



Heslop, P., Blair, P. S., Fleming, P. J., Houghton, M. A., Marriott, A. M., & Russ, L. S. (2014). The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. *Lancet*, 383(9920), 889–895. [https://doi.org/10.1016/S0140-6736\(13\)62026-7](https://doi.org/10.1016/S0140-6736(13)62026-7)

Publisher's PDF, also known as Version of record

Link to published version (if available):
[10.1016/S0140-6736\(13\)62026-7](https://doi.org/10.1016/S0140-6736(13)62026-7)

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The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study



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Summary

Background The Confidential Inquiry into premature deaths of people with intellectual disabilities in England was commissioned to provide evidence about contributory factors to avoidable and premature deaths in this population.

Methods The population-based Confidential Inquiry reviewed the deaths of people with intellectual disabilities aged 4 years and older who had been registered with a general practitioner in one of five Primary Care Trust areas of southwest England, who died between June 1, 2010, and May 31, 2012. A network of health, social-care, and voluntary-sector services; community contacts; and statutory agencies notified the Confidential Inquiry of all deaths of people with intellectual disabilities and provided core data. The Office for National Statistics provided data about the coding of individual cause of death certificates. Deaths were described as avoidable (preventable or amenable), according to Office for National Statistics definitions. Contributory factors to deaths were identified and quantified by the case investigator, verified by a local review panel meeting, and agreed by the Confidential Inquiry overview panel. Contributory factors were grouped into four domains: intrinsic to the individual, within the family and environment, care provision, and service provision. The deaths of a comparator group of people without intellectual disabilities but much the same in age, sex, and cause of death and registered at the same general practices as those with intellectual disabilities were also investigated.

Findings The Confidential Inquiry reviewed the deaths of 247 people with intellectual disabilities. Nearly a quarter (22%, 54) of people with intellectual disabilities were younger than 50 years when they died, and the median age at death was 64 years (IQR 52–75). The median age at death of male individuals with intellectual disabilities was 65 years (IQR 54–76), 13 years younger than the median age at death of male individuals in the general population of England and Wales (78 years). The median age at death of female individuals with intellectual disabilities was 63 years (IQR 54–75), 20 years younger than the median age at death for female individuals in the general population (83 years). Avoidable deaths from causes amenable to change by good quality health care were more common in people with intellectual disabilities (37%, 90 of 244) than in the general population of England and Wales (13%). Contributory factors to premature deaths in a subset of people with intellectual disabilities compared with a comparator group of people without intellectual disabilities included problems in advanced care planning ($p=0\cdot0003$), adherence to the Mental Capacity Act ($p=0\cdot0008$), living in inappropriate accommodation ($p<0\cdot0001$), adjusting care as needs changed ($p=0\cdot009$), and carers not feeling listened to ($p=0\cdot006$).

Interpretation The Confidential Inquiry provides evidence of the substantial contribution of factors relating to the provision of care and health services to the health disparities between people with and without intellectual disabilities. It is imperative to examine care and service provision for this population as potentially contributory factors to their deaths—factors that can largely be ameliorated.

Funding Department of Health for England.

Introduction

Premature deaths of people with intellectual disabilities compared with the general population have been consistently identified since the 1970s.^{1–9} People with more severe intellectual disabilities have been recognised as having shorter life expectancies than those with mild intellectual disabilities.^{2–5} Predictors of early mortality in this group include limited mobility,^{3,10,11} reduced feeding ability,^{3,12} incontinence,³ institutional care,⁴ and hearing deficit¹³—most of which correlate with increasing severity of intellectual disability. Some premature mortality in people with intellectual disabilities might be expected because they often have important comorbidities and associated polypharmacy,^{14,15} which can contribute to early

death; however, there are other broader determinants of health relating to the environment, provision of care, and access to health-care services that might contribute to premature death.^{16–18} These broader determinants are increasingly being recognised in national and international policy statements.^{19,20}

The Confidential Inquiry into premature deaths of people with intellectual disabilities, commissioned by the Department of Health in England after the Michael Report²¹ concluded that there was a high likelihood of avoidable deaths of people with intellectual disabilities, attributable to untreated ill health and shortcomings in the provision of health care. An important aim of the Confidential Inquiry was to establish how similar or

Published Online
December 11, 2013
[http://dx.doi.org/10.1016/S0140-6736\(13\)62026-7](http://dx.doi.org/10.1016/S0140-6736(13)62026-7)

See Online/Comment
[http://dx.doi.org/10.1016/S0140-6736\(13\)62190-X](http://dx.doi.org/10.1016/S0140-6736(13)62190-X)

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different the circumstances leading to deaths of people with intellectual disabilities were when compared with people without intellectual disabilities. In this Article, we report the findings of the Confidential Inquiry, with a particular focus on the comparison between avoidable deaths and the contributory factors to premature deaths in people with and without intellectual disabilities.

Methods

Study design and population

The study area included five (former) Primary Care Trust areas in southwest England with a population of nearly 1.7 million and a mix of urban and rural communities. The proportion of adults with intellectual disabilities identified by general practitioners (GPs) in the study area was 0.48% (n=6962); children with intellectual disabilities formed 2.5% (n=8543) of the school population.

The Confidential Inquiry reviewed the deaths of people with intellectual disabilities aged 4 years and older registered with a GP in the study area who died between June 1, 2010, and May 31, 2012. The definition of intellectual disabilities was as described by Emerson and Heslop.²² Severity of intellectual disability was established by professional opinion or descriptors (available from the authors on request). The Confidential Inquiry investigators established a network to notify them of all deaths of people with intellectual disabilities, which included health, social-care, and voluntary-sector services; community contacts; and statutory agencies. Additional checks were made with GPs, prisons, community groups and leaders, development workers in minority ethnic communities, and services supporting people with intellectual disabilities to ensure that all eligible deaths had been reported.

For a subset of deaths of people with intellectual disabilities, the investigators reviewed the deaths of people without intellectual disabilities as comparator cases. They were registered at the same GP practices as those with intellectual disabilities who had died, and were much the same in age, sex, month of death, and broad category of death. Further contextualisation of the findings was made by reference to national mortality data.

Study approval was obtained from the NHS Research Ethics Committee, local NHS Research and Development teams, and the (former) National Information Governance Board (Section 251 approval).

Procedures

Core data were requested from all agencies providing services or support to the adults with intellectual disabilities who had died. Friends or family members who wished to contribute to the review were interviewed by an experienced specialist intellectual disabilities nurse. Paid carers and health-care and social-care professionals were interviewed by a Confidential Inquiry investigator, who also reviewed all case notes pertaining to the

individual and did a root cause analysis²³ of the death. The median number of informants per case was seven (range one to 15). The UK Office for National Statistics provided data about the coding of individual cause of death certificates for all but three cases; the cause of death for these cases were taken from post-mortem reports. All available information was collated into a standardised format and presented at a local review panel meeting to which all involved professionals were invited. The focus of the meeting was to review and discuss the circumstances of the death and any contributing factors, record good practice, and identify lessons learned and recommendations that could be made. Documentation from each case was then anonymised and scrutinised by the Confidential Inquiry overview panel, an external, multidisciplinary group of health-care and social-care professionals and family carer representatives.

For the deaths of children (<18 years) with intellectual disabilities the local statutory child death review team took the lead in conducting a review of the death, but the Confidential Inquiry overview panel, which was given full access to the reports of the child death review process, then reviewed each case again. The process of investigating the deaths of the comparator cases was the same as for the deaths of adults with intellectual disabilities.

The Office for National Statistics²⁴ defines avoidable deaths as those that are preventable, amenable, or both. A death is preventable when all or most deaths from that cause (subject to specific age limits when appropriate) could be avoided by public health interventions in the broadest sense. A death is amenable when, with the medical knowledge and technology available at the time of death, most deaths from that cause (subject to specific age limits when appropriate) could be avoided through good quality health care.

A death was deemed premature if, without a specific event that formed part of the pathway that led to death, it was probable (ie, more likely than not) that the person would have continued to live for at least 1 more year. This approach allowed consideration of whether something had (or had not) happened in the care of the person that might have contributed to the death and of additional life-limiting factors (such as lifestyle or comorbidities).

Contributory factors to deaths were identified and quantified by the case investigator, verified by the local review panel meeting, and agreed by the Confidential Inquiry overview panel. Contributory factors were grouped into four domains: intrinsic to the individual, within the family and environment, care provision, and service provision.

Potential comparator cases were identified from listings of deaths at general practices where the death of a person with intellectual disabilities had been reported. The comparator group was not matched on a 1:1 basis but was weighted (balanced) by month of death, broad cause of death, age at death, and sex to produce a similar distribution to a subset of people with intellectual

disabilities. The subset of people with intellectual disabilities was not preselected but was chosen on a month-by-month basis as candidates with the closest weighting criteria to the potential comparator cases.

Statistical analysis

Data not normally distributed were presented with medians and IQR and analysed with Mann-Whitney and Kruskal-Wallis tests. For categorical data, the χ^2 test was used, except when the expected cell count was less than five, in which case the Fisher's exact test was used.

Role of the funding source

The sponsor of the study had no role in study design, data collection, data analysis, data interpretation, or writing of the report. The corresponding author had full access to all the data in the study and had final responsibility for the decision to submit for publication.

Results

The Confidential Inquiry reviewed the deaths of 247 people with intellectual disabilities aged 4 years and older at the time of their death (table 1^{25,26}).

The total number of people with intellectual disabilities in the study area is under-estimated in official sources, making it difficult to calculate a death rate. Using the total study area population, the crude annual death rate for people with intellectual disabilities was 7.4 deaths per 100 000 population, this finding equates to 16.2 deaths per 1000 of the population who have intellectual disabilities, nearly twice the rate of 8.8 deaths per 1000 of the general population.²⁷

The median age at death for the 247 people with intellectual disabilities was 64 years (IQR 52–75; range 4–96); 14 of the deaths were of children aged 4–18 years. This finding contrasts with age at death for the general population in England and Wales in 2011 (figure²⁸). Nearly a quarter (54, 22%) of people with intellectual disabilities were younger than 50 years when they died, compared with 9% in the general population. The median age at death of male individuals with intellectual disabilities was 65 years (IQR 54–76), 13 years younger than the median age at death (78 years) of male individuals in the general population of England and Wales.²⁵ The median age at death of female individuals with intellectual disabilities was 63 years (IQR 54–75), 20 years younger than the median age at death for female individuals in the general population (83 years).²⁵ Median age at death decreased with increasing severity of intellectual disability (mild 68 years [IQR 58–77], moderate 64 years [52–75], severe 59 years [31–72], profound and multiple 46 years [41–68]; Kruskal-Wallis test $p=0.0005$), although the median age at death of those with mild intellectual disabilities was still substantially younger than the general population.

When categorised according to the International Classification of Diseases-10 (ICD-10), about the same

proportion of people with intellectual disabilities and of the general population had the underlying cause of death as respiratory system disorders, digestive system disorders, or external causes (table 2). Significantly more deaths of people with intellectual disabilities were attributable to congenital and chromosomal disorders or causes relating to the nervous system, whereas significantly more deaths in the general population were due to heart and circulatory disorders (table 2).

Avoidable deaths accounted for 24% of deaths in England and Wales in 2011.²⁴ Of the 244 people with

	Intellectual disabilities cohort (N=247)	Sample population of England and Wales* (N=480 467) ²⁵
Age at death (years)		
5–24†	27 (10.9%)	0.6%
25–34	7 (2.8%)	0.8%
35–44	13 (5.3%)	1.9%
45–54	28 (11.3%)	4.2%
55–64	50 (20.2%)	8.9%
65–74	58 (23.5%)	16.4%
≥75	64 (25.9%)	67.3%
Sex, recorded at death		
Male	143 (57.9%)	48.4%
Female	104 (42.1%)	51.6%
Ethnicity		
White UK	237 (96.0%)	80.5%‡
Non-white UK	10 (4.0%)	19.5%‡
Severity of intellectual disability		
Mild	98 (39.7%)	NA
Moderate	77 (31.2%)	NA
Severe	53 (21.5%)	NA
Profound and multiple	19 (7.7%)	NA

Data are n (%). NA=not available. *In individuals aged 5 years and older. †Data include one child aged 4 years. ‡N=56 million.²⁵

Table 1: Characteristics of the study cohort of people with intellectual disabilities, and data for the total population of England and Wales in 2011

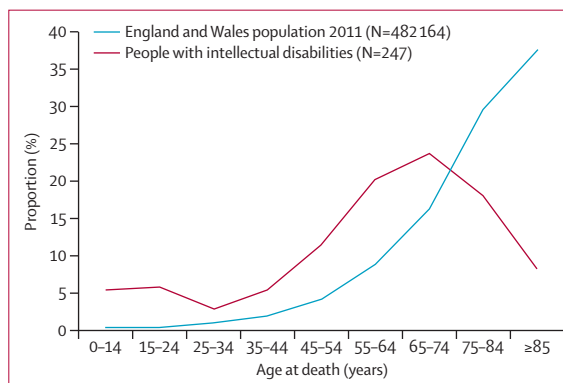


Figure: Age at death of people with intellectual disabilities compared with that for people who died in England and Wales in 2011. Reproduced from the full report of the Confidential Inquiry.²⁸

intellectual disabilities for whom final ICD-10 coding of cause of death was available, avoidable deaths accounted for 49% (119) of deaths. The proportion of deaths preventable by public health interventions was 21% for the population of England and Wales and 21% (52) in the cohort of people with intellectual disabilities.

The difference between the proportion of avoidable deaths in the general population and the intellectual disabilities cohort was entirely accounted for by causes of death deemed to be amenable to good quality health-care: 13% of deaths in England and Wales were from causes amenable to good quality health care, compared with 37% (90 of 244) of deaths in the intellectual disabilities cohort.

Within the intellectual disabilities cohort, individuals whose deaths were amenable to good quality health care were younger than those whose deaths were not amenable (median age 58 years [IQR 43–59] vs 70 years [57–79]; Mann-Whitney $p < 0.0001$), had more severe intellectual disabilities (37% [33 of 90] had severe or profound intellectual disabilities vs 25% [38 of 154]; $\chi^2 p = 0.04$), were more likely to have died from an underlying cause of death related to congenital and chromosomal abnormalities (20% [18 of 90] vs none; $\chi^2 p < 0.0001$), and were less likely to have had support from a partner or significant friend (24% [22 of 90] vs 38% [58 of 154]; $\chi^2 p = 0.03$) than were those whose deaths were not amenable to good quality health-care.

The Confidential Inquiry overview panel concluded that 42% (100) of the 238 deaths about which they reached agreement were premature.

For the comparator study, there were no significant differences between the subset of 58 people with intellectual disabilities and the remaining 189 people in the intellectual disabilities cohort regarding season of death (48% [28] of the intellectual disabilities subset and 54% [102] of the rest of the intellectual disabilities cohort died in winter [October–March]; Mann-Whitney $p = 0.45$),

and although there was a slight excess of cancer-related deaths in the subset (29%, 17) compared with the rest of the cohort (18%, 34), the broad categorisation of underlying cause of death was much the same in the two groups ($\chi^2 p = 0.29$). There were fewer male individuals in the subset (50%, 29) than in the rest of the cohort (60%, 113), and fewer with severe or profound intellectual disabilities (19% [11] in the subset vs 32% [60] in the rest of the intellectual disabilities cohort), although neither of these differences reached significance ($\chi^2 p = 0.19$ and $\chi^2 p = 0.14$, respectively). For this comparison, we deliberately focused on deaths in people younger than 75 years, who in population terms would have been deemed to have died prematurely according to Office for National Statistics definitions; thus the intellectual disabilities subset was significantly younger (median age at death 61 years [IQR 52–67]) than the remaining 189 people with intellectual disabilities (67 years [51–77]; Mann-Whitney $p = 0.006$).

The 58 comparator cases were broadly weighted with the subset of 58 people with intellectual disabilities for age, sex, time of death, and broad cause of death. Median age at death was 60 years (IQR 53–63) for the comparator group and 61 years (52–66) for the intellectual disabilities subset (Mann-Whitney test $p = 0.36$). There were more male individuals (59%, 34) in the comparator group than in the intellectual disabilities subset (50%, 29) although this difference was not significant ($\chi^2 p = 0.35$). Season of death did not differ between the groups (50% [29] of the comparator group and 48% [28] of the intellectual disabilities subset died in winter; Mann-Whitney $p = 0.83$). Slightly more individuals in the comparator group (40%, 23) had cancer as their underlying cause of death than did the intellectual disabilities subset (29%, 17), but the broad categorisation of cause of death did not differ between the two groups ($\chi^2 p = 0.64$). However, weighting the comparison by broad categorisation of death excluded a proportion of deaths largely prevalent among individuals younger at death in the general population (related to alcohol, drugs, and suicide) that were not prevalent among those who died with intellectual disabilities. Most individuals in the comparator group (95%, 55) and in the intellectual disabilities subset (98%, 57) were of white British ethnic background. In view of the paucity of work experience and reduced educational opportunities and the predominance of residential care for those with intellectual disabilities, it was not possible to use traditional markers of socioeconomic status to match the two groups.

Of the intellectual disabilities subset, 69% (40) died from underlying causes of death considered to be avoidable according to the Office for National Statistics' categorisation, compared with 66% (38) among the comparators, a non-significant difference ($\chi^2 p = 0.64$). However, there were significant differences when considering whether the deaths were deemed preventable or amenable. Deaths preventable by public health interventions were more common in the comparator group

	Intellectual disabilities cohort (N=247)	All deaths in England and Wales* (N=480 467) ²⁵	p value†
Heart and circulatory disorders	53 (21%)	28.8%	0.01
Cancer (neoplasm)	50 (20%)	29.6%	0.001
Nervous system	39 (16%)	3.8%	<0.0001
Respiratory disorders	37 (15%)	14.0%	0.66
Congenital and chromosomal	18 (7%)	0.2%	<0.0001
Digestive system	12 (5%)	5.1%	0.86
External causes	10 (4%)	3.6%	0.71
Endocrine, nutritional, and metabolic	7 (3%)	1.3%	0.06
Mental and behavioural disorders	6 (2%)	6.4%	0.01
Other	15 (6%)	7.4%	0.43

Data are n (%) or %. ICD=International Classification of Diseases. *In individuals aged 5 years and older. †From χ^2 test.

Table 2: Most frequent ICD-10 categories of underlying cause of death for the study cohort of people with intellectual disabilities and for all deaths in England and Wales in 2011

(25%, 14) than in people with intellectual disabilities (17%, ten) although not significantly so (χ^2 $p=0.33$), whereas deaths from causes amenable to change by good quality health-care were significantly more common in people with intellectual disabilities (38%, 22) than in the comparator group (9%, five; χ^2 $p=0.002$).

The proportion of premature deaths was 52% (30) in the intellectual disabilities subset, and 43% (25) in the comparator group, a non-significant difference (χ^2 $p=0.34$). Of those deaths classed as premature, neither age nor causal classification was a factor in recording the death as premature or not.

We compared the detailed circumstances leading to death in the intellectual disabilities subset and the comparator group (table 3). We identified significant differences between the intellectual disabilities subset and the comparator cases in all four domains. In particular, a significantly greater proportion of deaths in the intellectual disabilities group had inadequate or inappropriate accommodation for the person's needs; family or paid carers who did not feel they were listened to; problems in advanced health care and planning; problems in recognising the person's needs and adjusting care when needs changed; and poor adherence to the Mental Capacity Act,²⁹ particularly in relation to assessment of a person's capacity to make a decision and to the decision making process regarding that person's health care.

Discussion

Our data suggest that, on average, male individuals with intellectual disabilities die 13 years earlier than the population of England and Wales, and female individuals die 20 years earlier. Avoidable deaths from causes amenable to change with good quality health care are more common in people with intellectual disabilities than in the general population. When compared with people without intellectual disabilities, contributory factors to premature deaths in people with intellectual disabilities include problems in advanced care planning, adherence to the Mental Capacity Act, living in inappropriate accommodation, adjustment of care as needs changed, and carers not feeling listened to.

Our findings are observations of associations that might not all be causally linked to each death reviewed by the Confidential Inquiry. However, the consistent patterns in the findings suggest that meaningful changes to practice can be recommended. By reviewing the circumstances leading to the deaths of a subset of people with intellectual disabilities and a comparator group of people without intellectual disabilities, we have shown that contributory factors to the deaths of people with intellectual disabilities occur across several domains, especially in relation to care and service provision (panel 1). Although these findings should be considered with caution because of the small sample sizes and the weighting criteria used, they suggest that all parties involved in the provision of care and support to people

	Subset of intellectual disability deaths (n=58)	Comparator deaths (n=58)	p value*
Intrinsic factors			
Lifestyle choices†	12 (21%)	24 (41%)	0.02
Dependence on others for mobility and feeding	15 (26%)	6 (10%)	0.03
Family and environmental factors			
Inadequate or inappropriate accommodation for the person's needs	19 (33%)	3 (5%)	<0.0001
Family or paid carers not feeling listened to	8 (14%)	0	0.006‡
Factors regarding the provision of care			
Problems in advanced health and care planning	24 (41%)	6 (10%)	0.0003
Problems with recognising needs and adjusting care as needs change	24 (41%)	11 (19%)	0.009
Problems with coordination of care and information sharing	26 (45%)	15 (26%)	0.03
Problems with record keeping and accessing records	20 (34%)	10 (17%)	0.03
Factors regarding service provision			
Problems with the Mental Capacity Act being followed	21 (36%)	5 (9%)	0.0008
Delays in the diagnosis and treatment of health-care problems	39 (67%)	27 (47%)	0.02

Data are n (%). *From χ^2 test. †Eg, smoking, alcohol, use of non-prescribed drugs, unhealthy diet. ‡From Fisher's exact test.

Table 3: Factors identified as having contributed to the deaths that were significantly different for the intellectual disabilities subset and comparator cases

Panel 1: Research in context

Systematic review

We searched the Cochrane Library, Medline, and Embase, for reports in English published from Jan 1, 2000, to Oct 1, 2013, using the terms "confidential inquiry" (or "enquiry") and "intellectual disability/disabilities" or "learning disability/disabilities". We also searched the same sources using the key words "mortality review" and "intellectual disability/disabilities" or "learning disability/disabilities".

We identified only one report, that of Tyrer and colleagues,⁶ which was a population-based study in one area of the UK that explored cause-specific mortality in adults with intellectual disabilities compared with the general population. Tyrer and colleagues concluded that strategies to reduce inequalities in people with intellectual disabilities should focus on decreasing mortality from potentially preventable causes, such as respiratory infections, circulatory system diseases, and accidental deaths.

Interpretation

The Confidential Inquiry into premature deaths of people with intellectual disabilities was the first of its kind in England. It reviewed the deaths of all known people with intellectual disabilities over a 2-year period in an area of England that had a total population of 1.7 million individuals. A comparator group of people of a similar age and cause of death as people without learning disabilities was investigated to place the findings in context. Each death was reviewed in depth and involved all agencies and support services in contact with the deceased. All reports were anonymised and were then reviewed by an external multidisciplinary overview panel.

Our findings show that people with intellectual disabilities were likely to die, on average, 16 years earlier than the general population. A range of potentially modifiable factors were related to care and service provision, and all aspects of care provision, planning, coordination, and documentation were significantly poorer for people with intellectual disabilities than for the comparator group of people without intellectual disabilities. The findings suggest that although some individual factors are of importance, factors relating to care and service provision contribute to excess mortality in people with intellectual disabilities.

with intellectual disabilities must examine problems with care and service provision as contributors to premature deaths; these factors can largely be ameliorated and are inherently unjust. With this in mind the Confidential Inquiry proposed 18 recommendations (panel 2) that, if implemented, would lessen the risk of premature death in people with intellectual disabilities.²⁸

The strength of the Confidential Inquiry is that it has taken a population-based approach to reviewing in depth all known deaths of people with intellectual disabilities in a particular geographical area that is broadly representative of England as a whole. Without a comprehensive register of people with intellectual disabilities, it is difficult to be sure that we reviewed every eligible death, but the wide-ranging notification system provided

confidence that few, if any, deaths were missed. The inclusion of people with mild intellectual disabilities was important to ascertain contributory factors for premature deaths across the spectrum of intellectual disabilities, but we acknowledge that there is no clear dividing line between those who do or do not have intellectual disabilities. Our reliance on past evidence of intellectual disabilities,²² professional opinion, or descriptors to define the degree of intellectual disability differs from the methods of other studies, although the proportions we identified are in line with the predicted new entrants to social care from 2011 to 2030.³⁰

The number of deaths of people with intellectual disabilities was two and a half times more than the number we originally estimated on the basis of reports in the scientific literature.²⁷ Such a discrepancy draws attention to the absence of comprehensive registration and mortality data for people with intellectual disabilities in England. A need exists to link data about cause of death with appropriate registers of adults and children with intellectual disabilities, so that the age and cause of death of people with intellectual disabilities can be monitored at a national level, and can be reviewed within a health equalities framework.

Results of a study by Lavin and colleagues⁵ suggested that mortality in people with intellectual disabilities in Ireland might be 10–16-times higher than in the general population, whereas Tyrer and colleagues⁶ reported a three-times increase in mortality in people with moderate to profound intellectual disabilities in the UK, which is in line with our finding of a two-times increase in people with mild, moderate, severe, and profound intellectual disabilities. Nearly a quarter (22%) of people with intellectual disabilities were younger than 50 years when they died, compared with about 9% of the general population. We showed that the risk of dying at an early age was greatest for people with more severe intellectual disabilities, but the median age at death of people with mild intellectual disabilities (68 years) was still substantially younger than in the general population. Therefore, our results do not support findings from Finland⁴ that life expectancy of people with mild intellectual disabilities is approaching that of the general population.

Twice as many deaths were deemed avoidable in the intellectual disabilities cohort as in the general population in England and Wales. Importantly, we identified no difference in deaths preventable by public health interventions: the difference was wholly explained by deaths amenable to change with good quality health care. People with more severe intellectual disabilities, with congenital and chromosomal abnormalities, or without support from a partner or significant friend were particularly likely to have deaths amenable to change with good quality health care, suggesting that a targeted approach to the improvement of care is needed for these groups.

Panel 2: Recommendations of the Confidential Inquiry into deaths of people with intellectual disabilities

- 1 Clear identification of people with learning disabilities on the National Health Service central registration system and in all health-care record systems.
- 2 Reasonable adjustments required by, and provided to individuals, to be audited annually and examples of best practice to be shared across agencies and organisations.
- 3 National Institute for Health and Care Excellence guidelines to take into account multi-morbidity.
- 4 A named health-care coordinator to be allocated to people with complex or multiple health needs, or two or more long-term conditions.
- 5 Patient-held health records to be introduced and given to all patients with learning disabilities who have multiple health conditions.
- 6 Standardisation of annual health checks and a clear pathway between annual health checks and health action plans.
- 7 People with learning disabilities to have access to the same investigations and treatments as anyone else, but acknowledging and accommodating that they may need to be delivered differently to achieve the same outcome.
- 8 Barriers in individuals' access to health care to be addressed by proactive referral to specialist learning disability services.
- 9 Adults with learning disabilities to be considered a high-risk group for deaths from respiratory problems.
- 10 Mental Capacity Act advice to be easily available 24 h a day.
- 11 The definition of serious medical treatment and what this means in practice to be clarified.
- 12 Mental Capacity Act training and regular updates to be mandatory for staff involved in the delivery of health or social care.
- 13 Do not attempt cardiopulmonary resuscitation guidelines to be more clearly defined and standardised across England.
- 14 Advanced health and care planning to be prioritised. Commissioning processes to take this into account, and be flexible and responsive to change.
- 15 All decisions that a person with learning disabilities is to receive palliative care only should be supported by the framework of the mental capacity act and the person referred to a specialist palliative care team.
- 16 Improved systems in place nationally for the collection of standardised mortality data about people with learning disabilities.
- 17 Systems in place to ensure that local learning disability mortality data are analysed and published on population profiles and joint strategic needs assessments.
- 18 Establishment of a national learning disability mortality review body.

Reproduced from the full report.²⁸

Contributors

PH was lead author, grant-holder, and manager of the Confidential Inquiry, and contributed to all aspects of the study design, data collection, data analysis and interpretation, and writing of the Article. PSB was statistician for the Confidential Inquiry, and contributed to all aspects of the study design, data analysis and interpretation, and writing of the Article. PF was chair of the overview panel of the Confidential Inquiry, and contributed to all aspects of the study design, data collection, data analysis and interpretation, and writing of the Article. MH was lead investigator for the Confidential Inquiry, and contributed to all aspects of the study design, data collection, data analysis and interpretation, and writing of the Article. AM was project worker for the Confidential Inquiry with particular responsibility for management and support of the overview panel, and contributed to all aspects of the study design, data collection, data analysis and interpretation, and writing of the Article. LR was lead nurse for the Confidential Inquiry, and contributed to all aspects of the study design, data collection, data analysis and interpretation, and writing of the Article. All authors approved the final version.

Conflicts of interest

We declare that we have no conflicts of interest.

Acknowledgments

A full list of acknowledgments is given in the final report.²⁸ We thank the families and formal and informal contacts of those who had died whose deaths were reviewed. We thank the Department of Health, England, who funded this work.

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