Clinical Guidelines Contribute to the Health Inequities Experienced by Individuals with Intellectual Disabilities

Implementation Science 2012, 7:42.
Mizen LA, Macfie ML, Findlay L, Cooper SA, Melville CA

Dr Lindsay Mizen
Honorary Clinical Fellow

RCPsych Faculty of the Psychiatry of ID Conference
27th September 2013
Background

- Health inequalities – “differences in health status or in the distribution of health determinants between different population groups” (WHO)
- Health inequities – “avoidable inequalities in health between groups of people” (WHO)
- People with intellectual disabilities (ID) experience significant health inequalities
- Clinical guidelines aim to improve quality of healthcare and patient outcomes
- Only some guideline organisations state they consider health inequalities in the process
Aim & Research Questions

- **Aim:** to examine whether clinical guidelines address the health inequalities experienced by people with ID

- **Research questions:**
  1. Do clinical guidelines identify individuals with ID as a group who are at increased risk of the disorder?
  2. Do clinical guidelines include content relevant to the specific health needs of persons with ID?
  3. Do guideline development processes take into consideration the specific health needs of persons with ID?
Measurements

International Clinical Epidemiology Network (INCLEN) Equity Lens:

1. Do the public health recommendations in the guidelines address a priority problem for disadvantaged and privileged populations?
2. Is there a reason to anticipate different effects of intervention in disadvantaged and privileged populations?
3. Are the effects of the intervention valued differently by disadvantaged compared to privileged populations?
4. Is specific attention given to minimising barriers to implementation in disadvantaged population?
5. Do plans for assessing the impact of the recommendations include disadvantaged populations?
Data Collection

- Semi-structured data collection tool
- 3 sections:
  - Population relevance
  - Guideline content
  - Guideline development process
Selection of Guidelines

- National Guideline Clearing House
- 9 health problems of higher prevalence in people with ID:
  - Bipolar affective disorder
  - Schizophrenia
  - Obesity
  - OSA
  - Accidents/injuries or falls
  - Dementia
  - Epilepsy
  - Osteoporosis
  - Upper GI disorders
Guideline Selection Criteria

- English language
- International
- From countries with guidelines available for $\geq 2$ of the 9 health problems
Data Extraction

- Guidelines read and searched electronically by 2 medically qualified independent raters

- 8 search terms:
  - Disability
  - Impairment
  - Learning
  - Disabilities
  - Handicap
  - Mental
  - Retardation
  - Intellectual

- Consensus meeting to discuss data & resolve discrepancies
Equity Lens Criteria Results

Number of Guidelines

Priority problem? | Different effects of intervention expected? | Interventions valued differently? | Barriers to implementation? | ID popn included in assessing guideline impact?

Equity Lens Criteria

Number of Guidelines
Equity Lens Criteria Results (2)

- Identified barriers to guideline implementation (Criterion 4) in the ID population:
  - Decision-making capacity
  - Access to generic healthcare services
  - Challenges during transition from child to adult services
Guideline Content

- 6 (17.1%) guidelines made recommendations specific to ID
Example Recommendations

- Information in an accessible form should be available to clients & carers (SIGN Epilepsy)
- People with LD and those supporting them should have access to specialist advice and support (NICE Dementia)
- Every therapeutic option should be explored in individuals with epilepsy in the presence or absence of LD (NICE Epilepsy)
- Collateral information from caregivers is important (Canada Schizophrenia)
- With LD & epilepsy, attention should be paid to possibility of adverse cognitive and behavioural effects of AED therapy (NICE Epilepsy)
BUT none of the recommendations were evidence based & they mostly emphasised need for appropriate specialist referral
Guideline Development

*GDG = Guideline Development Group
Discussion

● First study to examine whether guidelines address health inequalities people with ID

● Majority of guidelines didn’t meet any of the equity lens criteria for ID

● Guideline development processes may be missing chance to address health inequities in this population
Suggestions to Improve ID Guideline Equity

● Disseminate INCLEN guideline equity work
● Encourage organisational statement ensuring GDGs consider ID & make adjustments
● Ensure ID expert consultation
● Ensure ID relevant literature search
● **Ensure good quality ID research is conducted**
● Involve ID relevant stakeholders
● Provide easy read versions of guidelines
<table>
<thead>
<tr>
<th>PROGRESS</th>
<th>Plus</th>
</tr>
</thead>
<tbody>
<tr>
<td>Place of residence</td>
<td>Age</td>
</tr>
<tr>
<td>Race</td>
<td>Disability</td>
</tr>
<tr>
<td>Occupation</td>
<td>Sexual orientation</td>
</tr>
<tr>
<td>Gender</td>
<td>Other vulnerable groups</td>
</tr>
<tr>
<td>Religion</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>Socio-economic status</td>
<td></td>
</tr>
<tr>
<td>Social network &amp; capital</td>
<td></td>
</tr>
</tbody>
</table>
Conclusions

- Many clinical guidelines don’t yet meet equity lens criteria and so **may be contributing to the health inequities experienced by people with ID**

- This is relevant to other disadvantaged groups too

- Reasonable adjustments could be made to address them
Acknowledgements

Many thanks to:

University of Glasgow
• Dr Craig Melville
• Professor Anna Cooper

NHS
• Dr Linda Findlay
• Dr Marjorie Macfie

The Psychiatry of Intellectual Disability Faculty for the opportunity to present
References


- Dans AM et al: **Assessing equity in clinical practice guidelines.** *J Clin Epidemiol* 2007, **60**:540-546

- Evans T, Brown H: **Road traffic crashes: operationalizing equity in the context of health sector reform.** *Inj Control Saf Promot* 2003, **10**:11-12

- Oliver S et al: **Health Promotion, Inequalities and Young People's Health: a systematic review of research.** London: 2008