

Equal Access, Equal Care

Guidance for Prison Healthcare Staff treating Patients with
Learning Disabilities (2015)



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Equal Access, Equal Care

Guidance for Prison Healthcare Staff treating Patients with Learning Disabilities (2015)

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Equalities and Health Inequalities

Promoting equality and addressing health inequalities are at the heart of NHS England's values. Throughout the development of the policies and processes cited in this document, we have:

- Given due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and
- Given regard to the need to reduce inequalities between patients in access to, and outcomes from healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities.

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A booklet for Prison Healthcare Centres

This guidance is an introduction for all prison healthcare staff about the main points to consider when treating or managing a patient with known or suspected learning disabilities. It applies community healthcare policy and best practice regarding patients with learning disabilities to the prison healthcare setting. It is also a useful tool for any prison-based learning disability practitioners who wish to educate other staff on the relevant issues and in particular how to meet the healthcare needs of this vulnerable group.

1 Foreword

Historically, many people with learning disabilities have received poor care. This has been highlighted by Mencap in numerous reports, for example [‘Death by Indifference’](#) (2007) and more recently following the Winterbourne View hospital expose by Panorama, in 2011, which highlighted systematic abuse and subsequent prosecutions. There is however, some great practice we know of and lots of superb examples where people who have a learning disability are getting the right healthcare, social care and general support.

Prisons are very challenging environments to work in and for those on the receiving end of services it can also be challenging. This is particularly so for those prisoners who have a learning disability. This guidance is a critical resource designed to help healthcare staff to support this group of people. Both people with learning disabilities and the offender population typically experience greater health inequalities and are less likely to access healthcare services. This means that offenders with learning disabilities, whilst in prison, are much more likely to require medical assistance whilst also being less able to navigate the prison healthcare system or communicate any problems they may be experiencing.

It is important that all prison staff understand how to deliver safe and effective support for the day-to-day needs of offenders with learning disabilities. Prison healthcare staff have an important role here, in supporting and educating officers with this.

This guidance will help healthcare staff to comply with legal duties towards offenders with learning disabilities. It will provide staff with a deeper understanding of the healthcare needs and issues faced by this group. We hope that this resource will enable your department to have more appropriate tools and adaptations at your disposal, establish stronger links with others and also to improve communication with prisoners under your care. Everyone deserves dignity, and this resource will help staff make small changes that can have a big impact upon the health status of people who have a learning disability.

Ann Norman



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2 Learning disabilities: a definition

Learning disabilities affect around 1.5 million people in the UK. These are lifelong conditions which are neither an illness nor a disease.

The term 'learning disabilities' is used in relation to individuals who have the following characteristics:

- A significantly reduced ability to understand complex information or learn new skills- 'impaired intelligence'
- A reduced ability to cope independently- 'impaired social functioning'
- A condition which started before adulthood and has a lasting effect

Valuing People' White Paper (Department of Health, 2001)ⁱ

Many people with learning disabilities experience difficulties in communicating and expressing themselves, and in understanding ordinary social cues. They often need longer to process information and to respond to questions and can have difficulty recalling information and sequencing events. They can also be suggestible to the influence of others.

A person with learning disabilities may require extra support to live independently and to cope with everyday activities; for example, they may need help with:

- Filling in forms
- Explaining things
- Following instructions or directions
- Managing a home
- Concentrating for long periods
- Managing money
- Telling the time
- Keeping appointments
- Remembering information
- Reading and comprehension
- Writing
- Understanding social norms
- Using public transport

Like anyone else, people with learning disabilities will have different life experiences, strengths, weaknesses and support needs; everyone is different. Many people with learning disabilities will, however, share common characteristics, which if left unsupported, might make them especially vulnerable.

It is commonly accepted that certain IQ (Intelligence Quota) scores equate to 'mild', 'moderate' and 'severe' learning disabilities. For a more detailed discussion of the use of 'IQ' measures, you may want to refer to the information provided in the Royal College of Nursing (RCN) guidance '[Meeting the health needs of people with learning disabilities](#)' (2013)ⁱⁱ.

The term learning disability is not to be confused with a learning *difficulty* which is used to refer to any learning or emotional problem that substantially affects a person's ability to learn rather than the characteristics outlined in the above definition.

2.1 Prisoners who have a learning disability

Average estimates of prevalence of learning disabilities amongst adult offenders in the UK is thought to be between 2-10 percent. This figure is much higher for children who offend, of whom around one quarter has an IQ of less than 70.¹

Typically, offenders are found to have 'mild' or 'mild-moderate' learning disabilities. It cannot be assumed that their learning disability has been identified early on in the criminal justice system process.

There is also a significant percentage of the prison population who have 'borderline' learning disabilities, meaning their IQ score is just above the commonly used eligibility criteria figure of 70 - scoring between 70 and 80.² This group of people are classed as *not* having a learning disability and therefore do not qualify for learning disability support services. However, they are still likely to struggle with communication and some of the same everyday tasks as people with a learning disability.

New situations, such as being in the criminal justice system, can be especially unsettling for people with learning disabilities as they may struggle to understand what is happening to them and what is expected of them. This can induce feelings of anxiety, depression, and anger, and the individual may become agitated or withdrawn.

“Staff should check people with learning disabilities understand them. I ask them to say again what they mean in another way.”

(Ex-offender with learning disabilities, member of the Working for Justice service user group).

3 Caring for people with learning disabilities

In general, people with learning disabilities experience more difficulties accessing healthcare and have poorer health than the rest of the population. They are also more likely to die at a younger age because of health-related issues. The independent inquiry, [‘Healthcare for All’](#) (2008)ⁱⁱⁱ, found convincing evidence that people with learning disabilities have higher levels of unmet need and receive less effective healthcare treatment.

Mencap worked with the healthcare based Royal Colleges to produce charters for clinical commissioning groups (CCGs) and also hospital staff, encouraging them to sign up to a pledge on how to ‘Get it Right’ for people with a learning disability^{iv}. The main values cited include:

- All people with a learning disability have an equal right to healthcare.
- All healthcare professionals have a duty to make reasonable adjustments to the treatment they provide to people with a learning disability.
- All healthcare professionals should provide a high standard of care and treatment and value the lives of people with a learning disability.

¹ (Harrington and Bailey, 2005).

² (Mottram, 2007).

Additional measures are required to help this group of people achieve equality in their health status. It is best practice for healthcare services to use recommended specialist tools and procedures designed to facilitate a patient's communication and treatment when receiving care. For example, using 'Health Action Plans' for patients. These are clear and easy to understand documents that describe a patient's health status and the things they need to do to become, or to remain, healthy.

[Valuing People Now](#) (2009) stresses the importance of ensuring a person's wishes are upheld and respected and that they are kept firmly at the 'centre of things' which concern them. This 'Person Centred Approach' encourages staff to make every effort to ensure the person in question, plus those closest to them are involved in all relevant decision making and planning. Valuing People Now also recommended that as part of the offender management process there should be a health screening program that identifies an offender's learning disability and any physical and/or mental health issues they may have.

With the recent passing of [the Care Act](#) (2014) the Department of Health and the Ministry of Justice have reviewed the current social care issues of offenders, including those in prison. The Act states that the delivery of care in prisons is the responsibility of the local authority within which the prison resides. This includes the social care of prisoners with learning disabilities. There is still work to be done to implement these changes and to establish a closer relationship between social services and prisons. Guidance has been developed to help both parties.^v

“The person treating me may have to do the treatment different or explain things better so I can understand.”

(Ex-offender with learning disabilities, member of the Working for Justice service user group).

3.1 Care in a prison setting

Once in prison, a person with a known learning disability should be able to access the same level of healthcare support available to people in the community. Their increased risk of certain health conditions can be made worse by the stress of adjusting to prison life. Prison may also increase the barriers faced by someone with a learning disability trying to access healthcare, such as their ability to communicate their symptoms, to contact the healthcare centre and then remember their medical history, as well as understanding and complying with any treatment or well-being regime put in place for them.

Having a learning disability, in most cases, should not be '*medicalised*' in prison. It is not a medical condition in itself. The goal for healthcare should be to provide a service for prisoners with learning disabilities equal to that accessed by other prisoners; a process which is likely to involve making some reasonable adjustments (see page 26) to meet the additional communication and support needs of this group.

Healthcare staff, along with all other prison staff, have a duty of care towards this vulnerable group. Staff must be aware of ways in which this group may behave when confused or distressed and be able respond in an appropriate manner. This applies in particular to prisoners who have sensory-based symptoms and in ensuring clear communication to de-escalate and explain situations. Staff should enlist the help of trained prison officers for any potential behaviour management situations.

For some people, the criminal justice system can be the first time that they come into contact with healthcare services. Receiving much needed treatment for healthcare conditions and putting the right support in place could have a positive knock on effect in other parts of their life. It could also help reduce challenging behaviour or reduce a person's re-offending rate.

The prison healthcare system may not be the first criminal justice based healthcare service an offender receives. There is currently a programme of Liaison and Diversion schemes operating within some police and court services. These services are mandated to screen and support clients with possible learning disabilities. It is therefore vital that any progress already made is recorded and that all records are available to healthcare and other prison-based staff.

"It can be hard to explain what is hurting and where."

(Ex-offender with learning disabilities, member of the Working for Justice service user group).

3.1.1 Inspection criteria

Until recently, the 'Prison Health Performance and Quality Indicators' (PHPQI's)^{vi} were used to monitor the quality of healthcare for people in prison and included an indicator for people with learning disabilities. The Health in the Justice Indicators of Performance (HJIPs) have replaced PHPQI's and currently these do not include any indicator on learning disabilities.

It is hoped that the HJIPs will evolve in 2015-16 and may extend to include the community indicators used by GPs (Quality and Outcomes Framework, 'QOF'^{vii}). There is a requirement in QOF that the provider establishes and maintains a register of patients with learning disabilities. This allows for the monitoring of individual requirements plus specific reasonable adjustments and support.

The Care Quality Commission (CQC) assesses the extent to which prison healthcare centres are meeting the healthcare needs of prisoners with a learning disability. The CQC is currently revising the way they inspect prison healthcare services; a new module addressing patients with learning disabilities is under development.

HM Inspectorate of Prisons assess the extent to which the day to day needs of prisoners with learning disabilities are being met in a the prison setting. There has recently been a joint inspection of the treatment of offenders with learning disabilities in various stages of the criminal justice system. Phase 1 covered the police and courts stage^{viii} whilst phase 2 covered prison and probation.^{ix}

Whilst the recent prison inspection did not focus on healthcare, the findings and recommendations are very relevant for all areas of prison to help develop an appropriate setting and support for people with learning disabilities.

3.2 Capacity to make decisions

The term 'mental capacity' means being able to successfully make your own decisions. If someone was lacking capacity because of a disability or illness such as a learning disability, dementia or a mental health problem it would mean they would be unable to do one or more of the following four things:-

- Understand information given to them about a particular decision
- Retain that information long enough to be able to make the decision
- Weigh up the information available to make the decision
- Communicate their decision

It should not be assumed that a prisoner with learning disabilities lacks the capacity to make decisions. This should be ascertained on an individual basis and for each decision that needs to be taken. People with learning disabilities have as much right to make decisions for themselves as anyone else when they have the capacity to do so.

A person must be given all practicable help before anyone treats them as not being able to make their own decisions. This means staff should make every effort to encourage and support people to make decisions for themselves, for example by giving Easy Read information and making other reasonable adjustments to help them understand. If a lack of capacity is established, it is still important that the person is involved, as far as possible, in making decisions. Each decision has to be in the person's best interest, taking into the account the persons view, values and culture.

A recent audit of the use of the Mental Capacity Act in London prisons found knowledge to be lacking in some areas, particularly with frontline healthcare and other prison staff. The London prisons were found not to have adequate policies, procedures, training and guidance to support the use of the Act. The report recommends having Mental Capacity Act champions in healthcare teams and a stronger emphasis at leadership level and via supervision or staff monitoring. Useful resources about the Act can be found online and [guidance for commissioners](#) is available on the NHS England website.

In a prison healthcare setting, establishing whether someone has capacity mainly relates to issues concerning understanding and consenting to treatment. However, if a prisoner does not have the capacity to make well-informed decisions about their personal health, for example by making contact with healthcare services or attending a well-being check given during the reception process, then they may by-pass contact with healthcare services completely or until their health deteriorates further. Staff may want to refer to the Mental Capacity Act (2005) principles^x for further guidance.

4 Healthcare issues for people with learning disabilities

Many people with learning disabilities require help in recognising, explaining and meeting their own health needs and also with accessing healthcare services. A key document outlining the health issues faced by people with learning disabilities in the general population is the [RCN's 'Meeting the health needs of people with Learning disabilities'](#) (2013).^{xi} This covers common health conditions, gives background and policy information and also provides guidance on specific treatments.

The work of the Improving Health and Lives Learning Disabilities Public Health Observatory (IHaL)^{xii} has highlighted the main causes of health inequalities for people with learning disabilities in the community. [The Health Equalities Framework](#) (2013)^{xiii} is designed to support practitioners to focus their efforts on reducing health inequalities and to enable organisations to gather, analyse and act on better quality information about the causes of ill health.

A summary of the main issues outlined in such guidance is provided within this document along with recommendations as to how these may be applied to a prison healthcare setting.

4.1 Common health conditions

People with learning disabilities are at increased risk of experiencing:

- Epilepsy
- Sight or hearing problems
- Difficulties with eating and gastrointestinal problems
- Hypertension and respiratory disease
- Obesity (and therefore coronary heart disease)
- Poor dental hygiene
- Diabetes
- Thyroid problems
- Attention Deficit Hyperactivity Disorder (ADHD)
- Anxiety, phobias and panic disorders
- Depression
- Schizophrenia.

The [‘Confidential inquiry into the deaths of people with learning disabilities’](#) (2013) was tasked with investigating avoidable or premature deaths of people with learning disabilities.

As with the general population, the most common underlying causes of death were heart and circulatory disorders, and cancer. In people with learning disabilities, the final event leading to death was most frequently a respiratory infection. The most common reasons found for deaths being assessed as premature were delays or problems with diagnosis or treatment, and problems with identifying needs and providing appropriate care in response to changing needs.^{xiv}

A 2010 study^{xv} analysed primary care data for those using their local services. It found that for many health conditions access to, and quality of, healthcare for patients with learning disabilities was broadly similar to that of general patient population. However, there were significant differences in the following; higher rates of obesity, lower rates of contraceptive advice and smear tests, higher rates of seizures amongst patients with epilepsy, and lower rates of antibiotics prescribing for patients with urinary tract infections.

For a more detailed discussion on the treatment for these specific health conditions in people with learning disabilities please refer to the RCN guidance ‘Meeting the health needs of people with learning disabilities’ (2013).

People with learning disabilities are also more likely than others to suffer mental ill health. Any non-learning disability services delivering mental health treatments must therefore be aware how to adequately respond to patients with learning disabilities and mental health problems. See ‘reasonable adjustments’ on page 26 for more information.

People with learning disabilities should have a Health Action Plan and annual health checks to help them address and understand their own health and any conditions they may have. More information about these accessible health support tools can be found on page 23.

4.2 Health and lifestyle factors

4.2.1 Diet

Less than 10 percent of adults with learning disabilities living in community supported accommodation eat a balanced diet, with sufficient fruit and vegetables. For many prisoners, prison food may in fact provide a healthier diet. However, prisoners with learning disabilities are still likely to require additional advice, presented in a way they can understand, on what constitutes a healthy diet and why this is important. This includes the use of Easy Read menus in the canteen. See page 28 for more information on Easy Read.

4.2.2 Exercise

Over 80 percent of adults with learning disabilities do not engage in enough physical activity, meaning they are below the Department of Health's minimum recommended level. It is important to ensure that prisoners with learning disabilities are encouraged and supported to engage in physical activity in prison and that they understand that this is important for their health and well-being.

4.2.3 Obesity & being underweight

People with learning disabilities are much more likely to be either underweight or obese than the general population, as a result of poor diet and possibly related to a lack of cooking skills. The high level of obesity amongst people with learning disabilities is associated with an increased risk of diabetes and other health conditions.

4.2.4 Substance use

Of those adults who access learning disability services fewer smoke tobacco or drink alcohol compared to the general population. However, rates of smoking are considerably higher among adolescents with mild learning disabilities and among those who do not use learning disability services. People with learning disabilities with identified substance misuse issues are more likely to be male (61 percent) and to misuse alcohol, in particular.

Prisoners will generally have mild or mild-to-moderate learning disabilities and are less likely to be in contact with community learning disability services. Any prisoners with a learning disability and substance misuse issues may need extra support to understand both the health risks involved and how to quit or detoxify from a harmful substance.

4.2.5 Sexual health

Little is known about inequalities in the sexual health status of people with learning disabilities in the UK. A population-based study in the Netherlands reported that men with learning disabilities were eight times more likely to have sexually transmitted diseases.^{xvi} High rates of unsafe sexual practices have been reported among gay men with learning disabilities. There is also an issue to consider as to whether a person with learning disabilities has been supported, through sex education, to learn about and practice appropriate sexual behaviour. The increased vulnerability of this group in general, and through being in a prison setting, also means they are more likely to suffer sexual abuse. People with learning disabilities are also more vulnerable to exploitation, bullying and abuse of all kinds (physical, emotional, psychological, sexual, financial, etc). Feeling vulnerable can mean that they respond strangely to other people. They may be more aggressive, for example, or more withdrawn and quiet. Actual and perceived vulnerability may be further increased for people with learning disabilities in prison, particularly if they are experiencing ill-health as well.

The Health Equalities Framework (2013) report outlines how the ‘challenging behaviours’ displayed by people with learning disabilities can be a precursor to abuse from others, as well as inappropriate treatment and social exclusion. Episodes of challenging behaviour can be exacerbated in a prison environment or in times of distress, emphasising the need for increased communication and support to prevent such incidents from taking place.

“I have Asperger’s [Syndrome] and do not like crowds. I had a minor panic attack [when doing exercise at prison] as there were so many people around me. The guards laughed at me and said ‘get yourself together lad, you’re in prison’.”

(Ex-offender with learning disabilities, member of the Working for Justice service user group).

5 Autistic Spectrum Conditions

It is estimated that a disproportionately high number of prisoners have an autistic spectrum condition, i.e. autism or Aspergers Syndrome, however there is currently no national data to present exact figures. Whilst autistic spectrum conditions are not classed as a learning disability in themselves, recent research from the learning disabilities observatory indicates that around 20-30 percent of people with a learning disability also have an autistic spectrum condition.^{xvii}

Background information on autistic spectrum conditions can be found via the National Autistic Society website^{xviii} and other online resources. The Department of Health recently published the [Autism Strategy](#) (2014)^{xix} and [guidance on its implementation](#) includes a chapter specifically about autistic spectrum conditions in the criminal justice system. Some prisons also have specific projects running to ensure the needs of this cohort are being planned for and met.

In terms of additional health concerns associated with autistic spectrum conditions these often include extreme sensory sensitiveness, where people are highly aware of, or even painfully sensitive to, certain sounds, textures, tastes, and smells. One in four children with autism will develop seizures, which often start either in early childhood or when they become teenagers. Some people may have specific diets or supplement protocols which they find alleviate symptoms and reduce certain behaviours whilst others may have restricted food options for which they can tolerate.

The majority of people with autistic spectrum conditions would benefit from the recommended actions provided in this guidance. Additional actions and advice on working with people with autism and Aspergers Syndrome can be found online.^{xx} The National Autistic Society has also produced [guidance for staff working in the Criminal Justice System](#).^{xxi}

The National Autistic Society has developed a set of standards for prisons. Meeting these standards will allow prisons to claim ‘Autism Accreditation’ which is an internationally recognised quality standard. The standards have been developed for the various areas of prison life, including specific prison healthcare standards which must be met to gain accreditation. Once a prison registers for the programme they will be informed of the relevant standards to aim to achieve. These are currently being piloted in four prisons. Andrew Selous, Minister for Prisons, Probation and Rehabilitation, recently contacted all prisons to encourage them to take up accreditation.

6 Tackling the social determinants of ill health in a prison setting

The report by the Improving Health and Lives Learning Disabilities Public Health Observatory ('IHaL') (2010) identified five broad determinants of the health inequalities experienced by people with learning disabilities in the general population.

These include people experiencing:-

- The social determinants of poorer health such as poverty, poor housing, unemployment and social disconnectedness.
- Physical and mental health problems associated with specific genetic and biological conditions in learning disabilities.
- Communication difficulties and reduced health literacy (i.e. ability to read and understand health information).
- Negative personal health behaviour and life style risks such as poor diet, sexual health and a lack of exercise.
- Poorer access to, and quality of, healthcare and other service provision.

For each category, the [Health Equalities Framework](#) ('HEF') lists several specific 'indicators.' These are factors and situations that break down the various causes of inequalities. The HEF provides a full list and explanation of all determinant 'indicators', plus guidance and practical supporting materials for those wishing to conduct the recommended health inequality data collection and assessments.

"Reducing health inequalities must be a central aim of all learning disability service provision whatever the setting, approach or needs of recipients."

Health Equalities Framework (2013)

Whilst the HEF report does not explicitly cover the healthcare of prisoners, most of the social and genetic determinants are still relevant to members of the prison population with a learning disability. This includes those factors occurring before imprisonment that cause a person's ill-health as well as those relevant to prison life. Anecdotal reports state having found the HEF effective in prisons in terms of evidencing the need for additional resources to support learning disabled prisoners and also for anticipating what will be required by way of support post release.

The HEF (2013) Indicators are shown against each of the five categories of 'Determinants' shown in the below boxes. Certain items listed would equally apply to a prison healthcare setting. The extent to which frontline prison healthcare staff can affect changes based upon these indicators will vary. An understanding of the relevant issues and causes of ill health should, however, help with approaches to everyday healthcare delivery as well as planning future development to services.

Social Determinants

- Impoverished accommodation
- Lack of employment and meaningful activities
- Inadequate financial support
- Limited social contact
- Presence of additional marginalising factors
- Safeguarding issues

Genetic & Biological Determinants

- Lack of assessment of physical and mental health needs
- Lack of ongoing health needs review process
- Poor quality care plans / health action plans
- Absence of crisis / emergency planning & hospital passports
- Hazardous medication regimes and practices
- Unavailability of specialist service provision

Communication and health literacy

- Poor bodily awareness and reduced pain responses
- Difficulty communicating with others
- Carers' failure to recognise pain / distress
- Carers' inability to respond to emerging health problems
- Difficulties understanding health information and making choices

Personal health behaviour and lifestyle risks

- Poor diet
- Inadequate exercise
- Difficulties maintaining a healthy weight
- Harmful patterns of substance abuse
- Hazardous sexual health behaviours
- Other risky behaviours / routines

Deficiencies in access to and quality of health provision

- Organisational barriers
- Failure to promote choice and seek consent
- Poor transitions between services
- Lack of access to health screening / promotion
- Difficulty accessing mainstream primary / secondary services
- Difficulties accessing non health, community services

Used with the permission of the Improving Health and Lives: Learning Disability Observatory (iHal).

Working to tackle the causes of health inequalities for prisoners with known learning disabilities means addressing the majority of these indicators. Tackling the relevant social factors, such as 'meaningful activities' and 'safeguarding issues', would require joint protocols and discussion with other staff, such as prison officers and education staff.

The indicators under 'genetic and biological,' are healthcare based and are factors that healthcare staff should plan for and deal with directly. The same could be said for those listed under 'behaviour and lifestyle' factors, and also to a large extent the 'service quality' factors that aim to help create a healthcare service that is accessible and relevant to people with a learning disability, plus promote effective joint work with other services.

Addressing the 'communication' indicators is crucial in enabling equality of access to services and engagement with services. This determinant, and the recommended improvements to communication, would need to be applied prison-wide, by all staff, to enable a prisoner with learning disabilities to cope, understand and engage with the demands of prison life. Communication tips are given in Appendix 1 as well as in the Reasonable Adjustments section on page 26.

The majority of factors listed could be monitored in a prison setting and/or integrated into existing patient care or other assessments, such as equality impact or risk assessments. The closed prison environment means healthcare staff have the opportunity to meet the health care needs of prisoners with learning disabilities but also direct other staff and departments on ways to support and promote general well-being, thereby tackling the more indirect causes of ill-health for people with learning disabilities.

The Health Equalities Framework cites several organisation-based barriers for people with learning disabilities wishing to access healthcare services:

- The eligibility criteria for accessing social care learning disability services
- Failure to make 'reasonable adjustments' in light of the literacy and communication difficulties experienced by many people with learning disabilities
- Lack of expertise and '*disablist*' attitudes among healthcare staff
- 'Diagnostic overshadowing', for example symptoms of physical ill health are mistakenly attributed to either a mental health/behavioural problem or as being inherent in the person's learning disabilities.

When applied to a prison setting, these barriers may present in a number of ways. For example, when trying to obtain an assessment from social services. The fact people in prison tend to have more mild learning disabilities can be a barrier to accessing learning disability services for assessment and support in cases where the local authority serving the prison has a particularly restrictive eligibility criteria.

There is also the issue of non-disclosure, whereby a prisoner chooses to hide their disability. Identification can also suffer because of a lack of staff knowledge and training in learning disabilities as well as the additional effects of potential alcohol and drug issues 'masking' a prisoner's learning disability. Also, a person may not be aware they have a learning disability, possibly because they have had little contact with services throughout their life.

These barriers highlight the need for established links and protocols with outside learning disability services as well as the provision of basic support and intervention integrated into an individual's prison regime, where possible. Plus additional healthcare monitoring, information sharing and the use of tools such as Health Action Plans (see page 23).

As already outlined (see page 28) accessible communication is vital in order for a prisoner to achieve equal health status. This extends to ensuring all healthcare leaflets, posters and other written information are available in Easy Read format (see page 28 for more information).

6.1 Case Study

In 2010 a Jury at Preston Coroners Court returned a strongly-worded verdict regarding the death of a 23 year old prisoner. The prisoner had learning disabilities, was faecal incontinent, was known to have been bullied, and had gambling problems.

The prisoner had been put on the Adapted Sex Offenders Treatment Programme at the prison with insufficient support, and in 2005, when it was his turn to disclose full details of his offending to a group of fellow prisoners, he hanged himself.

The jury heard evidence that information was not passed on from one prison to another, or from prison healthcare to other relevant departments. Officers who knew of his disabilities "in particular his incontinence and vulnerability to bullying" did next to nothing to provide him with a safe or decent environment.

7 Screening for possible learning disabilities

Prison healthcare teams must be equipped to perform learning disability screening when treating a patient thought to possibly have a learning disability or if concerns are raised as part of the initial healthcare screen.

It is important to be able to recognise if a person has learning disabilities so the healthcare team can respond appropriately and communicate effectively. This will enable diagnosis and treatment and also accurate records. Prison healthcare centres may be the first port of call for prison staff that believe a prisoner may have a learning disability. Prison staff may need advice on how to proceed and how to support the prisoner.

Some screening related work is currently underway for prison staff via the National Offender Management Service ('NOMS') who are developing a set of questions and reporting capability within 'NOMIS', the case management system. This will improve their understanding of who might have various *hidden* disabilities which may require reasonable adjustments. Adjustments could include the provision of Easy Read information, adapted offending behaviour interventions, or day to day help with reading, writing, understanding and being understood.

The NOMS Equalities Group is due to revise the prison Equalities instructions in 2015. It is hoped there will be chapters on particular disabilities, including learning disabilities, with guidance on how to use the tool NOMS have developed to identify who might need support. It is important that once implemented, this is integrated with healthcare to ensure information about any prisoners identified is available should they become a patient.

Some people's learning disabilities are easier to recognise, typically evident by their increased need for support, but it can be difficult to recognise people with milder learning disabilities. They may be reluctant or ashamed to disclose the learning disability, or the areas in which they struggle, or may even be unaware that they have a learning disability. Learning disability practitioners in prison have reported that prisoners often 'mirror' others to try to fit in. This may include using long or complicated words (often incorrectly) to appear more plausible.

Various tools are used in the community to screen for possible learning disabilities, typically in the form of a set of questions with a scoring system that indicates the level of probability. A formal diagnosis of learning disabilities requires a professional assessment, typically performed by a psychologist or psychiatrist. A 'positive' on a basic screening tool can be helpful and demonstrates that the individual is likely to require support and reasonable adjustments. Well known tools used in the community include the 'Learning Disability Screening Questionnaire' and the Hayes Ability Screening Index, both of which have been validated for use with the prison population.

There are a number of points that staff may want to consider when deciding whether someone has a learning disability, although they are not totally indicative of learning disabilities and the points listed are not intended as an assessment or screening tool.

These are adapted from the RCN guidance 'Meeting the health needs of people with learning disabilities (2013):-

- Ask the person directly if they have learning disabilities. Note: be aware they may say 'no' to hide their learning disability or may be unaware.
- Does the person have a social worker, care manager or key-worker in the community?
- Did the person go to a special school or attend mainstream school but had extra support?
- Did the person attend a day centre?
- Has the person ever been seen by learning disability service staff or stayed in a learning disability hospital?
- Can the person read or write? Note: they may say 'yes' regardless, it is helpful to check.
- Can the person tell the time?
- Does the person struggle to communicate?
- Can the person remember certain everyday facts about themselves, where they live, their birthday, etc.?

Whilst this information may give a general indication, it is not designed for the offender population. Generally offenders with learning disabilities are less likely to be known to, or in regular contact with, learning disability services or supported by day-centres, etc. This emphasises the need to assess and work with the individual to address their particular needs whilst making more generic changes to things like written communication, for example, which will benefit many prisoners.

Staff working with remand prisoners also need to be aware of the risks involved in this environment. The faster turnover may mean general screening is neglected or a person's learning disability is less likely to be noticed. Extra care should be taken to ensure this group, and also those on short sentences, do not go unrecognised. Any screening or assessment information should be shared appropriately, for example, with the Courts.

8 Social Care and the Care Act

The Care Act (2014) includes reference to the delivery of social care in a prison setting. People with a learning disability are entitled to social care support in prison, as in the community. It is the responsibility of local authorities to ensure arrangements are made for care and support assessments for prisoners, and to provide care and support for those with eligible needs.

Local authorities should work with the prison and prison healthcare teams to produce care and support plans and local agreements between services that outline roles and responsibilities. This clear and close relationship will be important in ensuring the needs of prisoners with learning disabilities can be met appropriately and swiftly. Prison authorities will still have a 'duty of care' to support the day to day living of prisoners. For more information see the prisons chapter of the Care Act^{xxii}. Easy Read information about the Care Act is available for prisoners.^{xxiii}

9 The benefits of having learning disability nurses and practitioners in prison

Learning disability nursing is a person-centred profession with the primary aim of supporting the well-being and social inclusion of people with a learning disability. This is achieved through improving and maintaining physical and mental health, removing barriers and supporting the person to pursue a fulfilling life. This approach has much in common with other approaches to reducing re-offending behaviour.

For example, learning disability nurses will teach someone the skills to find work. This can be significant in helping people to lead a more independent, healthy life where they can relate to others on equal terms. Health-related activities are prioritised and plans for care take into account.

Within a prison setting, a learning disability nurse is typically part of the healthcare or Mental Health team. They support healthcare staff and other staff throughout the prison who are treating or managing offenders with known or suspected learning disabilities. They help the prison to put in place procedures for managing prisoners with learning disabilities in all walks of prison life and facilitate joined up working within the prison and with other organisations.

Healthcare staff, particularly learning disability nurses or specialists, often deliver learning disability awareness training to prison staff and to other healthcare staff. Free training packages specifically for use with criminal justice staff are available online (see 'Resources' on page 34).

Currently only a handful of prisons employ learning disability nurses or other learning disability practitioners. One barrier to employing more learning disability nurses in prison is simply the lack of awareness of this post as a possibility in prisons. There is also a lack of awareness of the need and the benefits of this role. When services assess their performance and identify any gaps in knowledge or skills, they can include the needs of patients with learning disabilities and plan accordingly to recruit a learning disability nurse or practitioner, if possible.

“The RCN absolutely encourages learning disability nurses to consider the opportunities of working with people in prison. They are able to support other health and justice staff to understand the need for specific care and support. They have good understanding of issues such as capacity, consent, communication needs and skills in de-escalation which can all help both prisoners and staff to cope in a very challenging environment.

Prison Governors and staff need to recognise the potential benefits of employing a specialist learning disability nurse and advertise vacancies in learning disability journals and forums”

(Ann Norman, Criminal Justice/Learning Disability Advisor, RCN)



It is important that all healthcare staff have a basic understanding of the needs of people with learning disabilities. This is especially true if a prison has not employed a specialist learning disability nurse to directly treat patients or advise other staff.

The recent HMIP Joint Inspection of how prisons are meeting the needs of offenders with learning disabilities cites HMP Parc as a best practice example. This prison screens every prisoner on their reception into the prison for all potential vulnerability factors and employs multiple learning disability nurses who actively support prisoners with a learning disability.

It has Easy Read communication prison-wide, prison staff and peer mentors are trained in learning disability issues and the prison has clear systems in place for meeting the needs of this group and those with related vulnerabilities, such as autism. The result has been a reduction in situations escalating into challenging behaviour and therefore a reduction in the use of segregation and challenging behaviour. As a private prison, HMP Parc has been able to demonstrate financial savings brought about by this approach.

***“The unique working environment of a prison has, as an LD nurse, provided many opportunities. There have been many opportunities to develop and adapt the skills that I have used in other settings to meet the needs of prisoners who have a learning disability. Joint working with all the departments and other providers within a prison has afforded me the opportunity to provide information and training about the needs of people who have a learning disability in general, how this will impact upon those who find themselves in prison and how these needs can be met.*”**

Working with individual prisoners and seeing how attitudes change positively towards them when staff are educated about their needs, and the impact that this can have on the individual, is satisfying and rewarding.”

Stephen Haynes

Prison Liaison Nurse (Learning Disabilities)

Works in HMP’s Surrey, Highdown, Send & Coldingley



10 Recommended actions for healthcare staff: Health assessments and treatments, including Health Actions Plans

A prisoner’s healthcare assessment presents an ideal opportunity for staff to investigate whether someone has known or suspected learning disabilities if it is not already noted in their personal information. Healthcare staff can then use best practice protocols when monitoring and treating the patient and can also advise prison staff of the prisoner’s everyday support needs, plus any other concerns they may have.

Healthcare teams should be prepared to be a possible first port of call for prison staff concerned about a prisoner having a potential learning disability. The team need to know the signs to look for, questions to ask, and whether there are any in-house learning disability experts, for example, an LD nurse or psychologist. They also need to have links with the relevant support services and a procedure in place for formal referrals and assessments.

Before a prisoner can attend healthcare they typically have to formally request an appointment. This often involves the prisoner filling out a form that requires their personal

details, which type of healthcare specialist they need and a description of their symptoms. Providing this information can present a significant barrier for someone with reading and writing difficulties.

Additionally, a prisoner may be too embarrassed to ask for help in completing the form or maybe unable to understand or explain their symptoms without expert support. Ensuring the process of applying for a healthcare appointment is simple and accessible is vital for removing this barrier to receiving healthcare.

“When nurses are asking questions they should reassure it is ok to answer”.

(Ex-offender with learning disabilities, member of the Working for Justice service user group).

10.1 Health assessments

The introduction of health checks for people with learning disabilities in the community has been shown to be effective in identifying unmet health needs. The effectiveness of these checks suggests that having them represents a ‘reasonable adjustment’ to the difficulties in identifying and/or communicating health needs experienced by people with learning disabilities.

It is vital that any questions or written assessment of a patient’s condition are in a form that they can understand. As part of a series of interviews with offenders, West Yorkshire Probation Trust^{xxiv} found that service users were negative about tick box assessment forms. One person reported he just ticked ‘No’ to everything on the checklist asking whether he had problems with substance abuse, reading and writing or anger management. He said this was because he did not really understand what the form was about and felt under pressure. Someone else reported that they should not just be handed a form. She had to ask her probation officer to read out the questions, but found it embarrassing to admit to needing help, *“It doesn’t feel nice to have to say you can’t read”*.

When assessing a person with known or suspected learning disabilities, there is a risk of their learning disability or communication problems masking or becoming confused with other issues. For example, mental health problems, intoxication, etc. It is important to pick apart these different influences upon behaviour.

It is standard practice for people with learning disabilities in the community to receive annual health checks, using the recommended format and administered in a way that this patient group can understand and fully partake. This is recommended by the Royal College of GPs amongst others. In the recently published [‘Everyone Counts: Planning for Patients 2014/15 – 2018/19’](#) (NHS England, 2013),^{xxv} under the ‘Health and Justice Measures’ annex it states that those patients with learning disabilities should receive annual health checks.

10.2 Health Action Planning (‘HAP’)

People with learning disabilities should have a Health Action Plan (HAP). A Health Action Plan is a personalised plan that explains what someone needs to do to get or remain healthy. It helps to ensure people get the services and bespoke support they need. The HAP should be in a format that is helpful and easy to understand for the patient.

Whoever is supporting a person with learning disabilities to do Health Action Planning is called a 'Health Facilitator'. This role can be undertaken by a health or social care professional, such as a learning disability nurse, or by a trusted relative. It is important that primary healthcare services, particularly the person's GP, are fully involved and support them and their Health Facilitator to implement the plan.

[Valuing People Now](#) (2009) suggests that as part of the offender management process (led by 'NOMS') there should be a health screening program that identifies an offender's learning disability and any physical and/or mental health issues. It is recommended that this should form the start of the individual's Health Action Plan and enable access to the appropriate education and rehabilitative programs.

Examples of Health Action Plans can be found via the links listed in the Resources section (page 34). These include generic HAP templates as well as some designed for use in a prison healthcare setting. There is also good practice guidance on how to carry out Health Action Planning (see Resources, page 23).

"I might want to say things but might not know how to say the word or what the word is for the problem – so don't bother saying anything."

(Ex-offender with learning disabilities, member of the Working for Justice service user group).

10.3 Getting consent for treatment

Someone with a learning disability may struggle to understand why a treatment is required. They may not be able to fully comply with any recommendations without the appropriate support. They may lack the capacity to make decisions about their health (see page 11).

Gaining consent for treatment from a patient with learning disabilities can take longer than average. It is vital they understand all information presented to them and that they are deemed to have mental capacity to make decisions, with or without support, as appropriate. This is likely to mean that any written information is presented in an easier-to-read format (see page 28). If it is felt a person lacks capacity to make such decisions, staff should refer to the [Mental Capacity Act](#) (2005) principles and guidance, plus the appropriate prison protocols.

For a more detailed discussion on the issues involved, plus policy and guidance concerning consent to examination and treatment, see the RCN guidance 'Meeting the health needs of people with learning disabilities (2013)' and also the Health Equalities Framework document (2013).

10.4 Planning for patients with learning disabilities

When planning and providing care for any prisoners with a learning disability who are patients in prison healthcare, you may wish to consider the following:-

- Give your name.
- Provide a clear introduction to the person and explain your role.
- Explain to them how they can get help if they need it.

- If prisoners are staying as an in-patient, provide orientation around the unit.
- It is important to consider how the person expresses when they are in pain and how the nursing team will recognise this.
- Some people with learning disabilities may act out behaviour that others consider challenging. This often occurs in response to communication issues, boredom or environmental factors such as noise. You could try to minimise potential triggers by consulting with others who know the patient well and checking for notes on their personal file.
- Being able to predict and know what is happening is often important to people with learning disabilities. Developing a routine as soon as possible for in-patients can therefore reduce anxiety. It may help them to have a timetable that shows them meal times and other activities.
- It may be beneficial to use photographs of key areas and people on the unit to support communication.
- When people with learning disabilities leave healthcare after a stay there they should be given a discharge sheet with accessible information covering diagnosis, treatment, when to return for follow-up, any possible side effects from medication plus details of who to contact if they have any problems.
- A useful reasonable adjustment for prisoners with learning disabilities would be a guaranteed follow-up appointment to ensure the person has been able to follow all instructions and maintain their health.

This list has been adapted from material featured in the RCN guidance '[Meeting the health needs of people with learning disabilities](#)' (2013).

"As a learning disability nurse in prison, I feel our role can make a massive contribution to learning disabled prisoners' lives and the positive task of reducing reoffending within this population. No matter how good our learning disability service is in the prison, the service should not stop at the prison gate. The prison learning disability nurse/service should provide a seamless transition into the community for the learning disabled prisoner being liberated. This way we improve opportunities for the prisoner AND reduce the possibility of them reoffending. "

Gary Docherty
Prison Learning Disabilities Nurse/LD Consultant Nurse
Formerly HMP Greenock



10.5 Patient Passports

A 'Patient Passport' is an Easy Read tool often used by people with learning disabilities. It is designed to explain a person's everyday needs and requirements, their primary health diagnoses, medications, allergies, etc and to give enough general information so that when it is handed to a care professional, they will be able to understand the person's needs, make them feel comfortable and treat them appropriately. These documents contain lots of useful information and are typically completed by the patient with the support of someone who knows them well. They are then updated by health and care professionals after any interventions or treatments.

The Department of Health have recently designed a Patient Passport template and guidance. Some prisons have also designed their own Patient Passports, with additional headings that relate to patients personal information when in a prison setting.

“I was confused when they were asking about my past and they said I was depressed but I was not....I felt it was too rushed. It’s hard to say things when in a rush”.

(Ex-offender with learning disabilities, member of the Working for Justice service user group).

11 Recommended actions for healthcare staff: Reasonable Adjustments

A reasonable adjustment is an alteration that an organisation makes to enable a disabled person to be able to carry out their duties/life without being at a disadvantage compared to others. Under the Equality Act (2010) and the Health and Social Care Act (2008) public sector agencies have a legal duty to make reasonable adjustments to their practices as required, making them accessible and effective for all.

Reasonable adjustments can take the form of anything from the use of ramps for wheelchairs, adopting a certain way of writing or speaking to ensure a person understands information, or allowing extra time for appointments. It refers to any additional tools used to access and deliver healthcare services, for example, ‘Health Action Plans’ (see page 23) or easy to understand forms for healthcare appointments. There is a large online database of reasonable adjustments and guidance via the iHal Reasonable Adjustments Database.^{xxvi}

The [Health Equalities Framework](#) (2013) cites “Communication Difficulties and Reduced Health Literacy” as one of the main determinants of health inequalities for people with learning disabilities. It defines this as “*the impact of a reduced ability to take in, understand and use healthcare information to make decisions and follow instructions for treatment on an individual’s health status.*”

A learning disability is largely defined by problems with some, or all, forms of communication. Therefore someone may need extra support, which can come in various forms, to allow them to fully speak, listen, write, understand what other people are communicating, understand body language, and explain or express thoughts and feelings. Some people with learning disabilities also have problems remembering things or concentrating for long periods of time so the appropriate reasonable adjustment in such cases could be the use of memory aids and regular breaks.

The nature of the required reasonable adjustment can also vary depending on the treatment for patients with learning disabilities. For patients with mental health problems, for example, the National Development Team for Inclusion has worked with healthcare specialists to develop a [Green Light Toolkit](#) that outlines all possible reasonable adjustments as well as providing other resources^{xxvii}.

One prison reported using ‘Supported Living Plans’ for those prisoners identified as having a learning disability. These serve to highlight any necessary reasonable adjustments required for the person’s day to day living. Other prisons have developed what they call ‘Prisoner Action Plans.’ These detail all relevant information about a prisoner with learning disabilities, combining healthcare information, where applicable, with general support and

supervision information. These also include Easy Read information for the prisoner to refer to (see page 28 for more information on Easy Read).

Effective two-way communication is crucial in ensuring equal access to healthcare services and being healthy. People need to be able to understand information they receive in order to make decisions about their health and need to be able to express themselves, explain their symptoms and to ask questions.

“It was hard to explain things in the prison reception. It was noisy and busy....It would be nice to always have the same staff.”

(Ex-offender with learning disabilities, member of the Working for Justice service user group).

11.1 Changes to the environment and procedures

A healthcare centre can be an unfamiliar environment which may cause prisoners attending it additional distress. This should be taken into account when assessing a patients' general well-being. Where possible, it may be beneficial to adjust the layout of an area or how information is displayed. Posters, signs, warnings, directions, and clocks are all designed to convey information and generally require a level of comprehension to be understood. Ensuring these are accessible is important.

For prisoners with certain sensory impairments reasonable adjustments can be used to enable them to do more. Sensory issues can be a part of having a learning disability and also related conditions such as autism or epilepsy. A prisoner may become very agitated by certain sensory stimuli such as, flashing/ fluorescent lights or loud noises. They may react to sudden or unexpected changes to their environment or routine that have not been well managed. Discovering and addressing appropriate reasonable adjustments will involve working with the individual in question.

A “quick win” suggested by offenders with learning disabilities is to use a digital clock rather than analogue clock when giving appointment times as it is more easily understood. When implemented in a juvenile prison this resulted in far more prisoners attending the prison weekly forum meetings as they understood what time it was on. Another quick win example is using ‘sun’ or ‘moon’ symbols on medication to explain when they should be taken.

With regards to changes to standard healthcare procedures, things such as appointment reminders and allowing extra time will help to ensure the patient remembers to attend and is more able to engage. It is important to keep detailed records of all required reasonable adjustments, areas for which the patient requires additional assistance (for example, with personal hygiene) and also the level and nature of their communication ability. It may also be necessary to do risk assessments on any required support and to work with officers to ensure the system, and the relevant staff, can safely accommodate these changes.

“They need to understand about having a learning disability and use the right words....When you have learning disability, your concentration worsens and you find it harder to talk about your history.”

(Ex-offender with learning disabilities, member of the Working for Justice service user group).

11.2 Use accessible information ('Easy Read')

Easy Read documents present information using simple words and pictures, making it easier to understand. The use of Easy Read is common in health and social care organisations. It can help anyone with reading or comprehension difficulties, including those with learning disabilities, learning *difficulties* and also people for whom English is not their first language. Easy Read is a reasonable adjustment that helps to ensure equal access to information for people with reading problems.

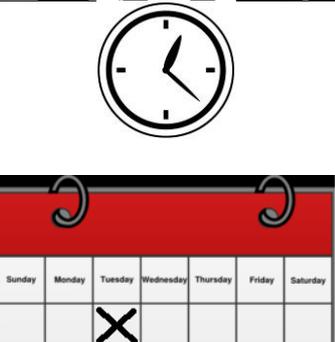
The use of Easy Read in prisons and prison healthcare centres is slowly becoming more common place, largely thanks to a few advocates within prisons, designing or commissioning documents and sharing what they have produced. There have also been some national documents commissioned by NOMS and there are currently several prisons using Easy Read prison-wide for all documents and resources used by offenders. See 'Resources' page 34 for more information.

It is best practice to review all current paperwork used with patients to make sure it is as short and clear as possible, with all technical terms and jargon explained in plain English with accompanying pictures. This includes posters on the wall, leaflets, forms, questionnaires, prescriptions, and instructions for medication use or other treatment information. Some prisons have also produced an Easy Read introduction to the healthcare centre and the services it offers, as well as information about local community healthcare services to help prepare for release.

See 'Resources' on page 34 for guides on how to produce your own Easy Read material or where to find examples of Easy Read documents already in use in prisons and the criminal justice system. If you decide to design your own documents rather than use one of the professional design organisations it is best practice to test your Easy Read materials with some prisoners before using them to make sure they are understood. Alternatively, you may want to adapt literature produced and tested within other prisons.

There is a range of Easy Read leaflets covering most health conditions available for free from www.EasyHealth.org.uk. There are also Easy Read leaflets for certain medications and audio versions of medication leaflets for some of the more commonly used drugs.

An example of Easy Read pictures and text:

	<p>You have an appointment with the nurse in the healthcare department.</p> <p>This is for your hepatitis vaccination.</p>
	<p>The appointment is at 1.20pm on Tuesday this week.</p>

11.3 Face-to-face communication

It is important to always speak clearly and slowly to the patient, using plain language and avoiding the use of jargon. Explain any technical words and ensure they understand things before moving on to the next point.

The following checklist is adapted from '[Sentence Trouble](#)' by the Communication Trust^{xxviii} and Nacro 'Speech, Language and Communication Difficulties' guidance (2011).^{xxix} It is designed to facilitate effective communication:-

- Give the person extra time to listen to and understand what is being said;
- Ask what things would help them to understand more easily;
- Emphasise important words that they should focus on;
- Provide the person with a brief summary of what you are talking about before giving a more detailed explanation;
- Give positive encouragement and feedback;
- Speak at a slower speed;
- Use short sentences, with appropriate pauses, to allow them to process new information;
- Use uncomplicated language that the person is familiar with;
- Use visual tools to encourage their understanding;
- Ensure that the person gives their own explanation of what has been said to them to check whether they fully understand what was said;
- Remind them about any future appointments;
- Flag-up anything the person has said which you do not understand.

See 'Resources' (page 34) for many more communication techniques and reminders, including ideas for planning meetings, understanding body language, and information on accessible written communication.

The booklet '[Positive Practice, Positive Outcomes](#): A handbook for Professionals in the Criminal Justice System working with Offenders with Learning Disabilities' (Department of Health, 2011) outlines the extra things prison staff should consider at the various stages of the prison journey, including induction, cell allocation and resettlement. See 'Resources' on page 34.

It is important to share information with all relevant prison staff concerning any prisoner with learning disabilities, including their support needs, to help ensure the prisoner receives the appropriate reasonable adjustments in all areas of their prison life.

Additional information on preparation, environment, verbal and written communication in a healthcare setting can also be found in the RCN guidance '[Meeting the health needs of people with Learning disabilities](#)' (2013).

The recommendations given will benefit all people with learning disabilities, as well as those with conditions such as learning *difficulties*, dyslexia, ADHD, autism, etc. Organisations may even want to consider the benefits of offering accessible information to all offenders who prefer this, regardless of whether they have a recognised condition.

“In reception, you have 10-12 people coming in, all trying to talk to the medical officer and they are rushed. By the time they see you the next day something could have happened. And they will all say ‘well they didn’t tell us about that when they came in last night’ – it is hard to say things in a rush”.

(Ex-offender with learning disabilities, member of the Working for Justice service user group).

12 Recommended actions for healthcare staff: Care pathways and planning for transitions

There is a need for multi-agency admission and discharge care pathways for people with learning disabilities entering or leaving healthcare services. Within prison, this may mean working with the staff who regularly manages the prisoner and pro-actively planning for the possible impact of their health condition upon their ability to cope with prison life.

Several prisons already have care pathways for prisoners with learning disabilities in place. These are typically developed by learning disability nurses, in collaboration with the healthcare team, the mental health team, education and others. Similarly, some prisons have learning disability referral protocols in place. These usually involve ensuring referral forms are placed and promoted throughout the prison, encouraging staff to record their concerns and allowing the healthcare staff to assess prisoners, as appropriate.

To ensure care pathways and protocols are effective, healthcare teams first need to ensure that all staff in the team and prison-wide are made aware of the fact that there is a significant number of prisoners with a learning disability and what their general needs are. One prison healthcare team admitted to neglecting this group initially simply because they were never made aware and no one in the team had any learning disability work experience. This changed once a learning disability protocol was put in place and links were made with a local specialist.

Discharge planning, both from healthcare services and from prison is an important part of the care plan for a prisoner with learning disabilities. Homelessness is also a risk factor for prisoners with learning disabilities resettling back into the community. All efforts must be made to ensure they are housed and supported appropriately. This may involve working with the local authority and/or learning disability services for the area into which the prisoner is resettling, as well as primary and secondary care services. Ensuring prisoners’ healthcare issues are communicated and the appropriate provision is put in place will help to ensure that their health problems are not exacerbated by the move back into the community.

Transition between services is often reported as being problematic for people with learning disabilities. Transition is generally used to explain the move from young people to adult services in the wider community, or childhood to adulthood. Prisoners can be faced with a range of potential transitions and transfers, such as moves between prisons, moving between prison and hospital, and leaving prison to return to the community. The important things to help ensure a smooth transition include:-

- pro-active, comprehensive transition planning,
- ensuring equal eligibility in new services,
- clear information shared between professionals, and
- a well co-ordinated effort between all relevant services.

These factors highlight the need for, and benefits of, developing transition protocols for prisoners with learning disabilities. These need to be detailed and specific. They should also give a clear outline of the role of other agencies. It is best practice to involve the person in question in the planning process. An effective way to help ensure a smooth transition and transfer of information to all potential agencies could be to allocate a 'liaison' role to a member of staff, as is often used in hospitals (hospital liaison nurses).

13 Recommended actions for healthcare staff: Health promotion and working with other care services and organisations

13.1 Health promotion

Whilst a prisoner with learning disabilities may not necessarily require medical treatment during their time in prison there is still an important role for healthcare staff with regards to providing health promotion or public health material in easier-to-read formats. Healthcare staff can also help by answering any queries other prison staff may have with regards to learning disabilities more generally.

Any prison-wide public health promotion and disease prevention programmes, for example smoking cessation or healthy eating campaigns, should be made relevant to people with learning disabilities and easy enough for them to understand. It is less likely that prisoners with learning disabilities will be aware of the increased risks of certain conditions faced by offenders, such as the risk of Hepatitis, or those risks for people with learning disabilities, such as obesity. Any public health or other health trainers working with prisoners need to be aware of the issues and needs of this group and plan to accommodate them.

Where healthcare services offer vaccinations or test for specific conditions, the availability and benefits of such interventions need to be clearly promoted and explained. It is also worth noting that some people with learning disabilities may never have had the opportunity to take part in population screening programmes. Any general health awareness material, such as the leaflets or posters often found in healthcare waiting rooms explaining health conditions, should be available in Easy Read format.

“Some people need reminders about washing and stuff like that... I need reminders about brushing my teeth.”

(Ex-offender with learning disabilities, member of the Working for Justice service user group).

13.2 Working with other care services and organisations

The social care needs of a person in custody or in prison were previously the responsibility of the local authority based in their home area. However, recent changes outlined in the Care Act (2014) state that it is now the responsibility of the local authority in the area of the prison. The Act guidance encourages partnership working between prisons and the relevant local authority/social services department to help prisoners with social care needs, which includes learning disabilities.

13.2.1 Community learning disabilities teams and local authorities

All local authorities have Community Learning Disabilities Teams (CLDTs), in some form. These are teams of different health and social care specialists who can give advice on adults with learning disabilities. They also accept referrals for assessments and provide support and therapies for people with learning disabilities. The teams will have links with all local learning disability services, such as supported-housing services and day-centres. It is best practice for prison healthcare departments to establish a link with their local CLDT, with named contacts and an agreed protocol for joined up work.

Some CLDT's may already have too many clients on their caseload and therefore be unable to provide help to everyone referred to them. Some areas also have referral eligibility criteria that are quite restrictive with regards to who they can support. It is therefore good practice to also develop close ties with local and national 3rd sector learning disability organisations. It can often be easier for learning disabled prisoner referrals to be passed to them upon discharge (see below).

See also the information on the Care Act in prisons and the role of local authorities meeting the social care needs of prisoners (see page 20). These new changes emphasise even more so the need for a close working relationship between local authorities and prisons and prison healthcare teams.

13.2.2 Independent/private providers and third sector organisations

There are many independent/private providers and third sector organisations in the form of national and local charities, not-for-profit organisations, and advocacy and voluntary organisations. These work on behalf of people with learning disabilities and can offer information, resources and local sign-posting.

Many organisations also offer direct services to people with learning disabilities, such as specialist supported living housing networks, day-centres, social activities and supported work programmes. The Community Learning Disability Team local to the prison should have contact details for other local learning disability organisations.

13.2.3 Learning Disability Partnership Boards

Most councils have a Learning Disability Partnership Board (LDPB) comprised of representatives from local organisations. These meet regularly to talk about opportunities and the support available for people with learning disabilities in their area. There is an important opportunity for a representative from the local prison to link in with their LDPB. This would encourage the sharing of mutually useful information and advice and help to develop recommendations for planning services for offenders with learning disabilities.

You can find out how to contact both your Community Learning Disability Team and your local Learning Disability Partnership Board via your local authority.

13.2.4 Liaison and Diversion services

There are multi-disciplinary teams called Liaison and Diversion schemes which currently serve 50 percent of the country. These teams support people at the police and/or courts stages of the criminal justice system. Historically their main focus has been on supporting people with mental health issues, however, there is now a move towards supporting people with various other conditions, including learning disabilities. Whilst the teams do not operate within prisons, it would still be beneficial for prison healthcare teams to establish

links with their local Liaison and Diversion schemes to promote conversation and plan for specific cases moving through the system locally.

13.3 Transferring prisoners to community hospitals

If a person's learning disability means that they are particularly vulnerable and cannot cope with the demands of the criminal justice system, even with support, then they should be assessed and possibly diverted to a more appropriate setting that can address both their care needs and their offending behaviour.

Prisoners assessed as not able to cope with prison because of their mental disorder, which includes learning disabilities, can be transferred to hospital under section 48 of the Mental Health Act (2005). The Department of Health has also produced guidance on this transfer process (see 'Resources' on 34).

13.4 Primary care planning during resettlement

People with learning disabilities visit their GP with similar frequency to the general population. However, given the evidence of greater health need it would be expected that people with learning disabilities should be accessing primary care services more frequently than the general population. The Health Equalities Framework (2013) reports that collaboration between GPs, primary health care teams and specialist services for people with learning disabilities is generally regarded as poor.

As a prisoner with learning disabilities prepares to leave prison and re-enter society there are additional things all staff working with them should consider. With regards to healthcare, ensuring that a prisoner is registered with their local GP service before they arrive in the area is vital in providing the bridge to external health and other care services. It is vital to pass on their medical history, notes concerning their care and communication needs plus written confirmation of their learning disability. Making links with wider appropriate care services, such as dentists or mental health services will also help to ensure a patient's care is can continue.

In cases whereby GP or other services will not allow registration until the individual is living in the area and applying in person (despite an explanation of the situation) it is important to prepare the individual for the event of registering themselves; explaining what is required and why it is important. They should be provided with all relevant information to establish contact and to pass on their medical history. A cover letter from the prison which they could present to the service would also be beneficial.

"I might want to say things but might not know how to say the word or what the word is for the problem – so don't bother saying anything. Staff need to probe a bit further and check."

(Ex-offender with learning disabilities, member of the Working for Justice service user group).

14 Resources

14.1 Networks and forums

The Royal College of Nursing online forums:

This has both learning disability and criminal justice nursing forums

www.rcn.org.uk/development/communities/rcn_forum_communities/learning_disabilities

www.rcn.org.uk/development/communities/rcn_forum_communities/prison_nurses/nursing_in_cjs_principles_of_nursing_practice

National Network for Learning Disability Nurses (NNLDN):

The NNLDN is a 'network of networks' which aims to support networks and nurses in the field of learning disabilities. The website contains lots of information on access to acute services

www.nnldn.org.uk

UK Continuing Care Network

A free-to-join network aimed at practitioners working in continuing care and learning disabilities

www.jan-net.co.uk

UK Forensic and Learning Disability Network

A free-to-join network aimed at practitioners with an interest in people with a learning disability in secure settings or at risk of contact with the criminal justice system

www.jan-net.co.uk

UK Health and Learning Disability Network

An open network, hosted by the Foundation for People with a Learning Disability (FPLD), with a focus on the health of adults with a learning disability

www.learningdisabilities.org.uk/ldhn

UK Mental Health in Learning Disabilities Network

Open to anyone with an interest in the mental health issues of people with learning disabilities

www.learningdisabilities.org.uk

14.2 Websites and online resources

Care and Treatment of Offenders with Learning Disabilities. This provides information on people with learning disabilities who have, or are at risk of, committing offences

www.ldoffenders.co.uk

Positive Practice, Positive Outcomes: A Handbook for Professionals in the Criminal Justice System working with Offenders with Learning Disabilities (Department of Health, 2011)

www.gov.uk/government/publications/positive-practice-positive-outcomes-a-handbook-for-professionals-in-the-criminal-justice-system-working-with-offenders-with-a-learning-disability

KeyRing Living Support Networks; Free training on learning disability awareness for criminal justice staff. An accompanying DVD of ex-offenders with learning disabilities talking about their experiences is also available
www.keyring.org/cjs-training

14.3 Easy Read information

Easy Health. This provides a wealth of free accessible (Easy Read) information and leaflets on a range of health related topics
www.easyhealth.org.uk

Easy Info (how to make information accessible). This provides guidance on how to make information accessible
www.easyinfo.org.uk

Mencap's Guidance on Making Information Accessible. This provides guidance on how to make information accessible
www.mencap.org.uk/what-we-do/resources-and-training

'CHANGE' guide to developing your own Easy Read documents
www.changepeople.co.uk/freebies.php.

The Dept of Work and Pensions (which includes The Office of Disabilities) guide on commissioning and developing Easy Read
<http://odj.dwp.gov.uk/docs/easy-read-guidance.pdf>.

KeyRing Living Support Network's Criminal Justice Pages. Here you will find links to many Easy Read documents designed specifically for use in the Criminal Justice System. Some of these are health related. You will also find information regarding how to access free Easy Read images if you work in the Criminal Justice System.
www.keyring.org/cjs-easyread

NOMS has created a website for prison and probation staff with guidance and resources on Learning *Difficulties* and Learning Disabilities in the Criminal Justice System.
www.lddnavigator.org.uk

14.4 Communication

'Crossing the Communication Divide: A toolkit for prison and probation staff working with offenders who experience communication difficulties' (NOMS)
www.rcslt.org/about/docs/crossing_the_communication_divide

'Sentence Trouble' (the Communication Trust). This is a website with advice on communication issues for children and young people who offend. There is also guidance by the same name.
www.sentencetrouble.info/

14.5 Health information

Improving Health and Lives Learning Disabilities Public Health Observatory (IHaL). This provides information and resources on the latest learning disabilities health related information.
www.improvinghealthandlives.org.uk/

Intellectual Disability Health Information. This provides a wealth of information on the health needs of people with learning disabilities.

www.intellectualdisability.info

Mental Health Act (2005). The Department of Health has also produced guidance on this transfer process. 'The procedure for the transfer of prisoners to and from hospital under sections 47 and 48 of the Mental Health Act' (2005)

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081260

Forensic care pathways for adults with intellectual disability involved with the criminal justice system. Royal College of Psychiatrists (2014). This report describes the key stages of the care pathway for people with intellectual disability who have been charged with committing, or are suspected to have committed, offences.

<http://www.rcpsych.ac.uk/pdf/FR%20ID%2004%20for%20website.pdf>

14.5.1 Annual health checks

IHaL; Making reasonable adjustments to primary care services: supporting the implementation of annual health checks for people with learning disabilities

www.improvinghealthandlives.org.uk/publications/1224/Makingreasonableadjustmentstopriarycareservices:supportingtheimplementationofannualhealthchecksforpeoplewithlearningdisabilities

IHaL have written three factsheets on health checks:

- Health checks: identifying health issues in people with behaviour that challenges
- The effectiveness of health checks for people with learning disabilities
- What makes health checks for people with learning disabilities work better

They can be downloaded

from: www.improvinghealthandlives.org.uk/projects/annualhealthchecks/detail

14.5.2 Health Action Planning (HAP)

Examples of HAPs used in the community

<http://easyhealth.org.uk/listing/health-action-plans-%28leaflets%29>

Examples of a HAP designed for use in prisons

www.keyring.org/cjs-easyreadexamples (under the 'prison' section)

Guidance on HAPs by Valuing People (Department of Health 2009)

http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_096505

Examples of a HAP designed for use in prisons

www.keyring.org/cjs-easyreadexamples (under the 'prison' section)

15 Appendices

15.1 Appendix 1 - Practical tips for good communication

15.1.1 General communication

- Use the person's name when addressing them at the start of a question or comment.
- Always explain to the person concerned exactly why they are in a new situation, what they should expect and when.
- Prepare the person for each stage of the communication, for example, "David, I will now ask you some simple questions" or "David, I will now explain what we are going to do next."
- Emphasise important words.
- Avoid using acronyms, abbreviations, sarcasm and metaphors.
- Be patient and calm whilst communicating; do not rush the person you are talking to. They are likely to need longer to process the questions and think about their answers.
- Use concrete terms not abstract references, for example, "At breakfast time" rather than "Early on."
- Break large chunks of information into smaller chunks, with short breaks.
- It may help to use visual aids when asking questions. For example, you could use photos or drawings to illustrate a point.
- Ask questions in the chronological order in which they happened. You could use a calendar and spoken prompts. For example, "Was it the day after you went to the doctors?"
- Keep the questions precise and not vague, for example, 'Where were you yesterday afternoon?' rather than 'Where have you been recently?'
- Avoid double-negative and unclear questions. For example, instead of "You were not in the shop, were you?" you could ask "Were you in the shop?"
- Be aware that repeating questions may suggest to the person that they have given the wrong answer the first time.
- The person must not feel pressured into a response. Many people are more suggestible or eager to give what they think is the 'desired' answer.
- It is important to check that the person understands what has been said. You can ask them to repeat the question or message in their own words, or they could be questioned further.

15.1.2 Planning interviews, hearings or meetings

- Careful planning will save time in the meeting and help to ensure a fair and calm response from the person. You may want to seek assistance from a health or social care professional or someone else who knows the person. For example, a member of their family, a social worker, or perhaps an advocate or friend they wish to be present (when permitted).
- If information is sent out before hand about the meeting or event, ensure it is easy to understand. The person may need assistance to organise attending, for example, with travel arrangements or with understanding and remembering the time and date.

- Wherever possible, several short interviews or sessions are likely to be more productive than one long session. This will help with the person's concentration levels and to reduce anxiety.
- Try to have sessions in a familiar environment and avoid changing the room each time. Ensuring the environment is free from distracting noises and that it is as calm and familiar as possible will help reduce anxiety.

15.1.3 Understanding body language

Often the body-language of people with learning disabilities and learning difficulties can be misleading and therefore misinterpreted. They may also find it difficult to read the body language of other people. This is particularly difficult for people with autism and Asperger's Syndrome.

- Do not assume that a lack of eye-contact means the person is not listening
- Just because the person is nodding does not mean they fully understand. Check that they understand by asking other questions
- The person may not understand social rules, such as taking it in turns to speak and giving people their personal space
- If the person appears agitated, restless or distracted it is likely to be because of their condition and the stress of the situation. Having a break may help
- Remember that the person may not understand the meaning behind other peoples' gestures or facial expressions.

People with learning disabilities and other communication problems often have problems remembering information. Using visual prompts can help to jog their memory. Also, 'Objects of Reference' can help people to remember actions, appointments or information. This involves giving the person an object to act as a reminder. For example, you could give someone a napkin or menu to remind them that they are to go to the canteen.

15.1.4 Written communication

From the very start, the criminal justice system involves filling in forms, reading letters and following written instructions and directions. At every stage, there is an opportunity to ensure the words used are in plain English, with all the technical terms and jargon explained clearly in the appropriate language. Taking this approach will help everyone entering the criminal justice system, regardless of them having a communication problem.

For those with recognised communication problems, such as a learning disability, additional measures are recommended (although, these changes could also potentially benefit everyone).

To ensure the person is given the best possible chance of understanding all written information, the text and layout should be made 'accessible'. There are some simple rules to help make written material more accessible.

15.1.5 Practical tips for written communication

- Use a simple, well shaped font, such as Comic Sans, Arial or Helvetica
- A minimum font size of 14 is recommended for those with a learning disability, visual impairment or poor literacy skills
- Increase the line spacing to spread the text lines (in 'Word' go to Format>Paragraph>Line Spacing)

- Limit the use of italics, underline, or bold
- Use bullet point lists, rather than long written paragraphs and use text boxes to summarise points
- Avoid using BLOCK CAPITALS as the word loses its shape
- Keep sentences short and simple
- Do not use documents with hand-written text as this would be too hard to read.
- Check the overall 'readability score' (in 'Word' go to Tools>Options>Spelling and Grammar> then tick the 'show readability statistics' box)
- Keep the layout simple and include plenty of blank space
- Avoid shiny paper with black text; the contrast causes difficulty for people with visual stress
- Off-white or pastel shades of paper are easier to read, particularly for people with dyslexia, but it is always advisable to ask the person what they prefer
- Using pictures (line drawings, photos, diagrams, maps, flow-charts and specialist cartoons and symbols) will make a document more accessible to someone with a reading problem
- Any pictures used should give clues about the meaning behind the text. There are several good 'Clip Art' and photo packages available as well as specialist Easy Read images designed for use on documents that are read by people with learning disabilities.

If you are using your own photographs make sure they do not have too much background information as this can confuse the message. It is important to provide clear and simple directions for any meetings or appointments. These need to be in an accessible layout, ideally with a map marking out significant landmarks. A contact number can also be included in case the person is delayed or lost. Some people with dyslexia or similar reading problems may prefer to receive documents electronically so they can use specialist software that reads the text aloud.

15.2 Appendix 2 – The ‘Gold Standard’ checklist

This list outlines best practice provision for prison healthcare centres treating patients with learning disabilities and working with the rest of the prison to support this group of vulnerable prisoners.

- Annual health checks for all prisoners with learning disabilities.
- Health Action Plans for patients with learning disabilities.
- Staff awareness and training on learning disabilities, the Equalities Act and Reasonable Adjustments.
- Multi-agency care pathways
- Accessible information; ensure all information is available in Easy Read.
- Awareness of the safeguarding issues of people with learning disabilities.
- Ensuring the needs of people with learning disabilities is included in public health promotion and planning.
- Ensure equal access to services and information (under the Disability Equity duty).
- Monitor progress with regards to prisoners with learning disabilities, including data collection on percentages, health issues, re-offending rates if possible.
- Their information then accompanies them when they plan resettlement and leave.
- Regularly review the capacity of the service to meet the needs of prisoners with learning disabilities.
- Service user involvement wherever possible; include prisoners with learning disabilities in the development of services.
- Provide support or adaptations for health promoting activities such as gym time, smoking cessation, diet advice, etc.
- Employ the correct number and type of trained learning disabilities practitioners in accordance with best practice, recommendations and population need.
- Ensure equal access to service for assessments and appointments.
- Ensure equal access to disease prevention, screening and health promotion activities for people with learning disabilities (including Easy Read information). This includes peripheral health services (dentists, opticians, etc)
- Reasonable adjustments are included in any healthcare and prison equality impact assessments pro-formas.
- Sufficient planning to meet and coordinate any additional needs of minority groups of prisoners with a learning disabilities (i.e. young people, women, ethnic minorities, etc)
- Provide and promote accessible complaints procedures should patients with learning disabilities wish to complain.
- Work with prison staff to advise on how to support prisoners with learning disabilities.
- Good partnership working with mental health teams and local organisations and specialists.

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