No assumptions: a Narrative for coordinated care and support in mental health

Introduction

This document describes some critical outcomes and success factors in the care, support and treatment of people who have continuing mental health needs, from their perspective.

It is a draft for comment and feedback.

We hope that when finalised it will help commissioners and service providers to organise person centred care for mental and physical health, and to know when they are achieving it.

NICE Quality Standard 14 on service user experience of adult mental health services, developed with people who use or work in the services, includes the quality statement:

“People using mental health services, and their families or carers, feel optimistic that care will be effective.”

We take this in the widest sense. To be optimistic about their care and support, people with experience of mental health problems want to see joined-up, preventive approaches that do not abandon them at key stages. They want their mental and physical health needs to be addressed together in a whole person approach.

This means mental health provision sits squarely within ‘integrated care’, which is defined for England as ‘person centred coordinated care’ in the Narrative coproduced by National Voices and Think Local Act Personal and adopted by all system leading organisations. Care and support planning is central to this Narrative.

Linkage to the national Narrative

This document is designed as an extension of that Narrative. The two should be used together.

It is our view that all the principles described in the Narrative apply to people with continuing mental health needs, as to other sub-groups with health, care or support needs.

As a generic tool, however, the Narrative may be missing some of the key features of this group’s care and support needs that are particular to managing mental health and wellbeing.
From listening to people with lived experience of mental illness, and with organisations working with them, it is clear that significant weight should be attached to, for example:

- the need to be free from stigma and discrimination
- the strong desire for and importance of peer support as an effective and equal form of provision to clinical and mainstream services
- the potential positive impacts of involving people with lived experience in the design and commissioning of services, and in their operation, and
- support for prevention and self management to stay well and avoid crises
- the responsiveness of staff, services and support organisations to people’s fluctuating needs – particularly so that crisis episodes are anticipated and well managed.

As this document was being produced, the Crisis Care Concordat, which commits public services to work better together to help people experiencing a mental health crisis, was published.

This contains a series of statements coproduced with people with lived experience by Mind, the majority of which we have endeavoured to build into this document.

Your feedback is important

This document was commissioned from National Voices and TLAP by NHS England.

This is an early draft. We intend to develop and improve it significantly through multi-stakeholder conversations and events.

We are therefore inviting you to give us feedback by Tuesday 11th March 2014 by email to: narrative@nationalvoices.org.uk putting ‘mental health’ in the subject line.

Here are some key questions to get you started:

1. Do you agree that these statements reflect things that are very important in supporting people with mental health problems?

2. Can you suggest improvements to any of the existing statements?

3. Should any of these statements be dropped?

4. What is missing?
**My daily life**

I feel safe.

I want a home, not just ‘accommodation’.

I have the same goals as other people: friends, meaningful activities and close relationships. These are recognised by support services, who work with me to achieve them.

My strengths, skills and talents are recognised and valued.

I am able to talk about my mental health without being stigmatised or discriminated against.

**The support I need**

I can refer myself to support services without waiting for a medical referral.

I have rapid access, within a guaranteed time, to talking therapies.

I have a choice of talking therapy so that I can find one appropriate to me.

I have the opportunity to make use of a personal budget for my support needs, for example to help my recovery or to stay well.

The people who support me over time work with me to build up my own capacity to stay well, manage any ups and downs and stay socially connected.

My GP and practice nurse are trained in mental health awareness and able to help me as a whole person.

Prescription decisions, and reviews of my medicines, take into account both my mental and physical health needs. The potential effects of medicines, including how they react with each other, are assessed and explained.

Services and professionals do not stigmatise me, either according to my health symptoms or my cultural or ethnic background.

Services and professionals do not make assumptions about me. They listen to me and don’t leap to solutions.

Staff are skilled in supporting me to be involved in decisions at the right level. They are ready to respond flexibly and change the way they work as my needs change.

Those who work with me bring optimism to my care and treatment, so that I can be optimistic that care will be effective.
The staff are skilled in supporting me to be involved in decisions at the right level. They respond as my needs change.

People focus on me as a person, not just my behaviour. My behaviour is seen in the light of communication and expression, not just as a clinical problem.

**Crisis: before, during, after**

When I need urgent help to avoid a crisis I, and people close to me, know who to contact at any time.

People take me seriously and trust my judgement when I say a crisis is approaching. I can get help fast.

If I have to wait for help, it is in a place where I feel safe.

As far as possible, people who see me in a crisis follow my wishes and any plan I have previously agreed.

If I need to, I can access additional services or change my support without unnecessary new assessments.

As far as possible I see the same staff members during a crisis.

If I do not have capacity to make decisions about my care and treatment, any wishes or preferences I express will be respected, and so will any advance statements or decisions I have made.

I am supported along my recovery journey and not left to ‘crash’ again.

I am supported to use my own talents, interests and strengths to achieve recovery and stay well.

I am supported to develop a plan for how I wish to be treated if I experience a crisis in future.

**The people close to me**

I choose who to consider the people ‘close to me’, who can support me in achieving mental wellbeing.

I am able to see or talk to friends, family or other people I say are ‘close to me’ at any time.
I can determine different levels of information sharing about me with my friends, family and people close to me.

I am confident that, if I need care or treatment, timely arrangements are made to look after any people or animals that depend on me.

**Staff, supporters and advocates that I trust**

My continuing care and support is arranged with people I know, trust and relate to.

Contact with people with their own experience of mental health problems, and of using mental health services, is available as part of my potential support.

This form of ‘peer’ support is equally valued with professional and clinical support.

Peer support is available at any point in my fluctuating health – as crisis approaches or takes over, in recovery, and when I am managing being well.

Groups and organisations led by service users are known to service professionals and used by them as a route to providing peer support.

I am confident that the services I may use have been designed in partnership with people who have experience of mental health problems.

Wherever possible, there are people with their own experience of mental health problems employed or otherwise used in the services that support me.

**Culture**

I experience cultural understanding when I am contact with services and professionals.

People who work with me understand how mental health problems can be triggered and how these are perceived in the culture I come from. The strengths of my culture are recognised as part of my recovery.

My own cultural understanding and explanation of my mental health is respected.

I can find peer support groups and services that understand my culture.
Appendix: core group and inputs considered

The core group involved in production

The development of this document is being jointly led by National Voices and Think Local Act Personal. Members of TLAP’s National Coproduction Advisory Group, who have experience of mental illness, together with organisations including Mind, Rethink Mental Illness and Certitude have contributed so far.

Some inputs considered by the group

2. The Mental Health Crisis Care Concordat, Department of Health and others, 2014.
3. ‘Service users’ experiences of recovery under the 2008 Care Programme Approach’, Mental Health Foundation and Ensun, 2012.
8. ‘Personalisation in mental health: Creating a vision; Views of personalisation, from people who use mental health services,’ Mind, 2009.