Are Health Checks for people with Intellectual disability leading to improved outcomes in England?

Dr Umesh Chauhan
Definition of Intellectual Disability

The term intellectual disabilities (ID) is used to describe a significant, lifelong experience that has three components:

• A significantly reduced ability to understand new or complex information, to learn new skills (significantly impaired intelligence) AND

• A reduced ability to cope independently (impaired social/adaptive functioning) AND

• Which started before adulthood (onset before aged 18) with a lasting effect on
Background

• 1.2 million people have Intellectual Disability (ID)¹

• Higher rates of mortality and morbidity²⁻⁴
  – People with ID are 58 times more likely to die before the age of 50 than the general population
  – 4 times more likely to have a preventable cause of death

• Routine Health Checks increase detection of health problems ⁵⁻⁸
Life expectancy

- People with ID will have a shorter life expectancy:
  - men with ID die 13 yrs younger (median age of death 65 years)
  - women with ID die 20 yrs younger (median age of death 63 years)
  - many of the illnesses people with ID die from can be prevented

(Confidential Inquiry Report, 2013: Reviewed death of nearly 250 with ID and 58 comparator cases)
Causes of death

• **Respiratory disease**: Leading cause of death (46%-52%); people with ID who smoke are 2 times more likely to have asthma: there is a strong link with obesity and respiratory disease⁹

• **Coronary heart disease**: 14%-20% of people with ID die from CHD

• **Cancer**:
  - higher rates of gastrointestinal and gallbladder cancer
  - increasing rates of breast and cervical cancers as people age
Health conditions

- **Sensory impairments:** People with ID are more likely to have vision, hearing and dental problems.

- **Physical impairments:** People with ID are 14 times more likely to be immobile and this has been associated with a sevenfold increase in death.

- **Epilepsy:** People with ID are 20 times more likely to have epilepsy, with seizures commonly multiple and resistant to drug treatment.
Why Do We Have Health Checks?

- People with learning disabilities are disadvantaged in elective (opt in) primary health care systems
  - Recognising ill health
  - Communicating
  - Getting access
- Health checks are the most important ‘reasonable adjustment’ we can make
Background

Quality Outcomes Framework (QOF) introduced an indicator for Intellectual disability in 2006

The practice can produce a register of patients aged 18 and over with learning disabilities.

Annual health checks for people with intellectual disabilities started 2008 as part of a Directed Enhanced Service (DES).
### Uptake of Health Checks 2008/9-2011/12 (%change from previous year)

<table>
<thead>
<tr>
<th></th>
<th>2008/9</th>
<th>2009/10</th>
<th>2010/11 (revised)</th>
<th>2011/12</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of people who</td>
<td>27,011</td>
<td>58,919</td>
<td>73,068</td>
<td>86,023</td>
</tr>
<tr>
<td>received a health check</td>
<td>(+118%)</td>
<td>(+24%)</td>
<td>(+18%)</td>
<td></td>
</tr>
<tr>
<td>Number of people identified</td>
<td>118,230</td>
<td>145,130</td>
<td>153,021</td>
<td>162,945</td>
</tr>
<tr>
<td>as eligible to receive a</td>
<td>(+23%)</td>
<td>(+5%)</td>
<td>(+6%)</td>
<td></td>
</tr>
<tr>
<td>health check</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>% of identified eligible</td>
<td>23%</td>
<td>41%</td>
<td>48%</td>
<td>53%</td>
</tr>
<tr>
<td>people who received a</td>
<td>(+78%)</td>
<td>(+18%)</td>
<td>(+11%)</td>
<td></td>
</tr>
<tr>
<td>health check</td>
<td></td>
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</tbody>
</table>

http://www.improvinghealthandlives.org.uk/
One of three studies

1. We wanted to know what it is like for people with intellectual disability to have a health check?

2. We also wanted to know what it is like for doctors and nurses to try and do health checks?

3. We wanted to know what doctors and nurses record in a health check?
Where did we go?

We looked at information from over 160 doctor’s surgeries.

We looked at the notes of over 4,000 people with intellectual disability.
## Data Analysis

<table>
<thead>
<tr>
<th>QOF targets’ processes</th>
<th>ID specific Health Check Processes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Coded Data</strong></td>
<td><strong>Coded Data</strong></td>
</tr>
<tr>
<td>Blood Pressure (annual)</td>
<td>Health Action Plan (annual)</td>
</tr>
<tr>
<td>Smoking Status (annual)</td>
<td>Visual Assessment (annual)</td>
</tr>
<tr>
<td>Ethnicity (ever)</td>
<td>Hearing Assessment (annual)</td>
</tr>
<tr>
<td>Body Mass Index (annual)</td>
<td>Bowel Assessment (annual)</td>
</tr>
<tr>
<td>Medication Review (annual)</td>
<td>Behaviour Assessment (ever)</td>
</tr>
<tr>
<td>Flu vaccination (annual)</td>
<td>Self-neglect Assessment (ever)</td>
</tr>
</tbody>
</table>
What did we find?

Most doctors’ surgeries are doing health checks.

More people with Intellectual disability are having health checks.
What did we find?

Only half of the people with intellectual disability are getting health checks.

Some parts of the health check are not being done as well as others.
What did we find?

People with intellectual disability have other problems like diabetes, asthma and being overweight.
QOF comorbidity prevalence in 2010 and 2011

Epilepsy
Diabetes
Hypertension
Depression
CKD
Thyroid
Mental Health
Obesity (BMI)

2010 Data
2011 Data
Case Finding of QOF conditions by health check in 2011 (condition not present in 2010)

- Epilepsy (P=0.07)
- Diabetes (P<0.001)
- Hypertension (P<0.001)
- Depression (P=0.8)
- CKD (P=0.02)
- Thyroid (P=0.03)
- Mental Health (P=0.4)

Health Check
No Health Check
Comorbidity Prevalence Data

<table>
<thead>
<tr>
<th>Comorbidity</th>
<th>England General Population (QOF)</th>
<th>2011 LD population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Epilepsy</td>
<td>0.0%</td>
<td>21.0%</td>
</tr>
<tr>
<td>Diabetes</td>
<td>5.0%</td>
<td>20.0%</td>
</tr>
<tr>
<td>Hypertension</td>
<td>10.0%</td>
<td>15.0%</td>
</tr>
<tr>
<td>Depression</td>
<td>15.0%</td>
<td>10.0%</td>
</tr>
<tr>
<td>Thyroid</td>
<td>20.0%</td>
<td>5.0%</td>
</tr>
<tr>
<td>Mental Health</td>
<td>25.0%</td>
<td>0.0%</td>
</tr>
</tbody>
</table>
## QOF Incentivised Processes

<table>
<thead>
<tr>
<th></th>
<th>Record by health check for 2011</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No Health Check [2358] (%)</td>
</tr>
<tr>
<td><strong>Medication Review (&lt;15 months)</strong></td>
<td>552 (23.4)</td>
</tr>
<tr>
<td><strong>Ethnicity (ever)</strong></td>
<td>1108 (47)</td>
</tr>
<tr>
<td><strong>Carer Detail (ever)</strong></td>
<td>569 (24.1)</td>
</tr>
<tr>
<td><strong>Influenza vaccination (annual)</strong></td>
<td>649 (27.5)</td>
</tr>
</tbody>
</table>
## Health Promotion Incentivised Processes

<table>
<thead>
<tr>
<th>Record by health check for 2011</th>
<th>No health check [2358] (%)</th>
<th>Health check [1674] (%)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alcohol data (annual)</td>
<td>455 (19.3)</td>
<td>1148 (68.6)</td>
<td>P&lt;0.001</td>
</tr>
<tr>
<td>Exercise assessment (annual)</td>
<td>583 (24.7)</td>
<td>1096 (65.5)</td>
<td>P&lt;0.001</td>
</tr>
<tr>
<td>Diet assessment (annual)</td>
<td>321 (13.6)</td>
<td>625 (37.3)</td>
<td>P&lt;0.001</td>
</tr>
<tr>
<td>Smoking Status (&lt;15 months) (excluding non smokers)</td>
<td>428/854 (50.1)</td>
<td>614/614 (92.6)</td>
<td>P&lt;0.001</td>
</tr>
</tbody>
</table>
## Screening Processes linked to QOF incentives

<table>
<thead>
<tr>
<th></th>
<th>Record by health check for 2011</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No health check [2358] (%)</td>
</tr>
<tr>
<td>Blood Glucose Test</td>
<td>495 (21)</td>
</tr>
<tr>
<td>Renal Function</td>
<td>772 (32.7)</td>
</tr>
<tr>
<td>TFT</td>
<td>623 (26.4)</td>
</tr>
<tr>
<td>Blood Pressure</td>
<td>1301 (55.2)</td>
</tr>
<tr>
<td>Cholesterol</td>
<td>621 (26.3)</td>
</tr>
<tr>
<td>Urine analysis*</td>
<td>210 (8.9)</td>
</tr>
</tbody>
</table>

*Screening for protein, blood and glucose*
# Intellectual disability specific health check Processes

<table>
<thead>
<tr>
<th></th>
<th>Record by Health Check for 2011</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No health check [2358] (%)</td>
<td>Health check [1674] (%)</td>
</tr>
<tr>
<td>Health Action Plan (annual)</td>
<td>9 (0.4)</td>
<td>342 (20.4)</td>
</tr>
<tr>
<td>Visual Assessment (annual)</td>
<td>74 (3.1)</td>
<td>743 (44.4)</td>
</tr>
<tr>
<td>Hearing Assessment (annual)</td>
<td>45 (1.9)</td>
<td>883 (52.7)</td>
</tr>
<tr>
<td>Bowel Assessment (annual)</td>
<td>5 (0.2)</td>
<td>94 (5.6)</td>
</tr>
<tr>
<td>Mobility Assessment (ever)</td>
<td>169 (7.2)</td>
<td>693 (41.4)</td>
</tr>
<tr>
<td>Behaviour Assessment (ever)</td>
<td>38 (1.6)</td>
<td>142 (8.5)</td>
</tr>
<tr>
<td>Self-neglect Assessment (annual)</td>
<td>7 (0.3)</td>
<td>19 (1.1)</td>
</tr>
<tr>
<td>Housing Dependency (ever)</td>
<td>300 (12.7)</td>
<td>504 (30.1)</td>
</tr>
<tr>
<td>Feeding Assessment (annual)</td>
<td>1 (0.04)</td>
<td>5 (0.3)</td>
</tr>
</tbody>
</table>
Regression Analysis

• Increasing age, female gender and the presence of comorbidity (e.g. diabetes) were associated with higher probability of receiving a health check.

• Health Checks associated with increased ‘new QOF Disease’ case finding and referrals for care to other health professionals.

• Size of intellectual disability register, practice list size and Index of Multiple Deprivation at the Super Output Area not significant.
Conclusion

• There is increased case finding in terms of people with intellectual disability and level of comorbidity

• Health checks associated with increased coding activity for QOF incentivised health screening, promotion and disease finding.

• Considerable variation in coding of other aspects of the health check.
what is it like for people with intellectual disability to have a health check?
Where did we go?

• We asked questions in two places:
  » East Lancashire
  » Haringey, London
What we did

• We looked into the lives of 32 people with intellectual disability
• Talked to 64 people
• Included those
  – Who had a health check
  – Who were not offered a health check
  – Who refused to have a health check
What did we find?

- Access (making an appointment with a doctor)
- Communication (talking to doctors and nurses)
- Continuity (knowing your doctor)
- Views on Health Checks
Access (making an appointment)

PwLD: “I phoned up the surgery.. It’s a bit hard to get through... you press 1 for booking appointments... yeah they (the receptionists) give you appointments when you need it.”

Family carer: “whenever you're in the doctors it's like, ring us on the day, ring us before 9, well sometimes I'm not here before 9. I do my best but sometimes I'm dropping my kids off at school.”
Communication problems

» With the practice
» With doctors and nurses
» Between doctors
Communication

PwLD: “I think it would help me if, like I say, I am bad at speaking, they would let me take my time and instead of saying “Come on, spit it out” you know what I mean?”

PwLD: “Every practice should give people with a disability a bit more time to see them. Instead of 10 minutes they should get 15. Because then you can really get to tell him (the doctor) my problem. Because with 10 minutes, you tell him half of it then you’ve run out of time.”
what is it like for doctors and nurses to try and do health checks?
What did we find?

The extra money helped doctors and nurses to make time to do the health checks.
Doctors and nurses feel they are getting better at doing health checks. They find this easier when 1 person is in charge of planning the health checks.
<table>
<thead>
<tr>
<th>Facilitator</th>
<th>Barrier</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Making sense</strong></td>
<td>Perceiving a value to health checks, over and above usual care</td>
</tr>
<tr>
<td><strong>Engaging</strong></td>
<td>Financial resource to support implementation and/or as the justification for prioritising care for this group</td>
</tr>
<tr>
<td><strong>Doing</strong></td>
<td>Resources – existing presence of skills (and interest) within practice, possibly enhanced by training</td>
</tr>
<tr>
<td></td>
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<tr>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Monitoring</strong></td>
<td>Contract acts as feedback that work is externally valued</td>
</tr>
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</tbody>
</table>
Normalising Care

☑ Automatic payment to practices for health checks linked to Read Coding
  ☑ CQRS (Calculating Quality Reporting System)

• Integration of health checks into QOF (similar to mental health)

• Health checks for all people with learning disability
Examples of Reasonable Adjustments

» Some Doctors’ Surgeries will phone you to make an appointment for a Health check and call again to remind you.

» Some doctors’ surgeries give you an appointment at a time when it suits you.

» Some doctors will come and see you in your home to do a health check.
Joined up care

» Community Learning Disability Nurses help to make and keep appointments.

» They also help to explain what doctors are saying.

» Health Action Plans also help doctors to know more about you.
Summary

- Health checks were introduced to decrease documented and substantial inequity in access.
- Health checks within a primary care setting have proven to be an effective method for detecting unmet needs.
- There is a need to develop a model of learning disability health checks in collaboration with people with intellectual disability, carers, and health professionals.
Confidential Inquiry Recommendations

• Routine collection of mortality data at national and local levels
• Enforcement reasonable adjustments
• Address fragmented care
  • Care coordination
  • Hand held records
  • Pathway between Annual health Checks and Health Action Plans
Confidential Inquiry Recommendations

- Addressing the weak link in the chain – diagnosis of illness
- Strengthen the protection of people under Mental Capacity Act
- Clarify Do Not Attempt Cardiopulmonary Resuscitation guidelines
Why develop standards for a national audit

- Insufficient data are currently available to effectively regulate learning disability services
- Concerns surrounding how primary and secondary care services make and record diagnoses for people with learning disabilities
- Lack of information about the way service users access mental and physical health services and health screening.
- The extent of integration between physical health, mental health and specialist health care is a particular concern in the learning disability population
- People with mild learning disabilities may have more difficulties accessing care than people with severe/profound learning disabilities, who are better known to services.
National Audit of Learning Disability (NALD)

• Feasibility Study
• Funded by Healthcare Quality Improvement Partnership (HQIP)
• Led by Royal College of Psychiatrist and RCGP

  – The aim of the study is to determine the feasibility and scope of a future national clinical audit of the physical and mental health care for adults with learning disability.
Key Stages

• Stage 1: Agreeing provisional audit standards
• Stage 2. Testing a system for extracting primary care data
• Stage 3. Testing a system for collecting secondary care data
• Stage 4. Testing out systems for measuring the experience of service users and carers
Stage 1: Agreeing provisional audit standards

• Standards are likely to cover several areas:
  – The experience of people with LD
  – Staff training and knowledge around LD
  – The frequency and quality of health care assessments
  – The frequency of screening, immunisations and health promotion
  – Assessment and care planning
  – The treatment delivered in primary and secondary care
  – The provision of reasonable adjustments.
Examples of potential audit standards

• Patient Level (service user and carer experience)
  – Percentage of patients who have a positive experience of
    i. GP Services and
    ii. GP Out of Hours
  (based on responses to the GP Patient Survey).
  – Friends and family test
Possible audit standards (related to QOF)

• The percentage of patients with learning disability who have had influenza immunisation in the preceding 1 September to 31 March
  – Coronary Heart Disease (CHD12)
  – Stroke or TIA (Stroke 10)
  – Diabetes (DM18)
  – COPD (COPD 8)
  – (All ≥ 65 years, chronic neurological disease, CKD, long stay care patients)
References


Collaborators

- Dr Joanne Reeve¹
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³ Freelance
Thank You

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