge from services due to life factors out of their control. Due to leading what's deemed as an erratic lifestyle, these factors can have an impact on how patients engage with services. Service users feel these factors are not considered and they often find themselves discharged from services. Some service users are unable to receive the treatment they need due to the complexities of their needs and these needs are not being addressed.

We have found frequently throughout our work that service users seem to have negative experiences when dealing with the Mental Health Crisis team. There has been a particular noticeable trend in the amount of service users that feel the crisis team don't always answer the phone and if they do they are not much help.

Our service users have regularly mentioned the frustrations at the lack of information and communication they receive from local mental health services. They are often unsure how to navigate the health care system. They don't know where to go for help and are not aware of other provisions in place across Darlington. We have been told by a number of service users throughout this report they did not know they had a care plan or in fact should have one. They have regularly expressed the feeling that they are not listened too, and decisions are often made without their input. This has highlighted concerns about staff attitudes within local NHS services. Service users feel they are treated differently because of their addiction.

The final thing that Healthwatch Darlington have noticed is the lack of resources and capacity NECA have in dealing with the needs of their services users. Despite this there has been a significant number of service users that feel NECA are the only service that support them, and they are regularly referred back to this service without their mental health needs being addressed. Service users are very frustrated by this as NECA are unable to meet their mental health needs.

Recommendations

Healthwatch Darlington's recommendations have been developed and underpinned using the service users voice. We have taken into account the areas of improvement and considered how these improvements can make a difference to the service users experience in the future.

- Healthwatch Darlington suggest that improvements need to be made to information sharing. Implementation of a new information pack upon access to services could make a difference. Healthwatch Darlington would like to offer support to Tees, Esk and Wear Valley NHS Foundation Trust in developing an information pack with service users at the heart of design. The implementation of a new information pack could include information about service users individual care plans and relevant third sector organisations where they can access further support.
- Healthwatch Darlington suggest providers and commissioners should support and work with NECA closely in order to meet the needs of their service users living in Darlington.
- Further to the development of the 'Mental Disorder and coexisting Substance Misuse (Dual Diagnosis) Clinical Link Pathway document. Healthwatch Darlington suggests that Tees, Esk and Wear Valley NHS Foundation Trust may need to review and develop the 'Care and Management' policy taking into consideration the service user's voice and allowing them a platform to do this. This policy should break down the current barriers that service users are experiencing when trying to access appropriate mental health treatment and support.
- Healthwatch Darlington suggest stronger working relationships need to develop between the Trust, third sector organisations and local services. This will help to develop information and signposting pathways. Healthwatch Darlington would like to hear more about the future plans to implement change.
- Healthwatch Darlington would like Tees, Esk and Wear Valley NHS Foundation Trust to explain how they currently review discharge procedures and care pathways. These procedures and pathways should be closely monitored as early discharge for vulnerable service users and difficulties in access to a range of more complex therapies has been a recurrent issue highlighted within this report.
- Healthwatch Darlington would like to find out how Tees, Esk and Wear Valley NHS Foundation Trust communicate with all staff to ensure that service users are not being discriminated against due to their mental health needs being perceived as drug or alcohol induced. We recommend that this is reviewed as local service users have regularly mentioned throughout this report their concerns about staff attitudes.

Feedback and Comments from Providers and Commissioners

Tees, Esk & Wear Valley NHS Foundation Trust:

"We are acutely aware of the difficulties patients with dual needs may have and continue to work hard internally and with partners to try and improve things.

We note that the group were concerned about waiting times for mental health services. This is something we monitor on a daily basis. Our community teams in Darlington are currently under significant pressure with an increase in referrals, and waiting times are longer then we would like (ie slightly above the trust target of 4 weeks). However, this is actively being addressed. Our crisis service almost always achieves their target of seeing individuals within 4 hours of a referral. Within IAPT, only one patient in October waited more then 28 days from referral to first treatment/first therapeutic session.

We acknowledge that the existing policy & procedure 'Care and Management of Dual Diagnosis' is outdated and the policy is currently under review. The Trust has decided however to move clinical considerations from the policy into the Clinical Link Pathway (CLiP) document. We feel the CliP is addressing barriers that service users are facing quite well. The aim of the CLiP is to provide practitioners with a visual toolkit that they can use in their everyday practice. Practitioners as well as service users feel that the CLiP document is a positive step in the right direction.

The Trust is keen to work together with Healthwatch Darlington to develop an information pack for patients as offered in recommendation one.

Tees, Esk and Wear Valleys used to provide substance misuse services in Durham and Darlington. When this was still the case it was much easier to maintain close links between mental health and substance misuse services. We acknowledge that after losing our contract in substance misuse there were some difficulties in joint working between the two organisations. Over the last years our working relationship with NECA has however very much improved. NECA provides in reach work into West Park Hospital and is usually invited to formulation and care planning meetings on the wards.

Until a few years ago we had advanced dual diagnosis practitioners that were separately commissioned. We have lost this funding and acknowledge that as a mental health service we have a responsibility in maintaining these links between the Trust and third sector providers. The Trust has therefore initiated a Dual Diagnosis Network for Durham and Darlington and provides administrative support as well as rooms for this network. The network has been meeting bi-monthly with an average attendance of 30 practitioners from the Trust, other providers as well as police.

We are mindful that relationships and links can always be improved but I feel that we are certainly heading into the right direction.

We are aware that service users with substance misuse and comorbid mental health problems face difficulties in accessing psychological therapies and are often discharged earlier without appropriate discharge plan. This is a general theme across

the country and the National Institute for Health and Care Excellence (NICE) has been highlighting these problems in their national guidance.

The reasons for these problems are very complex and include political and commissioning factors that we as a mental health organisation cannot change. We are however trying to constantly work on factors that we can address, such as staff attitudes and rigid processes that are inappropriate for this vulnerable group of patients.

The Trust has a training programme that aims at understanding knowledge and understanding of the needs of Dual Diagnosis patients. We can assure you that discrimination and negative attitudes inside our organisation are not tolerated. Whenever staff act incorrectly they are challenged. We cannot always change prejudices and negative attitudes of staff but we can challenge staff whenever patients are treated unfairly because of their substance misuse problem."

Public Health:

The report provides an insight into the complex nature of treatment and recovery and the experiences of individuals who are experiencing addiction in Darlington and the difficulties that they face in their recovery journey. The report will help inform the work we do with the current provider in improving the current services locally but also will inform the design and tendering of these services by the authority in the future.

What happened next:

Healthwatch Darlington had a meeting with Tees, Esk and Wear Valley NHS Foundation Trust to discuss the contents of this report and to hear about good practice.

We were told the Trust have made changes to the crisis team telephone line which no longer goes to West Parks Hospital switch board but now has its own stand-alone telephone line. The Trusts long term ambition is to leave no-one waiting longer then 1 minute before someone answers the phone. The new telephone line is in implementation stage, so staff capacity is currently being monitored and tested in order to achieve calls being answered quicker. Healthwatch Darlington was really pleased to hear about these developments.

The Trust told us that the Care and Management of Dual-Diagnosis' policy has now been updated. See appendix for further information.

We were told that additional protocols for dual-diagnosis patients/service users are in place. These protocols are to ensure that discharge is handled carefully with the view to move patients on with a 'Keeping Well Plan.'

When Healthwatch Darlington asked about service users care plans we were told development work to improve the process of completing care plans is happening this

year. We were really pleased to hear this as care plans was a frequent mention within our report.

The Trust gave Healthwatch Darlington further reassurance that service users will be listened too if they have concerns about staff attitudes or discriminatory behaviour. They told us that concerns should be reported to the Trust so that they can be investigated.

Healthwatch Darlington will be working with the Trust and inviting NECA to collaborate with us to design an information pack/leaflet which will provide patients/service users with the information they need to use mental health services. The Trust would like to involve service users and Healthwatch Darlington will be approaching NECA to arrange this. The Trust have suggested that information about raising concerns and making a complaint should be included. Healthwatch Darlington look forward to developments in the future.

The Trust have recognised that further development work is needed when it comes to information and signposting. Healthwatch Darlington have told the Trust about the Living Well Darlington directory website which a useful resource for signposting. The Trust welcomes working with third sector organisations and providers but also feel this needs to be tackled with a multi-agency approach.

Healthwatch Darlington asked the Trust about staff training and service users involvement. We were told that they have voluntary peer mentor roles which are open to service users to apply for, these roles provide patients and service users with a peer mentor. The Trust have also told us that the Dual Diagnosis Network is open to service user's representatives. Healthwatch Darlington are pleased to hear that service users do have opportunities to be heard. We look forward to hearing about future developments for service users representatives for dual-diagnosis patients living in Darlington to be involved.

Moving forward:

- Healthwatch Darlington will be working collaboratively with Tees, Esk and Wear Valley NHS Foundation Trust and NECA to engage service users with the development of a new information leaflet/pack which will include information about complaint procedures, care plans, keeping well plans and further information.
- Healthwatch Darlington will be sharing feedback with Darlington borough Council about information and signposting and how the Living Well Darlington directory which could possibly help with this.
- Healthwatch Darlington will be sharing information about service user opportunities to attend the Dual-Diagnosis network and to be a volunteer peer mentor.
- Tees, Esk and wear Valley NHS Foundation Trust will continue development work to improve the crisis line telephone line.
- Tees, Esk and Wear Valley NHS Foundation Trust will continue to develop processes to improve care plans and how these are completed.

Acknowledgments

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We would also like to thank our fantastic team of volunteer Health Connectors for their support in our engagement work with a special thank you to Gill Waite & Lorraine Dunn who helped conduct case study interviews. We appreciate your time given to this research project and value your involvement.

Reference:

Better Care for people with co-occurring mental health and alcohol/drug use conditions:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/625809/Co-occurring_mental_health_and_alcohol_drug_use_conditions.pdf

TEWV Business Plan:

https://www.tewv.nhs.uk/content/uploads/2018/08/short-summary.pdf

TEWV Care & Management of Dual Diagnosis Policy

https://www.tewv.nhs.uk/content/uploads/2018/09/Care-and-Management-of-Dual-Diagnosis.pdf

Mental Disorder and co-existing Substance Misuse Clinical Link Pathway (CLiP)

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