In Good Mental Health
Feedback from public event at The Assembly House, Norwich
6pm-8.30pm on Monday 19 November

As part of a review of Mental Health services in Norfolk and Waveney a number of public events were held to give stakeholders the chance to:

- hear about the review
- give their views about where Mental Health support is and is not working
- influence the development of a 10 year Mental Health strategy

Three events were arranged and widely publicised through the media and social media, through primary care, the hospitals, the voluntary sector and the CCGs in the area. For the Norwich event, 89 people pre-booked through the eventbrite page for the event and on the day we had 45 people in attendance. The presentations were from;

- David Edwards OBE, Chair, Healthwatch Norfolk
- Dr Liam Stevens, Chair of Great Yarmouth & Waveney CCG
- Alan Hopley, Chief Executive Officer, Voluntary Norfolk
- Amanda Green who gave a personal perspective on mental health support

Table discussions were held and feedback was gathered against the following questions:

**Workshop One: Your experiences of local Mental Health support and services:**
What is working? What needs to change? What are the current issues or barriers?

**Workshop Two: What does future Mental Health support look like?** How would these changes make a difference to you?

All feedback is to be independently reviewed and used to inform the draft Mental Health strategy. This draft will again be presented for further public and stakeholder feedback. Feedback from all events has been recorded against the following themes:

1. Complex, slow and hard to navigate processes
2. Poor integration of care
3. Issues with quality and consistency
4. Concentration on treatment rather than prevention
5. Community care not fully utilised
6. Other points made

Please note: The following are views expressed by individuals who attended this event which we have recorded verbatim. Where the written feedback was, in isolation, not clear we have included context by adding <notes>. However this was not possible for all the feedback and so, where we have not been able to add context, the written comments have been recorded here verbatim.
1. **Complex, slow and hard to navigate processes**
   Services can feel overly complicated and difficult to move through for service users and carers, as well as for health and care professionals.

   1. The reorganisation of Together, Mind and St Martins into Norfolk Community Housing Support has been a shambles. Experience staff were lost. A good person-centred service has been replaced by a one-size-fits-all approach. People do not know if they would still get help and if so when. Very distressing – a bomb has been put under a good service and now personal budgets are being cut so less help!

   2. Defensive culture of NSFT must change. Mistakes must be acknowledged and lessons learnt.

   3. Drops between 186 deaths last year to 146 deaths this year **cannot** be declared an improvement.

   4. Access to services must be simpler and pathways clearer.

   5. It should be easier to call mental health professionals.

   6. Not all families and carers have the financial resources to be able to visit and support their loved ones if they are placed out of county – we need local services for people.

   7. One carer said they were ignored by NSFT when they said their son was unwell and going to end-up in crisis. Her son went on to have a psychotic episode, which could have been prevented or better managed had she been listened to.

   8. Young GPs seem to have more training, awareness and understanding of mental health. It is pot luck whether you get a GP that understands and is interested in mental health though. As a consequence, the responses that people get when they talk to their GP and try to access mental health services vary considerably.

   9. There should be one list of the mental health services available – we should make sure that all health and care staff know about it and we should promote it to the public.

   10. If a person is under the care of NSFT then they can get support in a crisis. If someone is not, then they invariably end-up going to A&E.
11. To improve access to mental health services we need to improve support to GPs, nurses, receptionists and other people working in primary care as this is where most people go when they need help. We need to improve training to the primary care workforce so that people’s first experience is more positive. We also need to consider what support primary care can provide or ‘prescribe’ people whilst they are waiting for assessments or care from mental health services.

12. To improve access to services for people living in rural areas we need to go to them, with services being provided in either community settings or using mobile clinics. This can be expensive, but it is equitable and it will help to make sure that people get the care they need.

13. The group had mixed views on the use of technology. There was broad consensus that technology can be good for keeping people healthy and well, when people have low level needs and to support people are they’ve received treatment from formal services. However, there was concern that technology is not good for people in a crisis, that it may just not work in rural areas and that there are groups with certain conditions that it’s unlikely to help.

14. Clinicians in physical health services should be able to easily refer people to mental health services, so that they don’t need to tell people to go back to their GP for a referral.

15. There needs to be rapid escalation for crisis and this should be 24/7, working with the scaffolding already around the person. There need to be good care plans accessible to all relevant people.

16. Prevention of suicide – cannot stop all people but needs to be education, safety planning and tools.

17. Don’t let finance and politics get in the way of multi-agency working

18. Access in terms of transport – staff/professionals need to go out to people

19. IT systems don’t talk to each other.

20. How can homeless people access the support they need?

21. Clinical partners could help support diagnosis backlog.
2. **Poor integration of care**

Patients/service users & families find care to be disjointed, fragmented & confusing, with a lack of cohesion and communication between services, resulting in individuals 'falling between cracks'.

1. If you are in crisis you might get help (possibly) if you are a bit anxious and depressed – well-being service. All this in between with enduring mental health problems fall through the gap.

2. People with multiple problems should be helped – they are not helped by anyone as have more than one problem.

3. How are you going to make disparate organisations work together? Too much money is spent on consultations – internal inquiries surely tell you enough.

4. Protocol – where do you go when your family member is an adult?

5. <needs to be more> support for mental health workers. Not enough team work within the NHS – impacting on staff morale/sickness. Overworked as a team. Community Psychiatric Nurses (CPNs)/Crisis team <needs> more staff. Closer alignment with DWP.

6. Housing services need a better understanding of mental health conditions. One carer said that their son was going through a mental health crisis and so his behaviour did not meet the standards required in his tenancy agreement. He was deemed to have made himself intentionally homeless by behaving as he did and so he is no longer eligible for support with housing. The carer felt that this was wrong, because his actions were not intentional, he was in crisis and could not control what he did.

7. Some attendees said they think that people with mental health conditions currently get passed around from service to service, with no one service taking responsibility for the person who needs care.

8. The benefits system and the people working in it need to have a greater understanding of mental health. For example, people with mental health conditions are likely to find attending meetings difficult or stressful, and so it is unfair when they are sanctioned for arriving late.

9. Sharing data between organisations is really difficult. Lorenzo, the computer system used by NSFT, does not work with other computer systems, such as SystmOne or Liquid Logic.
10. There should be one health and care record for people – it should include contact details for the individual and their family / carers. At the moment staff waste time contacting colleagues from other organisations trying to find up-to-date phone numbers for service users and their family / carers.

11. <we feel that> triage of care is non-existent. Confidentiality excludes carers.

12. <there is> limited access to therapies. Personal budgets are restrictive.
   <patients are> often prescribed medication <with> limited alternatives

13. <you should> integrate Neuro Developmental Disorder (NDD)pathway with MH services properly.

14. Community mental health services should be built around GP clusters and include access to assessment so no onward referral is ever necessary.

15. There needs to be access to notes/crisis plans across the system. Social care needs to be more closely linked to health.

16. Police and ambulance service personnel have been sensitive in some cases. But there needs to be thought about the impact of police involvement and the criminal prosecution of people with MH issues.

17. The balance between medical interventions and support is not right. Medication manages/suppresses but it’s the support that makes the difference and there needs to be a partnership between the two.

18. How can we make this work with all the barriers that come out of the complex landscape within the STP?

19. There is a high level of referrals into service and limited time in primary care.
3. **Issues with quality and consistency**

Service users expressed concerns over inconsistent, slow and poor quality care across Mental Healthcare services in Norfolk & Waveney.

1. People with ASD need strategies to help cope with life – this is a continual process as every situation is different.

2. When families have a mentally ill family member that family are exhausted, desperate and need so much support.

3. Everyone is an individual. They need help and continual help if they have a lifelong problem e.g. ASD. They need to see someone who knows and understands ASD. People getting the correct help this would de-stress the other members of the family

4. Far more trained (highly trained) staff in mental health service. Mental health is highly complex and needs incredibly intelligent and highly trained staff in abundance.

5. Continual care should decrease significantly crisis care. Crisis care should be long term. For many it may need to be against their wishes but alongside loving/concerned/

6. Not to wait until crisis until any action is taken. To support families when their adult child is in crisis and to continue to have a dialogue with them. Families know their children better than the psychiatrist.

7. Frontline staff at NSFT are seen as caring. There was a concern about morale of staff at NSFT.

8. One person said that the ‘radical re-design’ resulted in lots of experienced staff leaving local mental health services.

9. One carer said they felt the level of support available has diminished over the past ten years. They thought that this was because there has been a reduction in funding over that time. For example, people now have much less contact with their care coordinator as they have bigger caseloads.

10. A carer and a mental health professional said that NSFT’s services do not have the right culture and that some of their buildings are not conducive to recovery. For example, Hellesdon is grey and depressing – and was compared by one attendee to a service in London which was bright and where
the staff wore Hawaiian shirts to work. One person said “It’s the culture at NSFT that needs to change most”.

11. One carer felt that their right to understand where their loved is located is not being met. They said that during a time of crisis their loved one withdrew consent for them to know where they were. They did not feel this was right and that NSFT need a different approach to data protection and consent, and that staff need training.

12. Mental health professionals need to have the resources to do their job.

13. Mental health professionals too often get drawn into crisis management rather than providing therapeutic support, and as a result some of the resources which are available to help people to recover aren’t used very often, such as gardens and kitchens which NSFT have.

14. There are gaps in services, particularly for young people and young adults whose conditions are not severe enough to meet the thresholds for NSFT’s services.

15. People are moved on too quickly and when they still need support, particularly from acute services.

16. One person said that the bed review was wrong and that we need more beds in Norfolk and Waveney.

17. One person said that CBT is effectively not being provided in Norfolk and Waveney at the moment.

18. There needs to be more respite care for carers of people with dementia.

19. Dual diagnose for people with mental health problems and alcohol misuse problems is important. One person said that the Recovery Partnership was great, but the new service which has been commissioned is not as good.

20. We need to ensure continuity of care for people, and communicate with people and their carers if there are changes to staffing, for example if a member of staff leaves or is unwell for an extended period.

21. Mental health professionals need to provide more personalised care, co-producing each individual’s care plan with them. They should also be better at involving family members in an individual’s care. Training is needed to achieve this cultural change amongst the workforce.
22. Talking therapies don’t work for everyone. The recovery model works well for some people, but not everyone, and we need a services that work for everyone.

23. We need a range of services for people with different learning styles – people might not engage with one approach, but they might with another or they might engage at a different time. Mental health professionals need time to get to really know people so that they can understand what treatment will work. We need to continue to re-evaluate with service users their treatment as needs change over time.

24. One carer said that NSFT needs better management practices in place to ensure they know where their staff are (and that colleagues can see each other’s electronic calendars), that their lone working policy is implemented, and that better records are kept. Meetings about individual service users should be better managed, for example everyone in the room should introduce themselves and there should a clear record of the decisions made.

25. We should give carers a PIN number so that mental health services can be sure that people are who they say they are when they call or visit.

26. Mentally ill people will often say what they know the professionals need to hear. Dialogue with families must be listened to in equal measure.

27. Neurological illness needs care and support – needs triangulation/transparency/honesty/education and long term therapies and strategies. So so so much investment at the ground level NOT consultancy NOT CEOs.

28. Not sharing care plans with family.

29. Not having staff capable of working with particularly intelligent children/adults.

30. <needs to be> Long term care or severe mental illness (SMI).

31. Stop putting people through benefits assessments processes. How many times can you measure someone? Tribunals: needs support from professionals. Not helpful to constantly <have to> justify needs. <think about> the wider impact on family.

32. Assessments are delivered by agency distant from mental health support.

33. Crisis – 4 day response. The response is slow. 24/7 <coverage> is needed. Only Monday to Friday <currently>. 111 offers limited support and not enough
time to deliver help. Geographical coverage – inconsistency of care. <Patients have to offer> repetition of story/case history.

34. There needs to be a pure crisis team that does what it says on the tin with a specific number.

35. Continuity of care is very poor. Crisis Resolution and Home Treatment Team (CRHT) offer limited response and assessment.

36. Carers support service is fragmented and the complaints process is ineffective.

37. There needs to be long-term care with consistent, regular contact

38. People with SMI – they are ill for life and should not be discharged

39. Services for people in recovery – there needs to be a step down provision.
4. **Concentration on treatment rather than prevention**
View that there is a lack of services focusing on preventative measures, with current focus heavily weighted in downstream treatment

1. As with physical illnesses PREVENTATIVE measures should be taken.

2. Men between 16 and 30 should be given yearly mental health checks and then given instant support as we know this is where a large proportion of mental health patients lie.

3. People are living on a knife edge. Managing support long-term. Nothing to support people with severe mental illness (SMI) who need a voice.

4. We need to focus on prevention of mental health problems and keeping people healthy and well. It is costing us millions having services that focus on treating people, and more importantly our system is causing significant damage to people’s lives.

5. In particular, one attendee said we need to focus on psychosis because it damages the brain and so every time someone has a psychotic episode their needs get more severe.

6. Lack of services (preventative) when needed. Too long waiting time. Not listening to family re: young adults’ capacity

7. People need to be treated at an earlier stage – more intensively.

8. <there needs to be a> transition from CAMHS

9. There needs to be activities to support independent living, with skills training

10. There should be life-long access to education. Still lagging behind physical health services.

11. There needs to be early preventative support with good information about managing your mental health. When given medication you need to talk about recovery.

12. In recovery the right word? Does it make people feel they are failing if they don’t recover?

13. There needs to be early support before crisis point

5. **Community care not fully utilised**
Feeling that service users are signposted to secondary/formal care settings too easily, with a lack of offering of care in less formal, community support settings

1. We need more trained staff. This would lead to staff being less stressed a smaller caseload and then they would be able to give the correct care and support – often this needs to be lifelong.

2. Barrier to change: voluntary sectors being linked to NWS etc.

3. Not all GPs can cope/familiar with SMI/MH Needs (prescribing). <needs to be> professional to professional advice. A dedicated MH worker in primary care.

4. Social prescribing – to deal with social needs.

5. Community based work is good and needed, but it can’t all be provided by the VCSE sector – we need mental health professionals working in the community.

6. The transition of care from statutory services to VCSE organisations does not always work well. Problems can be exacerbated when a VCSE organisation is applying for funding or waiting for a grant, and so not able to keep / take on staff to provide care.

7. A couple of people noted that the thresholds for formal services have gone up.

8. The group felt that the public don’t know that much about the range of services and support on offer, particularly from the VCSE sector, for people with mental health conditions.

9. Social prescribing is a good idea for low level needs, but has to be used appropriately and should be preventative.

10. There should be longer-term placements for people with serious conditions, not institutions, but community based approaches.

11. The pay and terms and conditions of people working in the VCSE sector are not as good as those working for statutory services.

12. One carer said that the peer support their son has received from the VCSE sector had worked well.
13. In addition to the VCSE sector, is there more that needs to or could be done with businesses to support both customers and employees with mental health conditions?

14. Dementia carer <needs> extended primary care appointments

15. What happens when a carer cannot care?

16. There used to be a safety net. All used to exist:
   a. NHS rehab unit for psychosis
   b. Long-term stays/wards
   c. Occupational therapy
   Now no care in the community for people in isolation

17. There is a financial burden for visiting MH patients out of area.

18. Some people don’t have network to underpin community support – rurality?
   Some people need help to access support. There also needs to be evening and weekend support. Need to remember the rurality of the whole area.

19. There needs to be a solid outreach team.

20. Communities need to be focussed on wider mental wellbeing. People should be encouraged to take the first step. There needs to be a triangle of are – cares/professionals/SUs

21. For supported housing/living there needs to be more staff/CPNs/Outreach teams.

22. Workforce planning: for instance there should be a personal budget - access to staff

23. <we think there is> Limited choice and availability. Need to scope agencies to carry out duties.

24. The presentation (at the event) was inappropriate and not reflective of the wider experience

25. Education: More people should be taking in schools.

26. ADHD is a common condition and needs sustained investment - ASD conditions. Autism provision needs to be in place. Guidelines around autism diagnosis are not being met (e.g. NICE)
27. Cannot let the smaller charities fold. Need to be in partnership with VCS and secure this. Need to develop a relationship with social prescribing.

28. There is no carer respite in Waveney. There is no MIND support in Waveney.
6. Other points made

1. Son was offered help if he went to prison. That is very bad. He should be offered help now. Also said he would get help if he was an alcoholic or drug addict, so he should become one.

2. Recovery in the bin:
   1. Some people can never recover
   2. Used to justify savage cuts
   3. Most ill made to feel guilty
   4. NSFT has more peer support workers than any other trust
   5. Worst trust in the country
   6. Used to justify cuts to services for more ill
   7. Assertive outreach
   8. Homeless
   9. Crisis team
   10. Deaths doubled

3. There must be parity between care for mental health/support for mental health and cancer care.


5. Serious Mental Illness – never discharged. There is no such thing as recovery but a lack of long term care.

6. Hellesdon – needs more acute beds

7. Carers – needs an expert on needs of loved ones, proportionate support, carers advice line <offers> slow response.

8. Please listen to carers! We do know what help is needed – we live with the problems on a daily basis.

9. Some people said they think there has been a reduction in the funding of mental health services and were very concerned about the amount being invested in services.

10. More broadly, a couple of people were very concerned about the wider reductions in public services and the impact that this has had on people’s
mental health and wellbeing. They noted that the wider determinants of health are really important and affect people’s mental health as much as their physical health. They said that austerity is a political choice.

11. One person said that it was important we hear individual’s experiences of local mental health services, but that our strategy must be based on a broad range of evidence and not extrapolated from the experience of a small number of people.

12. There is not parity of esteem or funding between physical and mental health services.

13. A few people said that we should use our own staff to plan and commission services, rather than external consultants.

14. A few people said that much might change over the next ten years, so our strategy will need to change and it might be more sensible to plan for a shorter period of time.

15. One person said we should stop asking people what is wrong with mental health services and just get on with fixing them, as that is what we pay managers in the health service to do.

16. What are we doing to learn from how mental health care and services are organised in other countries? For example Iowa does lots of rural outreach work.

17. Everyone has the right to the same quality of care

18. It is difficult to make a complaint and this causes a worry this will impact on care.

19. Attitude of staff - <we feel they> don’t care <and this> impacts on carers, carers assessment is ineffective. Staff need to interact with people. There needs to be a carers navigation system.

20. Everyone should be receiving <in the future> the same level of care support that Amanda (the presenter) has had.

21. People have ups and downs and services needs to be responsive to people’s change in moods

22. We should reduce the reliance on long-term care, <focus on> the resilience of the carer and recognise the warning signs.
23. Care planning can reflect needs but do not alleviate problems

24. Cycle of assessment for joined up care: the regularity of communication with professionals <building relationships can take time and unique needs can be masked,>

25. Professionals should recognise the expertise of/and involve carers

26. Those who shout the loudest <comment unclear>

27. There should be a UK-wide campaign recognising mental health needs.

28. MH impacts the benefits system, housing <and the> government has caused divisions. MH links to the government – responsibility from top level to local delivery.

29. DWP – should have mental health liaison officers so people only have to tell their story once to health, DWP, social care. People should be allocated to deal with people’s needs – not done privately. There needs to be more advocacy and local links. The system should advocate in behalf of the individual. Currently provided by VCSE?

30. <the system should> accept with judgement of professionals with less money on management and more on frontline care. No big pay offs!

31. What does support look like?
   1. Someone to go to, to be listened to
   2. Counselling vs. analytical therapy which is solution focussed
   3. Short term time limited support
   4. Good quality support in a community setting with flexible/weekend support
   5. A whole family approach with a key worker
   6. People are scared off of mental health and need to engage about it

32. What does support look like for employers?
   1. A whole person holistic approach
   2. Employers engaged
   3. Social networks
   4. Mental health education in schools
   5. Mindfulness in schools and communities
   6. Whole family approach to mental/physical
   7. Drop-in centre/partnerships
   8. Four day working week
9. Being OK to slow down
10. Leading by example (slowing down vs. being very busy all the time)
11. Managing mental health is a lifetimes work
12. Mental health assessment should be available

33. What works well:
   1. Recovery college – to learn coping strategies
   2. People taking responsibility – empowering people to understand their mental health – use technology or Apps
   3. Opening up the conversation about MH to overcome the misunderstanding and stigma around mental health
   4. Individual interactions with clinicians/practitioners. Lots of caring health professionals
   5. Mental wellbeing services
   6. Dementia services
   7. Listening is taking place.
   8. Wellbeing services have made a difference
   9. Norfolk mental health apprenticeship training

34. Recovery College: This offers confidence building. Focus on the individual and what they want. Taking responsibility and ownership of themselves with support. Gives tools and strategies to cope when things are not going well. Courses and workshops. Experience of work at the service users pace as they needed it. Peer support staff – working with people who have been through the same/similar experiences.

35. <it needs to be recognised that> medication is not the only answer and is only a sticking plaster. People need:
   1. Therapy
   2. Community support
   3. Education
   4. Advice to manage mental health
   5. Wellbeing service (therapeutic service)
   6. Proper gateway support

36. Our experience:
   1. NAF
   2. Stress related anxiety. Mother with dementia (95). No help for mother.
   3. Daughter 39 with MH problems and severe learning difficulties (no help)
   4. Care support self-funded
   5. Only option for moth was to section
   6. Can’t get in a home
   7. Not taking medication
8. Mother’s non-compliance.
9. Social services: talk to mother, recommend a home and medication offered
10. Raised issues with nurse
11. Should be on contact vs. multiple
12. Needs to be carer support
13. There should be housing officers for residents with MH issues to be referred to

37. Mental health problems are not a disease and there needs to be better information (e.g. from the GP)

38. The first point of contact for help most understand MH problems rather than a GP which medicalises the issue.

39. What needs to change?
   1. More events like this. Engagement events work well as long as used properly.
   2. Stronger leadership
   3. Get political – still accept very low quality of service for MH
   4. Service redesign involves more services users
   5. Cannot look at MH in isolation
   6. Needs to start early, in primary school
   7. Peer support targeted at everyone’s recovery
   8. Increased investment/resource
   9. A&E needs to be adapted to support NH patients
   10. Crisis team needs to respond positively in a pleasant environment
   11. Standardised approaches needed – consistent services required
   12. <more> staff training and development
   13. Carer and service user engagement with NSFT needs to improve at all levels and it has to be meaningful (upstream engagement required)

40. Home treatment should be separate. The system needs to be redesigned around people who are in crisis. <there needs to be> deinstitutionalisation, invest to save to be able to change services.

41. The voluntary sector needs to be resourced appropriately

42. Personal budgets offer choice and empowerment

43. Dedicated staff are working in adverse conditions. There needs to be a career path for valued, trained staff

44. <future MH support includes> community matrons
45. There needs to be a clear set of values, leadership and reflection and supervision

46. <a general point about> “failure of government, commissioners and Healthwatch

47. <A feeling that some staff are> making clinical decisions based on bed availability

48. How to measure best practice? Outcomes!

49. Need to look at other ways of accessing support such as online tools, link workers in surgeries

50. CCGs are not very transparent

51. Promote mental health vocational careers