
Rethink Policy Statement 27

Confidentiality and information sharing

Rethink Policy

Rethink believes that personal information about the health of a person with a severe mental illness should not be shared with other people without their consent unless there are justifiable grounds on a "need to know" basis. Informal carers should be given sufficient information about the illness of the person they care for to enable them to provide care effectively.

Policy development

- 1 The Code of Practice under the Mental Health Act should provide guidance about sharing information in relation to mental health care along the following lines:
 - a private confidences from service users to staff should not be shared with their informal carers;
 - b personal information provided by service users should only be shared with people who need to know it;
 - c particular care should be taken not to pass on damaging information without good cause, eg details of criminal history, except where this suggests continuing risks, eg of serious violence;
 - d the advantages to sharing information with people who provide them care should be explained to service users, eg to enable their informal carer to support them effectively. If they are unwilling to share information when they first become unwell, they should be encouraged to do so when better;
 - e an informal carer should be given sufficient information to enable them to provide care effectively notwithstanding a service user's refusal to consent to sharing that information with them;
 - f if a service user does not wish their informal carer to be given information about them, the informal carer should nonetheless be offered
 - an explanation of the agency's confidentiality protocol
 - information that is not confidential, eg on medication, coping at home, organisations that provide information and support, such as **Rethink**, and on the assessment of their own needs
 - support to provide care effectively;
 - g professionals should also share information with service users, eg about the side-effects of medication; failure by professionals to provide information that service users need to know must be challenged.
- 2 All agencies providing mental health services should have a similar approach to sharing information, recognising that some personal information needs to be shared between agencies to enable effective services to be delivered, eg so that they can work closely with each other.
- 3 Professionals should be trained to recognise the need to provide general information to concerned informal carers to enable them to provide support and relate effectively to the person they care for. Confidentiality should not be used as an excuse not to listen to informal carers or to inform them about general issues. Neither listening nor providing general information breaches

confidentiality.

- 4 Information given by informal carers in confidence at meetings or in writing should not be passed on to the service user without the informal carer's consent.
- 5 the following views expressed by service users need to be borne in mind:
 - there may be times, when service users are acutely ill, when it may be necessary to disclose information about them without their permission, but a reasonable attempt should be made to encourage them to share information before it is disclosed to people who need to know it
 - service users should be informed if information has been disclosed without their permission at the earliest opportunity
 - information about service users should only be disclosed to people who need to know it
 - gossip about service users is unacceptable
 - the confidentiality of people with a severe mental illness living in the community as well as those in hospital must be protected
 - service users should be consulted before decisions are taken about their treatment and care
 - care must be taken when giving information about diagnosis as this can lead to stigmatisation and stereotyping of service users
 - service users should share information with their informal carers to help them understand, for example, the side effects of the medication they are taking; they could then discuss with them issues such as "drug holidays" and reductions in medication
 - informal carers should share information with service users and help them obtain and understand the information that they need to know.
- 6 Advance statements should be used to enable service users to specify to whom information may be disclosed when they are unwell.
- 7 The outcome of any identification of any risk should be made known to everyone providing care either regularly or intermittently, including any informal carer.

Action

Rethink is pressing both nationally and locally:

- for operational policies in all mental health services to encourage information sharing with informal carers while recognising a service user's right to confidentiality of personal information
- to ensure that professionals involved in risk assessment let everyone providing a substantial amount of care, either regularly or intermittently, know of any identification of risk.

Questions and Answers

Q Why is information sharing so important?

A Because so many people are involved in providing care, including informal carers. They need to collaborate closely with each other to be able to do so effectively.

Q Why is it important to share information with informal carers?

A Because it helps them to care for service users effectively, including supervising the delivery of agreed treatment and social care plans. This can be done without disclosing personal information given to professionals by service users. Informal carers need to know, particularly, how best to help the person they are caring for and to understand their illness and treatment, including any side-effects.

Q Do service users have an absolute right to confidentiality?

A No; they have a right to confidentiality of personal information, which may need to be over-ridden through concern about their welfare and safety and that of other people.

Background

- 1 Most inquiries into failures in community care for people with a severe mental illness have pointed to:
 - breakdowns in collaboration between agencies
 - failure to listen to informal carers or take note of information that they have provided.
- 2 It is generally established in health and social care that there is a common-law duty of confidentiality. The Department of Health guidance, *The protection and use of public information* (1996), sets out the basic principles governing the use of patient information, which include:
 - a any information provided for one purpose should not be used for a different purpose or passed to anyone else without the consent of the information provider; however, this "duty of confidence" should not be applied so rigidly as to put a patient or the public at a disadvantage;
 - b information can be passed on with the patient's consent;
 - c information can be passed on without the patient's consent on a "need to know" basis if it
 - is needed through concern with their care and treatment, or its use can be justified eg risk management, or
 - is required by statute or court order, or
 - can be justified for other reasons, eg to protect the public.
- 3 The review of NHS use of personal information, led by Dame Fiona Caldicott (1998), found that there was a general lack of awareness about confidentiality across the NHS. The review included the following recommendations as good practice:
 - justify the purpose for which information is required
 - restrict access to this information to a strictly "need to know" basis
 - everyone with access to this information should be aware of their responsibilities.
- 4 In Northern Ireland it is incumbent upon service providers to ensure that the confidentiality of patient information is maintained at all times. Information systems and procedures must comply with *Protection and use of patient and client information* (1996) and the associated *Trust policies* (1997).

- 5 The Green Paper, *Reform of the Mental Health Act, 1983* (1999), recommends including guidance on information sharing in the Mental Health Act Code of Practice.
- 6 The BMA ethical guidance, *Confidentiality and disclosure of health information* (1999), says that respect for confidentiality is an essential requirement for the preservation of trust between patients and health professionals. It should only be breached in exceptional cases and with appropriate justification. Disclosures to informal carers may, however, be made where:
- it is clearly in the individual's interest, and
 - it is impractical or impossible to obtain their valid consent, and
 - disclosure is not contrary to their expressed or known wishes.
- nb **Rethink** believes that point c is too restrictive.
- 7 The *Human Rights Act 1998* introduced into UK law the fundamental rights and freedoms of the *European Convention on Human Rights*. Article 8 gives the right to respect for a person's private and family life, their home and their correspondence. This right can only be restricted in specified circumstances.
- 8 Institute for Psychiatry and **Rethink** research in 2004 includes the following recommendations on information sharing with informal carers:
- a clear differentiation need to be made between general, personal and sensitive personal information
 - the different professional and informal care responsibilities need to be recognised
 - a thorough explanation, in separate or joint sessions, should be given to service users and informal carers of an agency's protocol on confidentiality, the potential benefits of information sharing and how personal information might be used in practice
 - when a service user is deemed to have lost mental capacity and withholds consent, staff should continue to negotiate with the service user to try to discern why consent is withheld; the dignity of those losing or have lost mental capacity should be respected
 - consent should be reviewed regularly about what may and may not be shared
 - the service user should be kept informed about how their information is being used without consent, unless this would compromise personal safety
 - informal carers should be provided with general information, eg carer contact points.

Other related Rethink policies

- 1 Information provision to service users and their informal carers.
- 2 Involving service users and informal carers in mental health services.
- 3 Medication for people with a severe mental illness.
- 4 Meeting the needs of adult carers of people with a severe mental illness.

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Rethink is the operating name of the National Schizophrenia Fellowship. Our Mission Statement is:
Working together to help everyone affected by severe mental illness, including schizophrenia, to recover a better quality of life.

