**Health promotion and screening for people with intellectual disability**

People with intellectual disability have significantly worse health than those without, with a higher level of complex health needs and life expectancy for men and women thirteen and twenty years shorter respectively than the general population. The increasing role of general practice in delivering and coordinating care across health and social care settings requires expert generalist skills to implement an integrated approach to care across organisational settings. This article explores how general practice can improve the health of people with intellectual disability by making reasonable adjustments with regards to health promotion, disease prevention, screening and detection.

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| **The GP curriculum and health promotion and screening for people with intellectual disability**Clinical module 3.11: Care of people with intellectual disability. As a GP caring for people with intellectual disability, you should:* Recognise the importance of the principle of fairness and equality, irrespective of the innate abilities of the individual
* Recognise that in every consultation you must make the effort to identify, monitor and review the progress of all persons who have difficulties with communication, social relationships and managing their own affairs
* Recognise that respect for diversity may involve challenging the values of the local community and society in general
* Be aware of the atypical morbidity and mortality prevalent in people with intellectual disability and the atypical presentation of acute and chronic physical and psychiatric disorders
* Be aware of the additional skills of diagnosis and examination needed in those who are unable to describe or verbalise symptoms and where to obtain specialist advice and help
* Be aware of the effects intellectual disability has on the life history of the person and family, particularly at times of transition
* Be aware of the effects intellectual disability has on the aging process, particularly in the development and recognition of dementia
* Understand the value of conducting regular (annual) health checks

Appreciate the role of your own practice population in the evolution of services for people with intellectual disability. All mainstream services should offer people with intellectual disability professional resources and facilities that are appropriate and tailored to their needs |

Intellectual disability is a term used to describe people with impaired intelligence and ability to understand and learn new information and skills, with impaired social functioning and a reduced ability to live independently which started before adulthood (Department of Health 2001).Intellectual disability is used interchangeably with learning disability. The RCGP curriculum uses the term intellectual disability as it is more precise and does not include specific learning difficulties such as dyslexia or dyspraxia. Intellectual disability covers a wide range of abilities and disabilities, skills and limitations ranging from mild to severe and profound. Common intellectual disabilities include Downs syndrome, Fragile X syndrome, cerebral palsy and certain autistic spectrum disorders. The prevalence of intellectual disability is approximately 3% of children and 2% of adults, although 3 in 4 adults with intellectual disability remain undiagnosed and are unknown to services (Emerson 2004). In total, an estimated 1.2 million people in England have an intellectual disability (Emerson, Baines, Allerton & Welch 2012). Like the general population, people with intellectual disabilities are also living longer with an associated risk of death from risk factors common within the general population.

However, people with intellectual disability are more likely to suffer major illnesses, develop illness earlier and life expectancy for men and women is thirteen and twenty years shorter respectively (Heslop et al. 2014). Compared to the general population, people with intellectual disability have higher overall levels of chronic disease such as diabetes (18.5%) and greater use of primary care (Carey et al. 2016). Obesity and respiratory disease are significant comorbidities, with obesity affecting up to 51% of people with intellectual disability compared to 29% of the general population (Stedman & Leland, 2010) and respiratory disease affecting 19.8% compared with 15.5%. The main cause of death is respiratory disease (52%) related to pneumonia and aspiration. The confidential inquiry into the premature deaths of people with learning disabilities (CIPOLD) in 2014 found 42% of deaths to be premature, most commonly due to delays or problems with diagnosis or treatment, problems identifying needs and providing appropriate care in response to changing needs (Heslop et al. 2014).

**Barriers to healthcare**

There are a number of barriers to healthcare that people with intellectual disabilities face (Figure 1) which can be broadly related to individual health professionals interpersonal skills or system wide organisational deficiencies within health care which can result in poor health outcomes. Institutional Discrimination occurs when discrimination that has been incorporated into the structures, processes and procedures of organisations, either because of prejudice or because of failure to take into account the particular needs of different social identities (London Deanery 2012). There are insufficient checks and balances to challenge individuals or processes within the organisation which result in unequal and unfair treatment. The cumulative effect of such unequal treatment can have a devastating effect as highlighted by the Winterbourne View Hospital enquiry (Department of Health 2012). System barriers include inflexible processes and administrative procedures such as inflexibility in booking appointments, little consideration to transport issues or adjustments to how information is provided.

Limitations in interpersonal skills can result in diagnostic overshadowing, when clinicians may delay investigation or not appreciate symptoms due to associating them as part of the intellectual disability (Mason 2004). Individual barriers may include:

* Poor communication skills
* Lack of clinical knowledge
* Lack of confidence
* Time constraints
* Pessimistic views on outcomes and prognosis

Insert figure 1 here

**Individual/interpersonal adjustments**

A key area of improving the health of people with intellectual disability is to improve the education and training of clinicians in dealing with people with intellectual disabilities (Gribben & Bell 2010). The RCGP provides links to e-modules and there are a number of resources listed at the end of this article (See Box 3). Furthermore, one could contact their local learning disability team for further specialist training.

Interpersonal skills are extremely important in managing people with intellectual disability. Perez (2002) gave ten top tips for effective consultations with someone with an intellectual disability (See box 1 below).

Insert box 1 here

Judgement of capacity is an important part of consulting with and appropriately treating people with intellectual disabilities, in particular with regards to screening (Mental Capacity Act 2005). Capacity assessment includes that a person can understand information relating to a decision, retain it, weight the information and communicate their decision. As per the principles of the Mental Capacity Act, capacity should be presumed unless proved otherwise.

CURB (see box 2 below) is a mnemonic developed to help doctors assess a person’s capacity to make an appropriate decision (General Medical Council 2016).

Insert box 2 here

People with intellectual disabilities should be supported to make their own decisions if possible. A clinician can only make a decision that a person does not have capacity after taking all reasonable efforts to enhance capacity, such as use of easy to read information. Capacity is also decision-specific, so whilst someone with intellectual disability may not have capacity to make complex decisions about their care, their capacity should be assessed with regards to other decisions. If capacity is proved to not be present then assessment should be made as to what is in their best interest. For any significant decisions when a person does not have capacity, they should be referred to an Independent Mental Capacity Advocate (IMCA) who provides independent support to the person to make their decisions

**Health promotion and screening**

Health promotion and screening are effective ways of improving health. Currently there are several programmes in the UK, all of which people with intellectual disability are much less likely to access. Main UK screening programmes are listed below:

Cervical screening offers 3 yearly smears for women aged twenty five to forty nine, and 5 yearly from fifty to sixty four. An example of the inequality in uptake is that 84-89% of women in the general population are screened compared with 13-47% of eligible women with intellectual disability (Kerr et al. 2005).

Breast screening involves 3 yearly mammography for women aged fifty to seventy, and is being extended to seventy five. There is evidence that women with intellectual disabilities are not well informed about breast cancer and that uptake of breast screening is low (Trusedale-Kenedy, Taggart & Mcilfatrick 2011 and Emerson, Baines, Allerton & Welch 2012).

Bowel screening involves testing faecal samples for occult blood every two years for men and women aged sixty to seventy four. Risk factors for bowel cancer include being overweight, having a poor diet, and not taking enough exercise which all put people with intellectual disabilities at higher risk. The current method for inviting the population to take part does not take into account the need to provide accessible information for people with intellectual disability according to their need (easy read/ audio/ video) or have a system in place for sharing information between bowel screening services and other health professionals involved in their care. Primary care is in a unique position to facilitate such screening programmes by linking information (on uptake of screening) with prompts to support individuals at the practice level through knowing and using their preferred method for communication.

Abdominal aorta aneurysm (AAA) is a relatively new screening programme which involves an ultrasound scan for men aged sixty five or above. There is evidence that screening can reduce deaths from AAA by up to 50% (Thompson, Ashton, Gao, Scott 2009). Very little is known on the level of uptake in people with intellectual disability but is likely to be similar to other programmes and a structured approach should be taken to support those eligible.

Diabetic retinopathy (DR) screening is annual for all men and women with diabetes type 1 or 2. DR is often asymptomatic during the early stages but can be diagnosed and treated early through screening. There is very little evidence available on the prevalence of diabetes in people with intellectual disability, but it is likely to be higher (although may remain undiagnosed) due to higher prevalence of underlying risk factors such as obesity and sedentary lifestyle.

The NHS health check are offered every five years for people aged forty to seventy four to assess their vascular and circulatory risk, including checking blood pressure, body mass index and lipids. Cardiovascular disease is a leading cause of death amongst people with intellectual disabilities (Heslop et al. 2014). There is an opportunity to link prevention of these diseases to annual health checks for those aged 14 years and over with intellectual disability on the Quality Outcomes Framework (QOF) register which are part of an enhanced service with additional funding available to practices (NHS England & BMA 2015).

Annual health checks for adults with intellectual disabilities have been shown to be effective in identifying new health needs (Buszewicz et al. 2014) as well as providing an opportunity to review concurrent comorbidities (such as epilepsy and diabetes) and offer health promotion (access to dietary and smoking cessation services for example). Health checks are also important in young people with intellectual disabilities during transition from childhood, through puberty and adolescence to adulthood as they provide an opportunity to ensure coordination of care and that appropriate services continue from childhood and adolescence into adulthood. This reduces the potential loss to appropriate specialist follow-up.

Having a clinical lead for intellectual disabilities within the practice supports coordination and improves continuity of care and a structured team approach is often required involving all members of the practice with reasonable adjustments necessary by receptionists, clinicians and administrative staff in order to deliver health checks successfully. Despite 80% of practices offering health checks, less than 50% of people with Intellectual Disability currently receive health checks in England (Public Health England 2014).

Adjustments to call and recall for appointments include telephoning to remind individuals of their appointments rather than sending letters or offering to undertake health checks at their home. It may be necessary to undertake blood tests a week beforehand and may include a full blood count, c-reactive protein, urea and electrolytes, liver function tests, thyroid function tests, HbA1c (glycated haemoglobin), lithium monitoring if indicated, calcium and vitamin D if on anti-convulsant medication, follicule-stimulating hormone in a female with no period for 6 months, and a prostate-specific antigen may be considered in men over fifty. However, a person centred approach may require a single appointment when necessary investigations and examination are undertaken and the individual may see the practice nurse and then doctor for reasonable amounts of time, such as half an hour each. A template such as the Cardiff Health Check Template, as well as syndrome specific health checks, such as for those with Down’s syndrome or Fragile X syndrome should be considered as a prompt (Hoghton, 2010). If the person in unable to communicate pain, an assessment tool such as the Disability Distress Assessment Tool (DisDAT) should be used (Regnard et al. 2006).

**Specific areas to focus on during the health check include**

As well as review of pre-existing chronic disease, a focus should be on assessment of feeding, bowel and bladder function, behavioural disturbance, and vision and hearing (Chauhan et al. 2010). Assessment for visual and hearing impairment should be undertaken as these are more common in people with intellectual disability and may exacerbate the effects of an individual’s intellectual disability. Review of dental hygiene and missing teeth is advised as these may lead to swallowing problems or choking, so it is important to ensure there is access to dental services. Respiratory disease is a major cause of mortality and gastrointestinal assessment is important as almost half of people with intellectual disabilities suffer from gastrointestinal reflux disease and constipation (Hoghton 2010). Depression and dementia are common, however, evidence suggests there is also inappropriate use of psychotropic drugs to manage challenging behaviour (Sheehan et al. 2015) and specialist advice should be sought when there is uncertainty around the indication or ongoing need for therapy. Consider using the *Lester Positive Cardiometabolic Health Resource* as a simple assessment and intervention framework to protect the cardiovascular and metabolic health of those receiving psychotropic medication (Lester et al. 2012).

Contraception, in particular long-term reversible contraception, should be considered. An individual’s vulnerabilities and risk of abuse should also be assessed (Hoghton 2010). Figure 2 provides a summary of this.

Insert Figure 2 here.

Immunisations and vaccinations are an important area of health promotion. Childhood immunisations should be given as per the general population. Human pappiloma vaccination (HPV) is currently given to all girls twelve to thirteen years old and available on the NHS for any girl under eighteen. The Flu Plan prioritises people with intellectual disabilities as an at-risk group, and they should be vaccinated annually. Pneumococcal vaccination may also be considered. Tdap (tetanus, diphtheria and pertussis) vaccination is given to pregnant women around week twenty eight. Shingles vaccination is offered to those aged seventy to seventy nine. Due to a high prevalence of hepatitis B in people with intellectual disabilities in residential homes, vaccination is recommended (Public Health England 2014). Table 1 summarises this.

Insert Table 1

**Reasonable adjustments**

It is unlawful for a service provider to discriminate against a disabled person including not providing a service that is offered to the public, providing a lower standard of service and/or failure to make reasonable adjustments (Equality Act 2010). The Equality Act goes on to describe ‘indirect disability discrimination’ when a rule or practice which, whilst applying to all, discriminates against people with a disability and is not justified to meet a legitimate aim in a fair, balanced and reasonable way. It made reasonable adjustments compulsory when a disabled person experiences a ‘substantial disadvantage,’ as opposed to something ‘impossible or unreasonably difficult’. Reasonable adjustments are vast and varied allowing room for organisational creativity, which may differ depending on locality and what works. They may include changing policies, practices and procedures, providing auxiliary aids and services, providing alternative services when usual service location is not accessible and removing, amending or avoiding physical barriers. Some examples are below:

Longer appointment times for people with intellectual disability allow clinicians to go more at the pace of the individual and give more time in history- taking and explanation if needed. This can be easily arranged and a tool for ensuring it occurs could be for a ‘pop-up’ to be added to the clinical system so that staff are reminded to book double appointments whenever clicking on the name of person with intellectual disability.

The appointment of screening liaison nurses trained to work with people with intellectual disability who work with the screening programmes and general practices to identify people with learning disabilities eligible for screening. This improved the breast screening update from 36% to 69% in one region (Turner, Giraud-Saunders & Marriott 2013).

In conclusion, people with intellectual disability experience increased morbidity and mortality. The Marmot Review (2010) argued for ‘proportionate universalism’- that to improve health for all and reduce the steepness of the social gradient of health inequalities, action is needed with a scale and intensity that is proportionate to the level of disadvantage. Whilst this may have been intended on level of resource allocation and organisation, it can be just as poignantly argued on a clinician level that GP trainees and GPs should spend proportionately more time developing knowledge and skills to deal with people with intellectual disabilities.

**Key points**

* People with intellectual disability have much worse health outcomes than the general population with a life expectancy for men and women thirteen and twenty years shorter respectively.
* A major facilitator to improving the health of this population is through Primary Care, which may include annual checks, health promotion and screening.
* Mechanisms of improving the care of this population can be considered at an individual and organisational level.
* It is a legal requirement to make reasonable adjustments to ensure people with intellectual disability have access to the same level of services as the general population.
* There are a number of services available to support clinicians and Primary Care providers in improving the health of this population.

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Insert Box 3 here

Figure 1: Responsibilities for Care



Figure 2: Annual health checks:

Table 1: Immunisation schedule for intellectual disability

|  |  |
| --- | --- |
| **Immunisations** | **When given** |
|  |  |
| Childhood immunsations | As per general population (incl HPV) |
| Tdap | Pregnancy |
| Flu  | Annually |
| Penumococcus | Consider if indicated as a single dose of pneumococcal polysaccharide vaccine 23 (PPV23) |
| Hepatitis B | If in residential home |
| Shingles | As per general population (aged 70-79) |

Box 1: Perez’s top tips for effective consultations with people with intellectual disabilities

**Tip 1:** Offer the first appointment to someone who has intellectual disabilities.

**Tip 2:** Offer double consultation time.

**Tip 3:** Speak to the person with intellectual disabilities first, and only then check out with the carer if something is not clear. Be sensitive to the person's feelings and be encouraging.

**Tip 4:** Try asking open questions or changing the question round to check out if you still get the same response.

**Tip 5:** Explain the process of the consultation before you start.

**Tip 6:** Use language that the person understands at a simple level, or use a communication aid, i.e. pictures or symbols.

**Tip 7:** Sometimes it may be useful to get information from carers as well.

**Tip 8:** Always check out that the individual has understood by asking them to explain to you in their own words.

**Tip 9:** When you are talking about time, use events that the person might understand- for example rather than *in the morning*, one may use *before breakfast*.

**Tip 10**: Do not assume that the person will understand the connection between the illness and something they have done or something that has happened to them.

Box 2: Assessing Capacity: CURB

C - Communicate. Can the person communicate their decision?
U - Understand. Can they understand the information you giving them?
R - Retain. Can they retain the information given to them?
B - Balance. Can they balance or use the information?

Box 3: Further Information

The RCGP website has a number of useful links for further information below:

<http://www.rcgp.org.uk/training-exams/gp-curriculum-overview/online-curriculum/managing-complex-care/3-11-intellectual-disability/3-11-learning-resources.aspx>

Improving Health And Lives (IHAL) contains a vast array of public health information regarding intellectual disability.

<http://www.improvinghealthandlives.org.uk>

Easyhealth contains easy to read information.

<http://www.easyhealth.org.uk>

The British Institute of Learning Disabilities (BILD) works with organisations andn supports people with intellectual disabilities.

http://www.bild.org.uk

Mencap is an organsiation active in advocacy of people with intellectual disabilities.

https://www.mencap.org.uk

There are a number of useful online modules to increase knowledge such as:

<http://www.e-lfh.org.uk/programmes/general-practitioners>

The Challenging Behaviour Foundation provides advice on dealing with behavioural challenges in intellectual disability.

<http://www.challengingbehaviour.org.uk>