

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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Plain English summary

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People with intellectual and other types of developmental disabilities (IDD) (which may include autistic spectrum disorders) exhibit differences in cognitive functioning and day-to-day living skills that start in the developmental period. A small proportion of people with IDD can present with behaviour which cannot be safely managed in the community, and they may be detained in a secure hospital. Such hospitals, also called forensic hospitals or services, are high cost to the NHS, but little is known about patient outcomes from inpatient treatment. Research therefore needs to be undertaken in this area.

This project conducted preliminary work in preparation for a wider and more in-depth future project. We aimed to answer three questions:

1. What outcome 'domains' (areas) have been investigated in previous research on forensic services for people with IDD and how have they been measured?
2. What are the outcome domains that have most importance to users of such services and to their carers?
3. What do expert clinicians (e.g. psychologists, psychiatrists and nurses) consider are the most important outcome domains and measures?

We attempted to answer these questions by carrying out three linked studies:

1. a summary of the evidence from previously published research
2. consultation groups with patients with IDD from secure hospitals and their carers
3. an online survey of a panel of clinical experts.

Combining evidence from the three studies, we developed detailed categories of outcome domains and proposed ways of measuring these domains. With further refinement these could be used in future longitudinal outcomes research in forensic IDD services.

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