Current issues in Intellectual Disability: The View from Primary Care

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Aims of presentation

- Covid 19 and primary care – impact on people with a learning disability
- Current quality of care of people with a learning disability in general practice in England
- The nature of general practice in England – its pressures and problems
- Possible improvements to care of people
Coronavirus
Changes to GP consulting patterns

• Before Covid – 90% face to face

• Since Covid 90% start virtual

• And when face to face, using PPE
Ask My GP data – pre-Covid
Instructions to General Practice March 2020

- All patients who thought they may have Covid 19 directed to NHS 111
- Those patients deemed at highest risk prioritised for support – shielding – care plan reviews, access to medication, review of patients as needed
- Adopting remote triage as the default and delivering care and treatment remotely where appropriate and based on clinical judgement
- Manage essential face-to-face services (including home visits) through designating facilities/premises/teams to minimise the spread of infection to those who are suspected non-COVID, particularly those most at risk
- Protect the primary care workforce - PPE
Update August 2020

• Aim to restore clinical activity
• Reach out to vulnerable patients
• Remote triage but be open for face to face
• Use GMC guidance for remote consulting - https://www.gmc-uk.org/ethical-guidance/ethical-hub/remote-consultations
• Information about how the service is running should be accessible
• Maintain access to urgent care
• Proactively seek unmet clinical need
• Appropriate infection control
Impact of changes on people with a learning disability

• Shielding
• Communication
• Access to services
• Management of long-term conditions
• Routine care such as health checks
• Impact on service improvement initiatives
The Annual Health Check

Specification for enhanced service for Primary Care

A review of the patient’s physical and mental health that includes—

- the provision of relevant health promotion advice,
- a chronic illness and system enquiry
- a physical examination,
- a consideration of whether the patient suffers from epilepsy,
- a consideration of the patient’s behaviour and mental health,
- a specific syndrome check
- the production of a health action plan for all patients with a learning disability aged 14 years and over,
- a check on the appropriateness of any prescribed medicines,
- a review of coordination arrangements with secondary care,
- where appropriate, a review of any transitional arrangements, on the patient attaining 18yrs

**NHSE target uptake 2020/21 = 67% of those eligible**
Annual Health Check guidelines during COVID-19

Annual health check due → Issue Get Checked Out checklist and easy read letter explaining the new process → Schedule meeting via Zoom, Skype or other appropriate media → Consultation occurs via appropriate media

Triggers found during consultation

No triggers found during consultation

Appropriate arrangements made to support ongoing investigation in line with priority/severity of issue

Physical examinations/investigations will take place following lifting of COVID restrictions

CQRS payment claim made once all steps completed

Source: Leeds and York NHS Partnership Trust
Learning disability quality improvement in primary care = QI domain

- **Improve prevalence** on the GP register
- **Increase uptake of annual health checks** in people aged 14 and over, including personalised care planning
- Reduce unnecessary hospitalisations, promote health positively and reduce premature mortality.
- Optimisation of medications in line with the **STOMP** initiative,
- Recording **reasonable adjustments** required and evidence that these are being implemented
- Record preferred means of **communication**
- Use of **wider community support** through engagement with local community learning disability services
- **Collaboration with people with a learning disability** and their families
Update to QI domain September 2020

- Improve **prevalence** on register but specifically **BAME population** – this focus has been added after the publication of the Annual LeDeR report.
- **Restore health checks** but prioritise those with long term conditions
- Improve uptake of **flu vaccines**
- **Reasonable adjustments** – need to record ability to use virtual consultation
- Review all **DNACPR** decisions
General practice and people with a learning disability:
Quality of care – discussion of available evidence

https://www.rcgp.org.uk/learningdisabilities/
What is the role of the GP for their patients with a learning disability?

- Be able to **identify who has a learning disability** and record in the practice LD register
- Provide a **complete annual health check** (enhanced service – England)
- Provide **health promotion** including immunisations, preventive health advice eg on smoking and obesity, sexual health advice etc.
- Provide care for **long term conditions** eg diabetes
- Provide care for **syndrome specific problems** eg hypothyroidism in Down’s syndrome
- Provide **acute medical care**
- Monitor **life changes/transitions** and provide **palliative and end of life care**
- Contribute to **multi-disciplinary care** for those with complex problems
Research by Dimensions ‘My GP and Me’ 2018


• **66%** of GPs told us they have received less than a day’s training on how to meet the needs of patients with learning disabilities or autism

• **60%** of GPs say additional training is necessary

• **44%** of GPs would like additional training to ensure patients are getting the most out of their annual health checks

• **98%** of GPs say they would benefit from a short training session, led by people with learning disabilities or autism, on how to meet the individual needs of patients.
Attitudes to General Practice by people with a Learning Disability – Dimensions 2018

• People with learning disabilities or autism are 30% less likely to feel listened to by the GP
• Nearly 33% feel less likely to be treated with care and concern
• 60% of people said their GP did not make reasonable adjustments for them
• 59% of GPs identified communication issues between patients, support workers and GPs as an obstacle
• Just 50% of people felt they were involved in decisions about their healthcare.
25% of GPs say they don’t have enough time in their appointments to make reasonable adjustments.

48% of GPs identified a lack of clarity on when to use reasonable adjustments.

44% said they didn’t know which reasonable adjustments to make.

50% of GPs have identified a lack of training on making reasonable adjustments.

75% of GPs would like additional training on reasonable adjustments.
NHS Digital data collection


• Started 2014-15
• Covers 54% of the population of England
• Extracts data from GP systems – EMIS and Vision
• Shows prevalence of learning disability recorded on GP systems = 0.5% of the population
• But research suggests an estimated 2% of the population in England has a learning disability.

Annual health checks performed – as a percentage of those eligible aged 14 and over on LD register

NHS Digital
Experiences of Annual Health Checks, Voices from the Learning Disability Community

Of the respondents who completed the questionnaire, 69% (242) had had an Annual Health Check since May 2017 and 31% (111) had never had an Annual Health Check.

• For those who had had an Annual Health Check, positive experiences reflected the friendliness and patience of clinicians. However, concerns were raised regarding the quality of Annual Health Checks.

• Issues regarding quality stemmed from the length of appointments offered – usually only 10 minutes with only basic checks provided.

• We found that few GP practices provided information in an easy read format and/or communicated with service users in a way that was accessible for them.

• In some cases, staff in supported living accommodation “refused” to accompany service users, and some GP practices did not let service users bring support with them.

• Where respondents have not had an Annual Health Check, largely this is because they were not aware Annual Health Checks existed.

• A smaller number of service users questioned the importance of having an Annual Health Check, or found that barriers such as time or confidence prevented them from attending.

• Those aged 14-17 years old were less likely to have an Annual Health Check. For those who had had an Annual Health Check, they were given greater choice regarding appointment times and clinician
“I never knew my child could have an Annual Health Check, I never even knew they existed!”

“There is not much point going to an Annual Health Check as they don’t really check anything.”

“Having an Annual Health Check makes me feel better because the doctor can tell me if I am unwell or not.”
Standardised Mortality Ratio – NHS Digital

- 2014-17
- 2015-18
- 2016-19
Percentage of population who are obese – Learning disabled and non-learning disabled

NHS Digital

- 2014-15
- 2015-16
- 2016-17
- 2017-18
- 2018-19

LD | no LD
---|---
2014-15 | 37 |
2015-16 | 37 |
2016-17 | 37 |
2017-18 | 37 |
2018-19 | 37 |
Diabetes care - % of diabetics with acceptable HbA1C

NHS Digital
Hospital admissions of people with a learning disability

• Do health checks reduce hospital admissions?
  
  - No difference overall in emergency hospital admission
  - No change in rate of elective admission
  - Slightly lower admission rate for conditions amenable to ambulatory care

• Are hospital admissions of people preventable?
  
  *G. Glover, R. Williams & J. Oyinlola*
  - Hospital admission for ambulatory care sensitive conditions significantly more common in people with LD
  - Key causes of admission – pneumonias, seizures, constipation, dehydration
The problems facing general practice
Number of general practitioners and other staff involved in direct patient care

- GPs (including locums)
- GPs (excluding locums)
- Nurses
- Other staff providing direct patient care
- GP Locums

Change in estimated demand for general practice consultations since 2010

Source: Institute for Government analysis of The King’s Fund, ‘Public satisfaction with the NHS and social care in 2018: Results from the British Social Attitudes survey.’
Understanding the health care needs of people with multiple health conditions

Data analysed from 2014 to 2016 for 300,000 people in England. 36 health conditions considered, including physical and mental health conditions, ongoing symptoms such as chronic pain, sensory impairment and substance misuse.

• One in four adults had 2+ health conditions. This equates to approximately 14.2 million people in England with multiple conditions.

• In 2006/07, one in 10 patients admitted to hospital as an emergency had 5+ conditions. In 2015/16, the figure was one in three.
Multimorbidity in People with a Learning Disability – Dr Deborah Kinnear, University of Glasgow

Mean Age of 43.9 years

- 99.2% of participants had at least one condition
- 98.7% had two or more conditions

Mean = 11.00
(SD = 4.7)
The proportion of patients seeing their preferred GP always, nearly always or most of the time:

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<th>January – March 2009</th>
<th>August 2018</th>
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<td>77%</td>
<td>50.2%</td>
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Why worry about continuity of care?

- Increases patient satisfaction
- Increases uptake of health promotion
- Improves adherence to medical advice
- Reduces use of hospital services
- Lowers mortality rates

What might make things better?

• Support
• Training
• Collaboration
• Expertise
• Research
• System structures
GP engagement with people with a learning disability and their families

- Training involving experts by experience
- People with a learning disability and/or their carers being encouraged to engage with patient participation groups in primary care.

“Make stronger the relationship between patients and their practices, which is critical to the provision of modern, high-quality general practice”
LeDeR Annual Report 2019

Recommendation 6

Consider developing, piloting and introducing:

- Specialist physicians for people with learning disabilities who would work within the specialist multi-disciplinary teams.
- A Diploma in Learning Disabilities Medicine.
- Making ‘learning disabilities’ a physician speciality of the Royal College of Physicians.
Working well together
Thank you!