

Researching outcomes from forensic services for people with intellectual or developmental disabilities: a systematic review, evidence synthesis and expert and patient/carer consultation

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Scientific summary

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Background

A small proportion of people with intellectual and other types of developmental disabilities (IDD) can present with behaviour that contravenes the law, or that is otherwise high risk, and cannot be safely managed in the community. These individuals typically present with a high degree of clinical complexity and may be detained for treatment in a secure hospital under the Mental Health Act 1983 (amended 2007) (Great Britain. *Mental Health Act*. London: The Stationery Office; 2007). Although it is a health service sector with high levels of expenditure, with the NHS currently funding around 1800 secure beds, there is limited empirical information on patient outcomes from such forensic mental health services for people with IDD. In order for a future substantive longitudinal outcomes study to be informed and feasible, more needs to be understood about the outcome domains that are of importance and how they should be measured. A preliminary series of studies was therefore undertaken.

Objectives

- To synthesise evidence on the outcome domains that have been investigated in existing research from forensic services for people with IDD, in the broad domains of service effectiveness, patient safety and patient experience.
- To identify the views of patients in forensic IDD services and their carers on the outcome domains of most importance and relevance to them.
- To gain consensus on expert views on the outcome domains of most importance for use in future evaluation of forensic IDD services, based on the domains identified from the existing research and patient/carers views.
- To identify a framework of outcome domains (and potential associated measures and indicators) based on the research evidence and on the views of patients, carers and clinicians.
- To synthesise the information gathered in order to inform the design of a future longitudinal research project in the sector.

Methods

Three linked studies were conducted:

- Stage 1: a systematic review of the literature pertaining to a range of forensic services for people with IDD, focusing specifically on the outcomes that have been researched. Searches of the following databases were conducted on 1 July 2015: MEDLINE, PsycINFO, EMBASE, Allied and Complementary Medicine, Health Management Information Consortium, the British Nursing Index and the Cumulative Index to Nursing and Allied Health Literature from inception to May 2015. Similar outcome domains and measures were clustered together in a qualitative synthesis.
- Stage 2: a series of consultation discussion groups with patients and carers.
- Stage 3: a modified online Delphi expert consensus process conducted over two rounds using the items generated at stages 1 and 2.

Results

At stage 1, 60 studies that researched outcome domains in forensic IDD services (which included secure hospital-based and community-based services) were identified from the literature. This resulted in the construction of an initial framework of 31 outcome domains, under three superordinate domains.

The consultation with 15 patients and six carers at stage 2 added a number of domains to this framework, which particularly related to carer experience.

The Delphi process at stage 3 had 15 respondents at both round 1 and round 2; these were primarily clinicians in forensic IDD services. This process highlighted support for the validity of the framework and identified several key domains of most importance to clinicians. This survey also identified the outcome measures or indicators preferred by clinicians and those that are utilised currently in services. Both this survey and the systematic review identified a paucity of appropriate measures in some key domains, particularly in relation to treatment progress.

Conclusions

Together, these three linked studies resulted in the consolidation of a framework of key outcome domains and subdomains. It also led to a long list of provisional associated measures and indicators for these domains. With further development, this could eventually be utilised both by services and commissioners and in any subsequent empirical longitudinal study of forensic IDD services.

Implications for research

The policy context in IDD at the present time is of importance when future research is concerned. The Transforming Care programme and related developments, including a national service model associated with reduction in IDD hospital bed numbers, require that secure hospitals treating people with IDD produce accurate and relevant outcome data, both during treatment and following discharge. This project has reviewed previous research on outcomes and clarified what a future outcome data set should look like. An outline research design is proposed.

Study registration

This study is registered as PROSPERO CRD42015016941.

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