The impact of the Confidential Inquiry into premature deaths of people with ID in England (CIPOLD)

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What I will cover

- CIPOLD
- Measuring impact
- Impact on those reviewing deaths
- Impact nationally
- New national ID mortality review
What is a Confidential Inquiry?

Key features:
• A focused review of a particular issue
• The details of each incident are critically, independently and anonymously reviewed by a team of experts
• They are “confidential” in that details of the patients/cases remain anonymous, though reports of overall findings are published
• Their overall aim is to detect areas requiring improvement and devise recommendations to resolve them

What did we do?

We reviewed:
• All known deaths of people with ID
• In a region of SW England with a general population of 1.7m
• Deaths occurred between 1st June 2010 – 31st May 2012
233 adults with ID
14 children with ID
58 comparator cases
What did we find out?

- Deaths of people with ID at significantly younger ages than the general population
- A significant burden of avoidable deaths

<table>
<thead>
<tr>
<th>Preventable mortality</th>
<th>Amenable mortality:</th>
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<tbody>
<tr>
<td>All or most deaths from that cause could be avoided by public health interventions in the broadest sense.</td>
<td>All or most deaths from that cause could be avoided through good quality healthcare.</td>
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<tr>
<td>21% (all)</td>
<td>13% (all)</td>
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<tr>
<td>21% (ID)</td>
<td>36.5% (ID)</td>
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Confidential Inquiry and change

We sought to assess:

- Impact on practitioners participating in the process
- Impact of the wider adoption of recommendations arising from the Inquiry findings
Monitoring the impact of the work

- Formal feedback a few weeks after involvement (practitioners, families, panel members)
- National ‘roadshow’
- ‘Linked-In’ web group
- One year after the Inquiry, participants asked to report actions taken in response to CIPOLD
- Government response and action plan, and ongoing engagement at policy level
- Review of policy and associated documents

Impact on practitioners participating

- Better understanding and adherence to relevant existing legislation and guidance
- Increased awareness of multi-disciplinary colleagues and their roles – and developed improved ways of working together
- Enhanced holistic approach
Impact on practitioners participating

- Improved accuracy and completeness of documentation
- A focus on joint decision-making, and less of a tendency to make decisions in isolation
- Training needs identified and met
- Recognition of gaps in our knowledge about people with ID at strategic level

Impact of the adoption of recommendations - national level

- GP registers of people with ID expanded to be all age registers
- Annual health checks for people with ID now include 14-17 year olds
- Changes in the national flu immunisation plan – now more specific about targeting people with ID for immunisation
- New questions used at Care Quality Commission inspections of acute hospitals, specifically about care of people with ID
National ID mortality review programme

Key aims of the programme

• To drive improvement in the quality of health and social care service delivery for people with ID
• To help reduce premature mortality and health inequalities in this population

Key elements of the programme

• Support local areas to conduct standardised reviews of deaths of all people with ID
• Provide training and quality surveillance function
• Check that resulting action plans are followed up and improvements made to practice
• Analyse and report national data and trends, including through data linkage
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