

Confidentiality & information sharing with carers

More guidance



Introduction

Problems may arise when the disclosure of personal social services information on people who lack capacity is requested by those involved in their care. Decisions on disclosure must be justified, balancing the person's right to confidentiality with her/his best interests and the public interest. These judgments may be difficult to make.

The purpose of this briefing is to highlight factors that should be considered when social services staff receive a request from a relative or carer for information or documentation about an adult who lacks the capacity to consent to its release.

The briefing '*Confidentiality and Information Sharing with Carers*' Law Centre (NI) Community Care Information Briefing No 8 (LC Briefing No 8) will also be helpful on this subject¹.

New DHSSPSNI Code of Practice

A Departmental Code of Practice on Protecting the Confidentiality of Service User Information² has recently been issued. This Code affirms that whilst the sharing of social services users' personal information forms an essential part of social care, benefiting service users, this needs to be set alongside the expectation that all personal information will be kept confidential.

The Code recognises that particular care by social care staff is required to ensure that the right to privacy of people without capacity to consent to the release of information is respected.

Disclosure of information when a person lacks capacity

All adults are presumed to be capable of making decisions until the contrary is proven. As capacity is a decision-specific test, it should not be assumed that because someone has been assessed as incapable of making a certain decision s/he is not capa-

ble of making a decision to consent to the release of information. Likewise, incapacity to consent to the release of information should not be assumed on the basis of some other characteristics, for example, a learning disability. As capacity may fluctuate, where possible decisions should be postponed until a person may make a decision for her/himself. The right to privacy of social care information is not reduced because a person lacks capacity to consent to the release of information.

The Code states that, in general, a person with the capacity to make decisions about privacy issues should be able to exhibit all of the following:

- show understanding of the idea of disclosure of confidential information about her/himself;
- show understanding of the possible implications of agreeing to the disclosure of information or of refusing it;
- retain the information sufficiently to come to a decision;
- believe the relevant information;
- come to a decision;
- communicate the decision.

Best interests test

Where someone lacks capacity to make a decision on disclosure of information, then any disclosure must be strictly necessary and must be in the best interests of the person.

At paragraph 2.8, the Code states that disclosure in a person's best interests would usually be justified where it is believed that the '*person is a victim of neglect or of emotional or physical abuse, or at risk of suicide.*'

The Code goes on to say, at paragraph 4.6 that in determining best interests, the following factors should be considered:

- the service user's own wishes and values (where these can be ascertained) including any advance statements;
- the effectiveness of the disclosure, particularly in relation to other options;
- where there is more than one option, which option is the least restrictive of the user's future choices;
- the likelihood and extent of any benefit to the service user if the disclosure is made;
- the views of parents, if the service user is a child;
- the views of people close to the service user, especially close relatives, partners, carers or proxy decision makers about what the service user is likely to see as beneficial;
- any knowledge of the service user's religious, cultural or any non-medical views that may impact on the service user's wishes.

The Code also emphasises that, in determining best interests, particular consideration must be given as to how others' opinions are sought in order to avoid the inappropriate disclosure of confidential information.

Promoting a person's health and welfare

Disclosure to a close relative or carer using the best interests test need not be restricted solely to when there is a belief that the person is a victim of neglect, emotional or physical abuse or at risk of suicide. It may also be justified where it would protect and promote a person's health and welfare.

LC Briefing No 8 highlights that disclosure may be in the person's best interests where it would lead to future decisions on her/his health and welfare being properly informed.

Relevant factors to be taken into consideration include not only the likelihood and extent of any benefit to the service user if the disclosure is made but also if the disclosure is not made. Would a failure to disclose information inhibit the person's right to having properly informed decisions made on assessments of needs or social services provision?

Protecting confidentiality

The fact that information sharing may be beneficial does not diminish the continuing duty of confidentiality. Where appropriate, people who lack the capac-

ity to make decisions on disclosure must be informed in an accessible manner, using suitable communication supports, of the disclosure of their information. Whenever information is disclosed to a close relative or carer, the relative or carer should treat the information as confidential and not share it with anyone else, unless there are lawful grounds for this.

The need for a clear and unambiguous purpose for requesting information on people who lack capacity is a further means of ensuring confidentiality. In most cases, applications for disclosure of confidential information will be made by close relatives or carers who will have a clear, unambiguous purpose for the request. They will have a valid and understandable need for information where there may be problems in social services provision to the service user who lacks capacity. Such information may lead to greater awareness of needs and to improved services. It would patently be in the service user's best interests to disclose this information.

Exceptional rules for non-disclosure of social services records

Social services records may contain information relating to the physical or mental health or condition of the subject of the records or of any other person.

Where the disclosure of this information would be likely to cause serious harm to the physical or mental health or condition of the subject of the records or any other person, then this information may be withheld. However, it should only be withheld if the appropriate health professional has been consulted. Legislation³ defines the appropriate health professional. This would usually be the person who is currently or was most recently responsible for the clinical care of the person to whom the information relates.

This exemption will only apply in the most serious cases. The exemption does not apply where the person requesting the information is likely to be aware of the medical or health information.

The law⁴ also says that personal data held for the purposes of social work may be withheld where the disclosure to the data subject would be likely to prejudice the carrying out of social work, by causing serious harm to her/his physical or mental health, or condition, or that of another person. The restrictions may be permanent or temporary.

This exemption will only apply in exceptional circumstances and is confined to serious harm. One example may be where there is sufficient risk to the safety of a child for a child protection plan to be in place and where disclosure would prejudice the plan.

Trusts should be aware that the person requesting information which is being withheld may require special counselling.

Information Commissioner guidance on release of social services records

The Information Commissioner has produced a Data Protection Technical Guidance Note⁵ for release of social services records.

Of particular importance for protecting the privacy of people who may not have capacity to make a decision on the release of their information, the Guidance states that trusts should always satisfy themselves as to the identity of a person making a request for information. In most cases where the request is made by a close relative or carer, there will be an on-going relationship with the social services professional involved and identity can easily be verified.

Many people who receive social services may have physical, mental or emotional care needs and may therefore need a representative. The Guidance notes that this may make the service user vulnerable and if there is any reason to believe that the representative is falsely claiming to act on behalf of someone else then this should be investigated.

Extra checks should be made where the person is no longer in receipt of social services.

The Guidance recognises that some social services records may contain information which will cause upset on disclosure. The Guidance states that it is good practice to offer opportunity to view this information during a supportive interview with a social worker or counsellor.

Endnotes

- 1 Copies available from Law Centre (NI) publications unit or from www.lawcentreni.org/Publications
- 2 Code of Practice on protecting the Confidentiality of Service User information, January 2009, DHSSPSNI
- 3 Data Protection (Subject Access Modification) (Health) Order 2000 SI 413/2000
- 4 The Data Protection (Subject Access Modification) (Social Work) Order 2000 SI 415/2000
5. Data Protection Technical Guidance Note Subject access requests and social services records, September 2008, www.ico.gov.uk/upload/documents/library/data_protection/detailed_specialist_guides/sars_social_services_v1.0_260808.pdf

For any queries arising from this briefing, please contact the community care unit of Law Centre (NI) on the advice line (028 9024 4401) or, in individual cases, please feel free to refer a client directly.