GUIDELINES

Improving the experience of care for adults using NHS mental health services: summary of NICE guidance

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This is one of a series of *BMJ* summaries of new guidelines based on the best available evidence; they highlight important recommendations for clinical practice, especially where uncertainty or controversy exists.

Further information about the guidance, a list of members of the guideline development group, and the supporting evidence statements are in the full version on bmj.com.

Excellent service user experience is part of high quality healthcare, as well as a right and a necessity for all service users in the NHS.[1-3] It is especially relevant for people with mental health problems, who often have repeated and/or prolonged contact with services, with nearly a quarter of adults meeting criteria for a diagnosis of mental disorder in England.[4] Moreover, mental health problems are associated with considerable stigma in the health service, and users of mental health services, unlike any other health service users, can be detained and treated against their will under the Mental Health Act.[5] National surveys of mental health service users show that, although most are satisfied with their care, a substantial minority have a poor experience of care and many report finding it difficult to access services especially during crises.[6] Concerns have also been expressed about the quality of inpatient mental health services.[7] This article summarises the most recent recommendations from the National Institute for Health and Clinical Excellence (NICE) on service users' experience of adult mental health services; these recommendations come from the first NICE guidance for which a development group was chaired by a service user (jointly with a healthcare professional).[8]

Recommendations

NICE recommendations are based on systematic reviews of the best available evidence. When minimal evidence is available, recommendations are based on the Guideline Development Group's experience and opinion of what constitutes good practice. Evidence levels for the recommendations are in the full version of this article on bmj.com.

Relationships, communication, and information provision

Work in partnership with people using mental health services and their families or carers, ensuring that you:

- Offer help, treatment, and care in an atmosphere of hope and optimism
- Take time to build trusting, supportive, empathic, and non-judgmental relationships
- Foster autonomy, promote active participation in treatment decisions, and support self management
- Maintain continuity of individual therapeutic relationships wherever possible
- Offer access to a trained advocate
- Ensure that you are identifiable (for example, wear appropriate identification) and approachable
- Address service users using the name and title they prefer
- Explain any clinical language and check that the service user understands what is being said.

Provide comprehensive written information about:

- The nature of, and treatments and services for, mental health problems in an appropriate language or format, including any relevant *Understanding NICE Guidance* booklets
- Support groups, such as third sector (including voluntary) organisations.

Avoiding stigma and promoting social inclusion

- Take into account that stigma and discrimination are often associated with using mental health services
- Be respectful of and sensitive to service users' gender, sexual orientation, socioeconomic status, age, cultural, ethnic and religious background, and any disability
- Be aware of how presentation of mental health problems may vary in service users of different genders, ages, cultural, ethnic, religious, or other backgrounds.

Decisions, capacity, and safeguarding

Develop advance statements and advance decisions[9] with service users if they wish to do so, especially if their illness is severe and they have previously been detained and treated under the Mental Health Act. Document these in their care plans and ensure that copies are held by the service user and in primary and secondary care records.

When a service user has impaired capacity, check his or her care record for advance statements and advance decisions before offering or starting treatment. This is a legal requirement.

Access to care

When referring people to mental health services, ensure that:

- They are given or sent a copy of the referral letter
- They are offered a face to face appointment with a professional in mental health services, which should take place within three weeks of referral
- They are informed that they can change the date and time of the appointment if they wish
- Any change in appointment does not result in a delay of more than two weeks.

Assessment

When conducting an assessment:

- Ensure there is enough time for the service user to describe and discuss their problems
- Allow enough time towards the end of the appointment for summarising the conclusions of the assessment and for discussion, with questions and answers
- Explain the use and meaning of any clinical terms used
- Explain and give written material in an accessible format about any diagnosis given
- Give information about different treatment options, including drug and psychological treatments, and their side effects, to promote discussion and shared understanding

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Previous articles in this series

- Diagnosis and management of the epilepsies in adults and children (*BMJ* 2012;344:e281)
- Donor identification and consent for deceased organ donation (*BMJ* 2012;344:e341)
- Assessment and referral after emergency treatment of a suspected anaphylactic episode (*BMJ* 2011;343:d7595)
- Longer term management of self harm (*BMJ* 2011;343:d7073)

- Offer support after the assessment, particularly if sensitive topics have been discussed.

If a service user needs to wait before an assessment, ensure that this is for no longer than 20 minutes after the agreed appointment time; explain the reasons for any delay.

Community care

Develop care plans jointly with the service user, and:

- Include activities that promote social inclusion, such as education, employment, and volunteering
- Provide support to help service users realise their plan
- Give them an up to date written copy of the care plan, and agree a suitable time to review it.

Assessment and referral in a crisis

For people who may be at risk of crisis, the service user and the care coordinator should develop a crisis plan, which should be respected and implemented, and incorporated into the care plan. The crisis plan should include:

- Possible early warning signs of a crisis and coping strategies
- The support that will be available to help prevent admission to hospital
- Details of where the person would like to be admitted in the event of admission to hospital
- The practical needs of the service user if he or she is admitted to hospital (for example, childcare or care of other dependants, including pets)
- Details of advance statements and advance decisions
- Whether, and the degree to which, families or carers are involved
- Information about 24 hour access to services
- Named contacts.

Hospital care

When a service user is admitted to hospital, greet them using the name and title they prefer, in an atmosphere of hope and optimism, with a clear focus on their emotional and psychological needs, and their preferences. Ensure that the service user feels safe and deal with any concerns about their safety.

Undertake shared decision making routinely with service users in hospital, including, whenever possible, people who are subject to the Mental Health Act.

Assessment and treatment under the Mental Health Act

Detain people under the Mental Health Act only after fully considering all options with them (if possible) and with the family or carer if the person agrees. Alternatives to detention may include a review of their medicines, respite care, acute day facilities, home treatment, and crisis houses.

Explain to them, no matter how distressed they are, why the compulsory detention or treatment is being used. Repeat the explanation if they seem not to have understood or are preoccupied or confused. Ask if they would like a family member, carer, or advocate with them.

When detaining people under the Mental Health Act:

- Give them verbal and written information appropriate to the section of the act used, including “patient rights” leaflets detailing what is happening to them, why, and what their rights are
- Repeat this information if they seem not to have understood or are preoccupied or confused
- Give them, and their family or carer if they agree, information about the legal framework of the act
- Ensure they have access to an independent mental health advocate (which is a legal requirement).

Control and restraint, and compulsory treatment

Use these interventions, including rapid tranquillisation, as a last resort, only after all means of negotiation and persuasion have been tried, and only by healthcare professionals trained and competent to do this. Document the reasons for such actions in the person’s medical records and offer them the opportunity to add their own comments to their notes at a later stage.

Overcoming barriers

Guidance recommendations for healthcare professionals on communication and information sharing (especially when delivering compulsory treatment), and on shared decision making, aim to help improve service users’ experience. To provide service users with continuity of care and clear information on accessing mental health services, communication between primary and secondary healthcare services and between health and social care services needs to be as effective as possible. Improving the experience of care by people with mental health problems will also involve overcoming societal prejudice and related stigma about such problems and the use of mental health services.

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A PATIENT'S JOURNEY

Mood disorder in the perinatal period

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This is one of a series of occasional articles by patients about their experiences that offer lessons to doctors. The *BMJ* welcomes contributions to the series. Please contact Peter Lapsley (plapsley@bmj.com) for guidance.

A woman with bipolar disorder who became pregnant during a long period of severe depression describes how the support of a perinatal team was vital to her postnatal recovery

With a history of depression since my teens, I was finally diagnosed with bipolar disorder in my early 30s, when I was hospitalised with a manic episode in 2008. I was psychotic and dangerously out of control. Shortly after discharge I went into a depression that effectively paralysed me for the next 18 months. I was a shadow of myself, existing (in relentless pain) rather than living. I think you can only use metaphors to try and describe what severe depression feels like—words simply do not convey how bad it is. It was during this episode of depression that I became pregnant. I was shocked and scared when I found out—how on earth would I be able to take care of a baby when I could barely even get out of bed? I remember telling my community psychiatric nurse that I planned to commit suicide straight after the baby was born but that I would try to hold on until then.

At the time, I was taking lithium, which carries a raised risk of fetal heart malformations. By the time I discovered I was pregnant I was told it was too late to come off it, and given that I was seriously suicidal, my psychiatrist recommended I continue taking it. Waiting for the heart scan at 20 weeks was an extremely anxious time. I was referred to the new perinatal mental health service at the Whittington Hospital, London. I was thoroughly assessed by a perinatal psychiatrist at 16 weeks. She told me that I had a 1 in 2 chance of a relapse after the birth. It was around this time that my depression finally began to lift, so learning that the odds of my becoming ill again were so high was very upsetting.

MY OVERALL THOUGHTS

Perinatal mental health teams provide an invaluable service to women at what can be the most vulnerable time of their life

The role of these teams in recognising those women who are potentially at risk, and supporting them during both their antenatal and postnatal period, is critical in the prevention of mental illness. This is all the more reason to further resource and expand this Cinderella service

It would be beneficial for midwives to gain some training in mental health

WHAT MADE A DIFFERENCE TO ME?

Having a specialist perinatal mental health team

Having continuity of care. For example, being seen by the same midwife and obstetrician throughout my pregnancy and after the birth was extremely important

Good communication between professionals and agencies. Good communication was crucial to my care, especially after discharge. Unfortunately, the lines of communication between the hospital, my community mental health team, the liaison team, social services, and even within teams themselves broke down more often than not, and frequently I ended up being the one passing on information. This is surely taking patient led care a step too far

Having compassionate midwives on the ward who had an understanding of mental health

Having a private room postnatally

Prebirth planning

The perinatal team organised a multidisciplinary prebirth planning meeting when I was 32 weeks along, which I, my husband, and all the relevant health professionals involved in my care attended. This included my community mental health team, my general practitioner, and my named midwife. It was reassuring to see all these people in the same room. One of my main concerns was whether to discontinue the lithium so that I could breastfeed. It was very useful to hear the viewpoints of several different professionals, including a consultant paediatrician.

The outcome of the meeting was a birth plan, which contained a sort of contingency plan for the eventuality that I fall ill, along with a list of warning signs that I had identified with the help of my husband. The birth plan proved vital to my recovery after the birth, and I found that my early recognition of the warning signs was half the battle.

The birth

I had planned on having a completely natural birth. Instead, I was induced for almost 30 hours and ended up having an emergency caesarean section. My baby then aspirated meconium and had to be resuscitated. This was very traumatic. The first feeling I had after my baby was born was that I wanted to die because I was convinced that my baby would die. I became hysterical and then went into a state of shock and vomited. My baby was taken to the neonatal intensive care unit before I'd had a chance to meet her, and after that I felt a guilty reluctance to go and see her. This indifference carried on for the next few days as I became completely preoccupied with myself.

I couldn't sleep despite feeling exhausted, having not really slept for two nights, and I had to be given sleeping pills. My mind was racing, and even relaxing music would stimulate me. Fortunately I had my own room, which meant I was shielded to some extent from the noisy, stressful ward. I remember thinking that everything seemed sharper and brighter and that the ward notice board suddenly seemed blindingly red. I became obsessed with the idea of going on daytime television to tell my birth story. I was escalating into mania, and yet some of the midwives on the ward did not seem to appreciate how scary this was for me. I remember one of them saying to me when I told her I thought I was becoming ill, "You don't seem unwell." I replied with something like, "By the time it's obvious to you it's too late for me." I was very agitated and recall texting my sister to say that you have to be acting like a crazy person or killing yourself for people to take you seriously.

The aftercare

My postnatal care involved many different healthcare professionals. This was exhausting and stressful, and having to be seen by new people every day was at times detrimental to my mental health. The two constants were my named midwife, whom I'd seen regularly throughout

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Previous articles in this series
- Juvenile myoclonic epilepsy (*BMJ* 2012;344:e360)
- Gambling addiction (*BMJ* 2011;343:d7789)
- Amyloidosis (*BMJ* 2011;343:d6326)
- Facial disfigurement (*BMJ* 2011;343:d5203)

A CLINICIAN'S PERSPECTIVE

Specialist mental health services have grown in a somewhat piecemeal fashion, influenced by geography, politics, and personality. Although the French psychiatrist Jean-Étienne Dominique Esquirol described postnatal depression as early as 1838, the Section of Perinatal Psychiatry at the Royal College of Psychiatrists was inaugurated only in 1996. In 2004 the deaths of Daksha Emson, a consultant psychiatrist, and of her baby daughter provided impetus for further service development.

This patient came to our newly established perinatal psychiatric service at the Whittington Hospital in 2010. She had not benefited from preconception counselling as advocated by the guidelines of the National Institute for Health and Clinical Excellence and was taking lithium as prophylaxis against relapse of her bipolar affective disorder. Close working with our maternity colleagues ensured appropriate monitoring of the cardiac development during pregnancy. Lithium is associated with several cardiac anomalies, including Ebstein's, with a risk of cardiac defects that is 7.7 times higher than that of the general population.

Dose titration of lithium during pregnancy necessitates close monitoring to compensate for increased blood volume in the second trimester and to detect any other serious disorder—for example, pregnancy induced hypertension or diabetes, suggested by a reduction in glomerular filtration rate. Breastfeeding is contraindicated with lithium.

Medication management is only a small part of the functioning of a perinatal psychiatry service. Liaison with many other professionals from both health and social services is imperative. This is ideally documented at the 32 week multidisciplinary prebirth planning meeting mentioned by our patient in her article.

Risk assessment and management must incorporate mother and baby and the relationship between them. There are other important differences from other psychiatric specialities: puerperal psychotic illnesses have distinctive epidemiology, with the risk of postnatal relapse of bipolar illness being 40-70%. The onset of such an illness is often sudden and the presentation more "organic," with affective lability and visual hallucinations being common.

Perinatal services also have responsibilities to train staff working in acute care. Busy midwives must understand the role of sleep deprivation in triggering relapse, so that women at risk can be placed in side rooms if safe, or provide nursing care to minimise other relapse triggers.

We work collaboratively with our patients, explaining risks of untreated illness and balancing these against iatrogenic risks. Evidence, though accumulating, cannot be acquired through randomised controlled trials.

Controversy still exists regarding the ideal configuration of services. Equity of access in England varies as the 110 beds in mother and baby units are distributed unevenly across the country (number supplied by Professor L Howard, personal communication). Many services have grown from existing liaison services, which in London, for example, allow women living in one borough to receive care in another, but which cannot provide a community based service. Our patient lives outside the borough that has commissioned the Whittington service so should have received only a single assessment by us before return of her care to her locality mental health team. Without specialist input the risk of relapse could have been higher, with potential consequences for her, her baby, and her family and social contacts. And, as so often, prevention is better than cure.

Nisha Shah, consultant perinatal psychiatrist

my pregnancy, and the perinatal team, who came to see me almost every day after the birth during my two week hospital stay. The perinatal team closely monitored my lithium levels and made sure that the midwives on the ward chased up and administered the appropriate medication.

The weekend after the birth, when I was at my most vulnerable, unfortunately coincided with the perinatal team being off duty. Weekend cover was provided by the psychiatric liaison team, who were unfamiliar with my history. I remember recounting my birth story to the two liaison team nurses, telling them it was the most traumatic thing that had ever happened to me. Then, before I had finished, one of the nurses' beepers went off and she left the room without saying anything to me. Shortly afterwards, the other nurse walked out too, again with no explanation. I waited for probably over half an hour, becoming more and more anxious, to the point where I had palpitations and was actually shaking. I eventually stormed out of the room declaring I was going to see my baby and it was only then that they paid attention. The visit from the liaison team did nothing more than aggravate my already heightened mental state. What followed was a series of mental health workers, recruited by the liaison team, who were meant to provide me with one to one support. However, as they didn't seem to be properly trained it was counterproductive. I remember becoming very distressed when one of them came into my room when I was having private time with my family and talked at great length about himself and his career.

Ultimately, what helped me was having continuity of care and a team of specialists who had knowledge of my history and who were able to assess my mental health in the context of my birth. Without the high level of care and intervention that I received during my pregnancy and after the birth, I am certain that my chances of a relapse would have been much higher.

Looking ahead

My baby is now a happy, healthy 1 year old. The first few months were stressful, particularly as my moods were so volatile, but with the help of a very supportive husband and family and continuing treatment from my community mental health team (which included valuable psychological therapy) I managed to narrowly escape an episode of mental illness, and I have remained well ever since. I count myself very lucky. Not all women have the supportive family that I have, and most women who become ill during pregnancy or after the birth do not have ongoing mental health support. This problem needs to be resolved.

My husband and I are now thinking about the possibility of a second child. Although I am still taking lithium, my situation is very different from that of two years ago. I am well and now have the opportunity to plan for the next pregnancy. When the time comes, I hope that I can access the perinatal mental health service once again.

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