



An audit of the Irish National Intellectual Disability Database[☆]

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ARTICLE INFO

Article history:

Received 12 October 2009

Accepted 16 October 2009

Keywords:

Intellectual disability

Data audit

National Intellectual Disability Database

ABSTRACT

This study describes a national data audit of the National Intellectual Disability Database (NIDD). The NIDD is a national information system for intellectual disability (ID) for Ireland. The purpose of this audit was to assess the overall accuracy of information contained on the NIDD, as well as collecting qualitative information to support the improvement in the quality of data contained on the NIDD. A nationally representative sample was generated from the NIDD. Twenty-five auditors were recruited from senior staff within statutory and voluntary intellectual disability services and trained by the authors. They carried out 250 clinical interviews with individuals with ID, their families and/or paid carers, using structured questionnaires. The data collected were analysed using frequency analyses and compared with the existing NIDD data set to assess accuracy. Qualitative information was also collected. Overall, the results from the audit indicate that almost three quarters (72.2%) of all the data recorded on the NIDD are accurate, with 19.3% inaccurate, and 8.5% of the sought audit data not returned. The audit found that the NIDD significantly overestimated the need for enhanced residential care services. The study highlights the need for clinician and service user involvement in specialist service data collection, in order to both conduct valid research and to best plan for ID service development.

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1. Introduction

With improved healthcare, people with intellectual disabilities (ID) are living longer (World Health Organization, 2000), and are requiring a range of services (Kelly, Kelly, & Craig, 2009). In addition, as countries plan community based support services to people with ID and their families, the costs of these services are rising (Organisation for Economic Cooperation and Development, 2006). Many countries are developing services with an emphasis on service user involvement in the planning and evaluation processes of service delivery (e.g. Department of Health & Children, 2001). In addition to service planning, service-based and national datasets and databases are regularly used for research purposes (e.g. the US National Epidemiological Catchment Area Database, Judd & Akiskal, 2003; the Paediatric Intensive Care Audit Network, McKinney et al., 2005). Accurate data, therefore, need to be available to both research teams and governmental agencies to best understand the needs of the target population and to provide and plan person-centered specialist support services (National Disability Authority, 2007). The need to measure and maintain the quality of these data has been highlighted (German et al., 2001).

[☆] Approval to carry out study received from the National Intellectual Disability Database Committee.

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The National Intellectual Disability Database (NIDD) was established in 1995 to plan and provide appropriate services for people with ID and their families in Ireland. The objective of the NIDD is to provide a comprehensive and accurate information base for decision-making in relation to the planning, funding and management of services for people with an ID, as well as being a research tool. The Database incorporates three basic elements of information: demographic details, current service provision, and future service requirements. This information is obtained for each individual known to have an intellectual disability and assessed as being in receipt of, or in need of, a specialist service now or in the next 5 years. The data held in any individual record represent the most up to date information available for that person. The record is updated whenever there are changes in the person's circumstances or during an annual review process. Each year, an official extract is taken from the NIDD and this forms the core data set for reporting for that year. In 2007, there were 25,613 people registered on the Database; of these 24,898 individuals (97%) were receiving services which included day services (24,729, 99.3%), multidisciplinary support services (19,799, 79.5%) and residential services (8,262, 33.2%) (Kelly, Kelly, & Craig, 2007).

A data audit is a process by which the quality of data that are held within a database or organisation is reviewed systematically. In most cases the quality of the data is assessed in terms of accuracy, but other issues such as data recording protocol and staff training requirements can also be considered. For example, Weiss (1998) reports the findings of an audit of data associated with research funded by the US National Cancer Institute. This audit was conducted as a result of the NCIs responsible for ensuring the reliability of data generated as part of its funded programmes.

In late 2007, a national audit of the NIDD was undertaken to assess the overall accuracy of the data held. This was the second national audit; in 1997/1998 the NIDD was audited using a similar methodology (Keane & Mulvany, 1999). The main focus of the audit was on those people who were identified as requiring a residential service¹ in the NIDD data returned to the HRB in March 2007. The audit focused on residential services, as it was perceived that any discrepancy in these data are likely to have the greatest impact on service developments, with regard to staff and financial costs, as well as service user impact. Within this context, the aim of the audit was to obtain a valid indication of the accuracy and validity of data held on the NIDD. A secondary aim was to explore auditors' views of the process.

2. Methodology and materials

2.1. Sampling

A random sample of 300 cases was selected for audit from the 2007 NIDD (Kelly et al., 2007). The sample consisted of live cases (individuals with ID), with a moderate, severe or profound ID and requiring either a new or enhanced residential place or residential support in the period 2007–2012. It was agreed that an allowable error of $\pm 10\%$ should be specified at 95% confidence probability.

To obtain consent, a standard letter was issued by local health service offices to the sample of service users, their service providers and to the next of kin to explain the design and need for the data audit, the study design and to ask for their participation. Consent was returned to the health service staff who then compiled audit itineraries for their area. Service users, family members and key workers (or someone in the service who knew the service user well) were all encouraged to attend the audit interview.

Twenty-five auditors were chosen from a range of disciplines and training backgrounds across the four health service regions that exist in Ireland. Half of the auditors were drawn from the statutory service delivery sector and the other half came from the non-statutory sector. The audit teams consisted of nurses, psychologists, social workers, and other appropriately qualified service professionals and managers. No audit team member was assigned to the region in which he/she normally worked.

2.2. Audit instruments

Each audit interview involved the completion of two structured questionnaires:

- The standardised NIDD data form (available on request) with the selected individual. The data form was filled by the auditor as though it were the first time to complete it.
- An Audit Experience Questionnaire to probe further the level of satisfaction of each of the audit participants with the information contained on the data form that had just been completed. This questionnaire enquired about who attended the audit interview, possible reasons for non-attendance, possible differences of opinion of attendees on completion of the form as well as questions on why residential services were being sought. The Audit Experience Questionnaire also allowed the auditor to record his/her views with regard to the information and the urgency of the need for any change.

¹ Residential service is used here to describe a range of full-time or part-time residential care types, such as community group homes and larger campus residential centres, as well as residential support such as respite.

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