Implementation of good practice in mental health for adults with intellectual and developmental disabilities: the lessons from NICE Guideline 54

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Mental health problems in people with learning disabilities: prevention, assessment and management

NICE guideline: methods, evidence and recommendations

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NICE Guidelines cover:

Prevention

Assessing

Managing

Mental health problems in people with intellectual disabilities in all settings:

Health

Social Care

Education

Forensic and Criminal justice

Guidelines are for

- Healthcare professionals
- Social care practitioners
- Care workers
- Education staff
- Commissioners and service providers
- People with intellectual disabilities and their families and carers

and (academics)

Barriers to health care

Interpersonal

Diagnostic Overshadowing

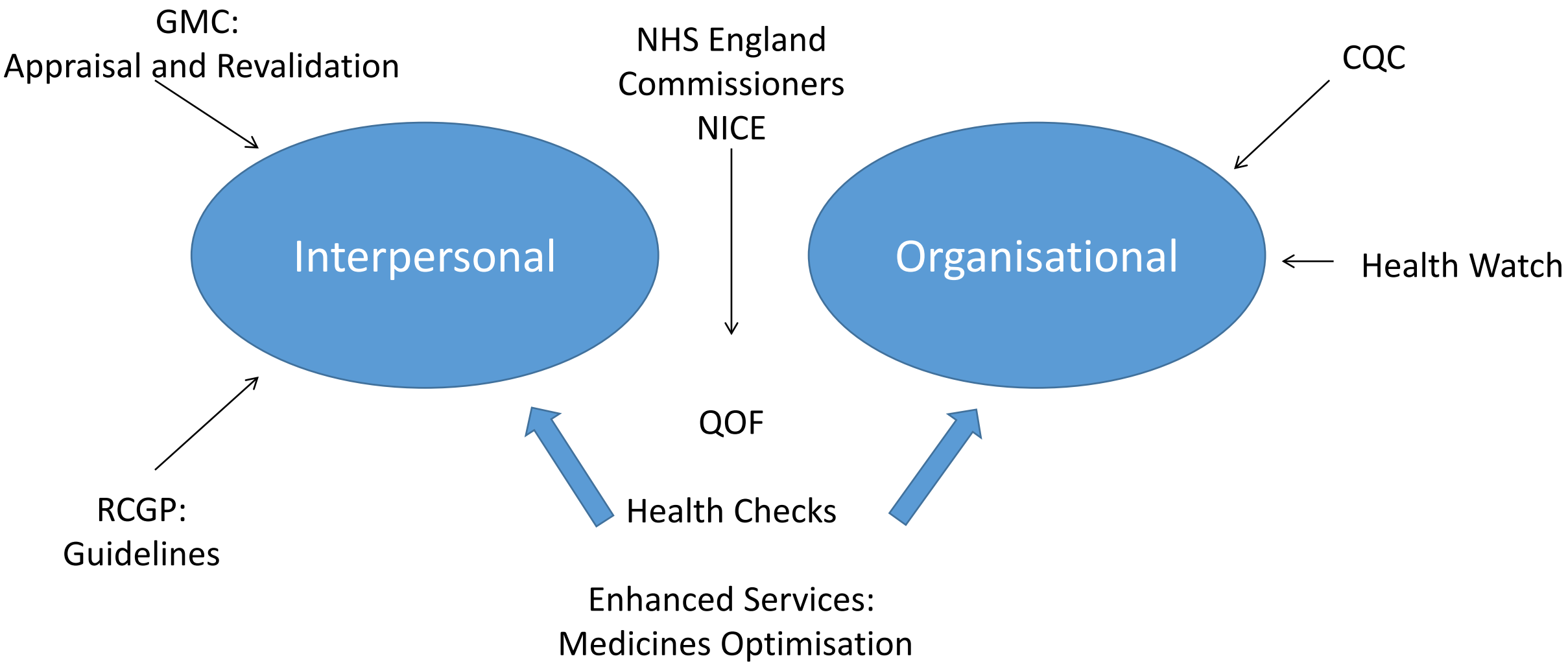
- Physical (and mental) health viewed as part of intellectual disability
- **Lack of clinical knowledge and confidence**
- **poor communication skills**
- Prognostic pessimism

Organisational

Institutional Discrimination

- Inaccessible Environment
- Inaccessible information
- Inaccessible transport
- **Poor interface between primary care and specialist care**

Opportunities for Intervention



Background

- Mental health problems in people with intellectual disabilities are more common than in the general population, with a point prevalence of about 30% (Cooper et al 2007b; Emerson and Hatton 2007).
- Mental health problems are also under-recognised in people with intellectual disabilities (Hassiotis and Turk 2012).
- Mental and physical health problems can be incorrectly attributed to the person's intellectual disabilities

Potential benefits of implementation

- Improved recognition of the symptoms and signs of mental health problems in people with intellectual disabilities, leading to effective treatment.
- Prevention of mental health problems in people with intellectual disabilities, leading to reduced costs.
- Reduction in the costs of treating mental health problems in people with intellectual disabilities.
- Reduction in associated support and social care costs.

Potential resource impact for NHS and local authorities in the following areas:

- Staffing
- Staff training
- Psychological interventions
- Annual health checks.

Quality Standards

- Standard 1: Young people and adults with intellectual disabilities have an annual health check that includes a review of mental health problems.
- Standard 2: People with intellectual disabilities who need a mental health assessment are referred to a professional with expertise in mental health problems in people with learning disabilities.
- Standard 3: People with intellectual disabilities and a serious mental illness have a key worker to coordinate their care.
- Standard 4: People with intellectual disabilities and mental health problems who are receiving psychological interventions have them tailored to their preferences, level of understanding, and strengths and needs.
- Standard 5: People with intellectual disabilities who are taking antipsychotic drugs that are not reduced or stopped have annual documentation on reasons for continuing this prescription.

Quality Standard 1: Annual Health Check

- Young people and adults with intellectual disabilities have an annual health check that includes a review of mental health problems.

  (Young people defined as aged 13-17 years)

Annual Health Check to include:

- A mental health review, including any known or suspected mental health problems and how they might be linked to any physical health problems
- A physical health review, including assessment for the conditions and impairments which are common in people with intellectual disabilities
- A review of all current interventions, including medication and related side effects, adverse events, interactions and adherence
- An agreed and shared care plan for managing and physical health problems (including pain).

Annual Health Check: Quality measures

- Structure:
  - Evidence of local arrangements to ensure that young people and adults with intellectual disabilities have an annual health check that includes a review of mental health problems
- Process:
  - Proportion of young people and adults with intellectual disabilities who have an annual health check that includes a review of mental health problems.
    - Numerator/denominator
- Outcome:
  - Identification of mental health needs in young people and adults with intellectual disabilities.

RCGP Toolkit

- http://www.rcgp.org.uk/clinical-and-research/toolkits/health-check-toolkit.aspx

Royal College of General Practitioners

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Annual health checks for people with learning disabilities - step by step toolkit

Health Checks for People with Learning Disabilities Toolkit

Purpose of the Step by Step toolkit for annual health checks for people with learning disabilities

People with learning disabilities (LD) have poorer physical and mental health than other people and die younger. Many of these deaths are avoidable and not inevitable.

Annual Health Checks can identify undetected health conditions early, ensure the appropriateness of ongoing treatments and establish trust and continuity care.

GPs and practice nurses have the much needed generalist skills to help people with LD get timely acce to increasing complex health systems.

Who is this toolkit for?

The toolkit collects guidance and resources to help GPs, practice nurses and the primary administration team organise and perform quality Annual Health Checks on people with a learning disability.

Research recommendations

- Develop case identification tools for common mental health problems in people with intellectual disabilities, for routine use in primary care, social care and education setting.
  - Dementia, depression and anxiety in adults
  - Depression and anxiety in children and young adults

Quality Standard 2: Assessment by a professional with relevant expertise

- People with intellectual disabilities who need a mental health assessment are referred to a professional with expertise in mental health problems in people with learning disabilities.

Conducting a mental health assessment

- A professional with expertise in mental health problems in people with intellectual disabilities should coordinate the mental health assessment, and conduct it with:
  - The person with the mental health problem, in a place familiar to them if possible, help them to prepare for it if needed.
  - The family members, carers, care workers and other that the person wants involved in their assessment
  - Other professionals (if needed) who are competent in using a range of assessment tools and methods with people with intellectual disabilities and mental health problems.

Quality Standard 3: Key Worker

- People with intellectual disabilities and a serious mental illness have a key worker to coordinate their care.

Quality Standard 3: Key Worker

- People with intellectual disabilities and a serious mental illness have a key worker to coordinate their care.
  - Appointing a key worker would improve care coordination and help services to communicate clearly with people with intellectual disabilities and their family members and carers.
  - Serious mental illness defined as having a diagnosis of:
    - severe depression or anxiety that is impacting heavily on the person's functioning
    - Psychosis
    - Schizophrenia
    - bipolar disorder
    - an eating disorder
    - personality disorder
    - schizoaffective disorder.

Key worker

- Structure
  - Evidence of local arrangements and written protocols to ensure that people with intellectual disabilities and a serious mental illness have a key worker to coordinate their care.
- Process
  - Proportion of people with intellectual disabilities and a serious mental illness who have a key worker to coordinate their care.
- Outcome
  - Patient and carer satisfaction with their key worker's coordination of care.

Quality Standard 4: Tailoring psychological interventions

- People with intellectual disabilities and mental health problems who are receiving psychological interventions have them tailored to their preferences, level of understanding, and strengths and needs.

Tailoring Psychological interventions

- Standard evidence-based psychological interventions are not designed to take account of the cognitive, communication or social impairments associated with intellectual disabilities.

Tailoring Psychological interventions

- Structure
  - Evidence of local arrangements to ensure that people with intellectual disabilities and mental health problems who are receiving psychological interventions have them tailored to their preferences, level of understanding, and strengths and needs.
- Process
  - Proportion of people with intellectual disabilities and mental health problems who are receiving psychological interventions that are tailored to their preferences, level of understanding, and strengths and needs
- Outcome
  - Quality of life of people with intellectual disabilities and mental health problems and their family members and carers.

Quality Standard 5: Annually documenting the reasons for continuing antipsychotic drugs

- People with intellectual disabilities who are taking antipsychotic drugs that are not reduced or stopped have annual documentation on reasons for continuing this prescription.

Is there really a problem?

In a study in England covering17,887 people with intellectual disabilities (and an additional 11,136 with autism) for adults with ID known to GPs (excluding only those in hospitals as inpatients) on an average day (2009-12)

- 17% were prescribed antipsychotic medication
- 16.9% antidepressants
- 4.2 % anxiolytics
- 2.7 % hypnotics

Glover G Williams R. Prescribing of psychotropic drugs to people with learning disabilities and/or autism by general practitioners in England. Public Health England 2015

Public Health England estimates that every day 30,000 to 35,000 adults with a intellectual disability are being wrongly prescribed an antipsychotic, antidepressant, a hypnotic or combinations. These are psychotropic drugs.

Unnecessary use of these drugs, puts people at risk of significant weight gain, organ failure and even premature death.

Evidence for withdrawal of antipsychotic medication: ANDREA-LD

- http://andrea-ldstudy.co.uk/
- 2 arm randomised double-blind placebo-controlled non-inferiority withdrawal trial
- Struggled to recruit within primary care despite opening up 15 sites

Facilitators and Levers

- Training for GPs with support to build confidence and share experience
- Improved patient, carer and paid staff understanding of their medication with identification of benefits and harms arising from the medication
- Consideration of reduction of dose, and/or number of medication types, as well as consideration of alternative approaches (e.g. positive behavioural support).
- Planning with resources

Evidence for withdrawal of antipsychotic medication: North East Experience

- Part of the learning disability health check
- Review of “inappropriate” antipsychotic prescribing through an “enhanced review”.
- Findings
  - 35% of people on the LD register were prescribed a psychotropic medication
  - 19% of people on the LD register may need an enhanced review
- Conclusion
  - Multiple medications increase complexity
  - Training of carer essential to support a reduction programme
  - Opinion of family/ carer/ essential

Dr Clare Scarlett –GP Clinical lead Newcastle/Gateshead and N Tyneside CCGs
David Gerrard – Pharmacist Northumberland Tyne Wear NHS Foundation Trust

Facilitators and Levers

- Primary care pharmacists
- IT systems and quality improvement programmes
- Tracking and progress monitoring
- Annual Health Checks
- Leadership

Quality Improvement Programme

- **Practice standard 1:** The indication for treatment with antipsychotic medication should be documented in the clinical records.
- **Practice standard 2:** The continuing need for antipsychotic medication should be reviewed at least once a year .
- **Practice standard 3**: Side effects of antipsychotic medication should be reviewed at least once a year. This review should include assessment for the presence of extrapyramidal side effects (EPS), and screening for the 4 aspects of the metabolic syndrome: obesity, hypertension, impaired glucose tolerance and dyslipidaemia (NICE schizophrenia guideline update CG82, 2009).

Research recommendations

- Develop case identification tools for common mental health problems in people with intellectual disabilities, for routine use in primary care, social care and education setting.
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Research recommendations

- For children and young people with intellectual disabilities, what psychological interventions (such as cognitive behaviour therapy and interpersonal therapy) are clinically and cost effective for treating internalising disorders?
  - Important outcomes could include:
    - Effect on mental health problem
    - Cost effectiveness
    - Health-related quality of life

Research Recommendations

- For adults with milder intellectual disabilities, what is the clinical and cost effectiveness of psychological interventions such as cognitive behaviour therapy (modified for people with learning disabilities) for treating depression and anxiety disorders?

Research Recommendations

- What is the clinical and cost effectiveness and safety of pharmacological interventions for anxiety disorders in people with intellectual disabilities who have autism?

Research Recommendations

- For people with more severe intellectual disabilities, what is the clinical and cost effectiveness of psychological interventions to treat mental health problems?

Research Recommendations

- What experience do people with intellectual disabilities have of services designed to prevent and treat mental health problems and how does this relate to clinical outcomes?

Thank you!

- Special thanks to Dr Matt Hoghton

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