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**Mortality of people with intellectual disabilities in
England: A comparison of data from existing sources**

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Mortality of people with intellectual disabilities in England: A comparison of data from existing sources

Abstract

Background At present there is limited statistical information about mortality of people with ID in England. This paper explores the data that are currently available.

Materials and Methods Four recent sources of data about mortality of people with ID in England are reviewed: The Confidential Inquiry into premature deaths of people with ID (CIPOLD); the 2013 joint health and social care ID self-assessment exercise; local registers of people with ID; and analysis of Cause of Death certificates.

Results Available data confirm that people with ID have a shorter lifespan and increased risk of early death when compared with the general population. The Standardised Mortality Rate for people with ID is approximately twice that of the general population in England, with little indication of any reduction in this over time.

Conclusions Comprehensive data about mortality of people with ID that take account of the age and sex distribution of the population is currently lacking in

England. Existing data suggest persistent inequalities between people with ID and the general population.

There is an urgent need for better monitoring mechanisms and actions to address these.

Keywords

Intellectual disabilities, learning disabilities, mortality data, England.

Mortality of people with Intellectual Disabilities in England: A comparison of data from existing sources

Introduction

This paper reviews and extends the existing recent literature about the mortality of people with intellectual disabilities (ID) in England. The term ‘intellectual disabilities’ is frequently used interchangeably with the term ‘learning disabilities’ and two definitions are commonly used:

- That included in the government’s Strategy for Learning Disability in the 21st Century, published in 2001 (Department of Health 2001). This defines ‘learning disabilities’ as including the presence of impaired intelligence with impaired social functioning,

which started before adulthood and has a lasting effect on development (Department of Health 2001).

- The definition of the Learning Disabilities Observatory, which is largely based on that of the 2001 Strategy for Learning Disability but clarifies the *exclusion* of people with 'specific learning difficulties' (such as dyslexia) who do not have significant general impairment in intelligence, people with Asperger's Syndrome if they have average or above average intelligence, and those with brain injury or trauma sustained in adulthood (Emerson & Heslop 2010). The authors offer practical guidance for identifying adults and children with learning disabilities.

In this paper we will use the term ID to refer to adults and children meeting the above criteria.

The distinction between mild, moderate, severe and profound ID is often made in England, although this is not usually based on IQ tests and scales assessing social adaptation as proposed by the World Health Organisation International Classification of Disease (ICD-10). Instead, such a distinction is based on an assessment of individual need and the necessary supports required to meet that need.

The total population of England in 2013 was 53.9 million (Office for National Statistics 2014), and most recent estimates are that there are 1,068,000 people in England with ID, of which 900,900 are adults – a rate of 21.7 per 1000 of the adult population and 27.0 per 1000 of the school-aged child population (Hatton et al. 2014). These are best estimates: there is no definitive record of the number of people with ID in England as such information is not collected nationally. However, less than a quarter (24%; n=214,352) of adults with ID are registered as having ID by a family doctor (GP) in the National Health Service (NHS) (Health and Social Care Information Centre 2014a) - '*a substantial underestimate of the true prevalence*' (Glover 2015 p. 14) and only 20% (n=177,389) of adults with ID in England are users of specialised social care services for people with ID. There is therefore a 'hidden majority' of people with mainly mild and moderate ID who are not recorded as having ID by their GPs, and who are not known to, or who do not use, specialised social care services for people with ID.

Evidence demonstrating significant health inequalities and premature deaths in people with ID has been available in England for almost two decades (Hollins et al. 1998; Disability Rights Commission 2006; Mencap 2007;

Michael 2008; Heslop et al. 2013), with all of the data being derived from sub-national studies or national inquiries rather than national vital statistics. Despite clear indications of excess deaths of people with ID, at present there is no data available at national level to provide robust evidence about standardised mortality ratios (SMRs) or causes of death in people with ID. This paper explores the data that is available and what it tells us about mortality of people with ID in England.

Materials and methods

In preparing this paper we have summarised and compared the findings of four sources of data about mortality of people with ID in England. Sources were excluded if they were small local studies with incomplete or missing data about some of the people with ID in that area.

The Confidential Inquiry into premature deaths of people with ID (CIPOLD)

The first source of data is the Confidential Inquiry into premature deaths of people with ID (CIPOLD). CIPOLD reviewed the deaths of people with ID aged 4 years and over who were registered with a GP in a clearly defined geographical area of South West England with a total

population of 1.7m. All deaths occurred over a two-year period from 2010-2012.

Deaths were notified to the CIPOLD team from a variety of local contacts, including primary and secondary care and community sources. Additional checks were made with GPs, prisons, community groups and community leaders to ensure that all eligible deaths had been reported. Each death was notified by an average of 1.7 sources but without a definitive register of deaths the completeness of reporting could not be verified. The UK Office for National Statistics provided details of the coding of Cause of Death certificates for all but three of those who had died – for these three post-mortem reports were used. For each death of an adult with ID, independent reviewers conducted a detailed examination of the circumstances leading to death, by interviewing paid carers, health and social care professionals, and family and friends of the decedent, and reviewing all care records or case notes pertaining to the individual. The median number of informants per case was seven. The information was collated and presented in a standardised format at a Local Review Panel meeting to which all involved professionals were invited, and the final report was then de-identified and scrutinised by an external,

multidisciplinary Overview Panel. For each death of a child (age 18 years or less), the national statutory Child Death Review team took the lead in the investigation (Secretary of State for Education and Skills 2006), but CIPOLD had full access to the documentation and each death was reviewed anonymously by the CIPOLD Overview Panel. Each review (of children and adults) identified potential contributory factors to the death, whether the death was expected or premature, lessons learned from the particular case, wider recommendations to be made and examples of good practice. Study approval was obtained by the NHS Research Ethics Committee and the (former) National Information Governance Board.

At the time of the publication of CIPOLD it was not possible to report age-standardised mortality ratios (SMR) because of a lack of data about the age structure of people with ID at national or regional levels in England. More recently, limited data about the age structure of the ID population have become available from the 2013 joint health and social care ID self-assessment exercise – the second source of data about mortality of people with ID in England.

The 2013 joint health and social care ID self-assessment exercise

The 2013 joint health and social care ID self-assessment exercise was the amalgamation of two previous annual reviews, one of which was primarily led by the health service and the other by local authority departments of adult social services. Amalgamating the reviews into a joint framework emphasised the contributions of both agencies and their shared responsibilities in providing care to people with ID (Glover & Christie 2014). The aim of the self-assessment exercise was to help commissioners and local people to assess how well people with ID were supported to stay healthy, be safe and live well (NHS England and ADASS 2014). It was not primarily intended to be a source of national data, although it does provide more complete data in some areas of interest than previously existed. To the extent that statistical data were requested, the intention was at least as much to draw attention to the types of measures of population structure, health problems and care and mortality of people with ID it was considered local planners should be looking at, and the extent to which these were known at a local level.

The 2013 self-assessment form was completed by nominated leads in each area Partnership Board. Partnership Boards are multidisciplinary groups that have been established in each local authority area in England. Their role is to contribute to the design, development, implementation and monitoring of health and social care services for people with ID in their area, aiming to promote the rights and inclusion of people with ID and improve the way in which they are supported by services. All Partnership Boards agreed to submit data for the self-assessment exercise.

The self-assessment exercise itself required the collection of information from a wide range of informants, including statutory and voluntary sector service providers, people with ID and family carers. It required both quantitative and qualitative information including demographic data, information about the health and safety of people with ID, and provision for them to live well in their communities. It also asked about perceived areas of best practice and areas of concern where improvements may need to be undertaken. For the first time, in 2013, the self-assessment exercise asked Partnership Boards to report (if they were able) how many people with ID resident in their area died between

1st April 2012 and 31 March 2013 in the five age bands 0-13; 14-17; 18-34; 35-64; 65 and over (Public Health England 2013).

Glover & Christie (2014) calculated adult standardised mortality ratios (SMR) for each Partnership Board where this was possible. In order to make comparative data locally relevant and to guard against possible bias if the areas providing data were unrepresentative of the population of England as a whole, they did this using the local population mortality rates for each Partnership Board area as the basis for the calculations. Data pertaining to children were not used because these varied so widely as to suggest that substantially different approaches to their estimation had been used. In order to ensure a tolerable level of consistency in the quality of the data, Partnership Boards were only included if their data:

- Included population numbers for the three adult age bands (18-34; 35-64; 65 and over).
- Included numbers of deaths for all three adults age bands.
- Indicated a prevalence of adults with ID that was equal to or greater than 1.5 per 1,000 population.

Given that all of the Partnership Boards comprising the CIPOLD area reported credible data about the age structure of the population with ID in their self-assessment framework returns, we were able to use these to calculate the SMR of adults with ID in the geographical area covered by CIPOLD. To do this we took published local figures from GP registers of adults with ID from 2009/10 to 2011/12 as the starting point for population estimates. We up-rated these ID population figures by around 10% to allow for the fact that only 90% of the deaths studied by the CIPOLD were of people on their GPs register. We did this calculation separately for each of the three age bands used and each of the five areas, as the rate of under-coverage varied slightly by age and the age structure differed for the five areas. We then calculated general population age/sex-specific death rates for each of the five areas for the relevant years. The ratio of observed to total expected deaths (the SMR) could then be calculated (Eayres 2008).

Local registers of people with ID

The third source of information about mortality is local registers of people with ID. Such local registers have previously existed in several areas of England in order to help plan, deliver and monitor provision for people with ID

in those areas. Many registers have been discontinued, but comprehensive registers currently exist in Sheffield and Leicestershire for their local populations.

The Sheffield case register was established in 1974. Inclusion in the register is optional but it has 90-95% estimated population coverage of all ages from birth to death. In 2013 the Sheffield City register included 3,587 people with ID of all ages (Burns 2013), most of whom had moderate to profound ID. Each registered person is visited every five years to ensure accuracy of the data.

The Leicester ID register was established in 1987, in response to demands from people with ID and their carers for better coordination and continuity of care. Individuals are referred to the register through a variety of health and social care channels with an estimated 95% acceptance of inclusion by carers. In 2012 there were approximately 3,400 adults included on the register; most had moderate to profound ID and were likely to need long-term support (University Hospitals of Leicester NHS Trust 2012). Each registered person is visited every five to seven years to update the data.

Analysis of Cause of Death Certificates

The fourth source of mortality data is a review of Cause of Death certificates reported by Glover & Ayub (2010). Glover & Ayub (2010) compiled lists of conditions that usually, sometimes (more than 1 in 7) or rarely (less than 1 in 7) cause ID, and degenerative conditions associated with ID; these lists were verified with expert advisers and the NHS Information Centre. They then obtained the computerised Cause of Death records of all deaths in England from 2004-2008. These stated the gender, dates of birth and death, age at death, up to eight causes of death and where the person usually lived. Using information from the Cause of Death certificates cross-referenced with the lists of conditions causing or associated with ID, Glover & Ayub calculated the age and cause of death of people with ID who were identifiable from Cause of Death certificates. The authors assumed that they would be getting only a partial view of deaths of people with ID, as in many cases it was likely this would not be apparent from the certified causes. They paid close attention to estimating the extent and patterning of this under-reporting and used methods drawn from occupational mortality studies to draw the strongest available conclusions in light of these deficiencies.

Data from more recent years (2009-2012) have since been analysed and reported (Hatton et al. 2014).

Results

The results will be presented in two main sections: the first relating to age at death, and drawing on data from CIPOLD and the analysis of cause of death certificates; the second relating to SMR and drawing on data from the 2013 joint health and social care ID self-assessment exercise, CIPOLD, and local registers of people with ID.

Age at death

CIPOLD reviewed the deaths of 247 people with ID (14 aged 4-17; 233 aged 18 or older) over the two-year period in question. The findings are reported in full by Heslop et al. (2013, 2014). The median age at death was 64 years (65 years for men; 63 years for women) ranging from 4-96 years. Nearly a quarter (22%) of people with ID were under the age of 50 when they died. The median age at death decreased with increasing severity of ID: the median age at death for people with profound ID was 46 years, severe ID was 59 years, moderate ID was 65 years and mild ID was 67.5 years.

CIPOLD confirmed that people with ID have a shorter lifespan and increased risk of early death when compared with the general population of England and Wales (Figure 1). Men with ID died on average 13 years sooner than men in the general population (65 years compared to 78 years); women with ID died on average 20 years sooner than women in the general population (63 years compared to 83 years). Even people with mild ID had a significantly younger median age at death (67.5 years) than people in the general population (80.5 years).

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Figure 1 here

Figure 1: Age at death of people with ID compared with the population of England and Wales in 2011 (from Heslop et al. 2013 p.24).

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Glover & Ayub's (2010) analysis of Cause of Death certificates also provides an insight into the age at death of people with ID. Glover & Ayub reviewed 2,362,095 Cause of Death certificates that had been issued in England from 2004 to 2008. From these they identified 7,480 people with definite or possible ID and estimated that 5,430 of these would have had ID – a rate of 2.3 per 1,000. This figure is about half of what we would expect based on calculations of people included on registers of

people with ID held by GPs (which are themselves an underestimate) and assuming that people with ID had the same lifespan as others. The age at death of those with ID, or with conditions commonly associated with ID, was analysed according to their specified condition. Table 1 shows the ages by which a quarter, half, and three-quarters of deaths had occurred for people with ID or conditions almost always associated with ID. A fuller version of this table is available in the report, including data about conditions such as cerebral palsy in which ID is common but affects fewer than half of affected people. Table 1 concurs with the CIPOLD observation that people with ID, or associated conditions, died at younger ages than people without ID – half of people without ID died by the age of 80, but the longest living people with ID were those with ID mentioned on their Cause of Death certificate but with no condition specified –half of these died before the age of 65.

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Table 1 here

Table 1: The ages (and Confidence Intervals) by which a quarter, half, and three-quarters of deaths had occurred for people with ID or conditions associated with ID (amended from Glover & Ayub 2010. p.15)

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Detailed analysis of the pattern of age at death of people with ID, or conditions associated with ID by Glover & Ayub (2010) suggested variation in age at death according to different conditions associated with ID. People with Down's syndrome for example, appeared to have a low proportion of death in young adult life, followed by a sharp increase in deaths at age 50-65. Amongst groups with conditions where ID is common but present in under half of those affected, two stood out as having distinct age at death profiles. People with hydrocephalus/spina bifida (about 38% of those with hydrocephalus have ID) showed a sharp increase in mortality at age 30-45 with decubitus ulcers being a significantly common immediate or contributory cause of death. People with cerebral palsy (about 44% have ID) showed high rates of death at all ages with aspiration pneumonitis being a significantly common cause. Similar patterns of age at death were found for males and females.

More recent analysis of updated data drawn from Cause of Death certificates suggests that from 2008-2011 the median age at death of people with ID or a cause of death associated with ID had risen marginally from 53

years to 57 years, but that the increase was unlikely to be statistically significant (Emerson et al. 2013).

Standardised Mortality Rates

Two-fifths (44%; n=68) of Partnership Boards submitted useable data to the 2013 joint health and social care ID self-assessment exercise from which the standardised mortality ratio (SMR) of their area could be calculated. Although these should be interpreted cautiously given the wide range of estimates of ID population data from Partnership Boards around the country, the median SMR for people with ID was 2.13 (inter-quartile range 1.09 to 2.83) suggesting twice as many deaths of people with ID as would be expected if the local age-specific death rates for people without ID had applied to them (Glover & Christie 2014). However it should be noted that in addition to the number of Partnership Boards unable to provide sufficient data for the calculation (noted above), the full reported range went from 0.14 to 7.07 suggesting that data collection mechanisms were not consistently reliable. For the CIPOLD area, the SMR in the period studied was 1.92 (95% Confidence Interval 1.68 to 2.18).

These SMRs are rather lower than the SMR reported by Tyrer & McGrother (2009) using data from the Leicester ID register. Tyrer & McGrother calculated SMRs by age and sex for 503 adults with moderate to profound ID who died between 1993 and 2006 and reported an SMR of 2.28 for males and 3.24 for females. Overall mortality was almost three times as high (SMR 2.77) in adults with moderate to profound ID compared with the general population. More recent analysis of the Leicester data by Emerson et al. (2014) has explored trends in age-standardised mortality rates and life expectancy of adults with moderate to profound ID over a 33-year period. Emerson et al. (2014) found a sustained reduction in age-standardised mortality rates over the period in question, similar to the pattern observed in the general population of England and Wales, with the absolute gap in mortality rates remaining constant at an average of 776 excess deaths per 100,000 among people with ID. They concluded that there was 'little evidence of any closing of the gap in age-standardised mortality rates or life expectancy between people with intellectual disabilities and the general population' (Emerson et al. 2014 p.94).

Discussion

This paper has reviewed existing sources of data about the mortality of people with ID in England. Each of the sources has its own limitations: first, the CIPOLD data and findings from Case Registers in Sheffield and Leicester describe specific regions and may not reflect the situation in other parts of England where both the demography of people with ID and quality and availability of the health and social care may differ. Secondly, demographic and mortality data requested from Partnership Boards for the 2013 ID self-assessment exercise was frequently not available, and the data that were provided were usually based on registers of people with ID held by GPs which underestimate people with mild and moderate ID in particular. Thirdly, the coding of Cause of Death certificates of people with ID has been found to be subject to coding errors (Ouellette-Kuntz 2005; Tyrer & McGrother 2009; Landes & Peek 2013) and data extracted from Cause of Death certificates identify fewer than half of people with ID who die; indeed in the CIPOLD study less than a quarter (23%) of people with ID were identified as having ID or a condition associated with ID on their Cause of Death certificate (Heslop et al. 2013). Fourth, some sources are likely to exclude people with mild to moderate ID. Simply on the basis of numbers of observed people it is clear that all of

the sources reported are only able to include at best a quarter of those who could be presumed to fall within the definition set out in the introduction.

The information that we have drawn from existing sources, suggests a reduced life expectancy for people with ID, an age adjusted mortality ratio for people with ID at twice that of the general population in England, and little indication of any reduction in this over time.

Comprehensive numerical data about mortality of people with ID that can take account of the age and sex distribution of the population are currently lacking in England and there is an urgent need for better monitoring mechanisms and actions to address health inequalities faced by people with ID.

The lack of comprehensive mortality data has been identified as problematic by the English Department of Health (Department of Health 2013a; Department of Health 2014) and NHS England has committed to monitoring excess under-60 mortality in people with ID (Department of Health 2013b) and establishing a national mortality review function for people with ID (NHS England 2014). Yet how excess under-60 mortality in people with ID can be measured is proving to be challenging. At

present there is no single data source that can provide the necessary data.

The most promising way forward would be data linkage between GP registers of people with ID and national mortality data held by the Office for National Statistics (ONS). There exists a centrally managed process through which Read-coded data can be extracted from computerised notes systems in GP practices. Linking ONS mortality data to this GP data is technically possible using a person's NHS number as the common identifier. The data linkage process is managed for the NHS by the Health and Social Care Information Centre, but delays in processing requests and information governance concerns have proved to be difficult obstacles to overcome during the past two years.

There are additional uncertainties to take into account when considering the availability of robust data about the mortality of people with ID in England. First, GPs are currently paid for maintaining a register of people with ID at their practice, but it is uncertain whether and with what degree of accuracy they would continue to do so if this financial incentivisation were to stop. Secondly, information governance concerns largely orchestrated by

the *Big Brother Watch* campaign (<http://www.bigbrotherwatch.org.uk/>) have led to assurances by NHS England that patients will have the right to opt out of their data being shared for purposes other than the provision of direct care. To what extent people with ID will choose to do this will not be clear for several years. Finally the current squeeze on public spending is likely to lead to alterations in the administrative prevalence of people with ID in receipt of services, as people with mild or moderate ID will be increasingly likely to remain outside adult service provision. Each of these factors could have an impact on the availability, accuracy and comparability of robust data about mortality of people with ID in England in the future.

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Conflict of interest

None

Permissions

Permission obtained from Professor Gyles Glover to use (amended) Table 1.

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<http://www.library.leicestershospitals.nhs.uk/pubscheme/Documents/What%20our%20priorities%20are%20and%20how%20we%20are%20doing/Annual%20report/ALN%2>

[0Service%20Annual%20Report%202011-2012%20Final%20Version.pdf](#)

Accessed 29 December 2014.

Table 1: The ages (and Confidence Intervals) by which a quarter, half, and three-quarters of deaths had occurred for people with ID or conditions associated with ID (amended from Glover & Ayub, 2010. p.15)

Condition	Deaths (n)	Quarter of deaths occur by this age (CI)	Half of deaths occur by this age (CI)	Three-quarters of deaths occur by this age (CI)
Down's syndrome	2,163	49 (48-50)	56 (56-57)	61 (61-61)
Microcephaly	154	3 (2-4)	10 (7-11)	28 (19-37)
Other conditions usually associated with ID	618	2 (2-3)	8 (6-11)	39 (34-44)
Degenerative conditions associated with ID	376	6 (4-7)	12 (11-14)	28 (22-35)
ID mentioned, but no condition specified	887	52 (50-54)	65 (64-66)	77 (75-78)
<i>No ID</i>	<i>2,354,659</i>	<i>70 (70-70)</i>	<i>80 (80-80)</i>	<i>87 (87-87)</i>