Report on audit of practice in commissioned services in relation to people with learning disabilities

London Health in Justice and Other Vulnerable Adults London Clinical Network (HiJOVA LCN)

2017

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About the London Health in Justice & Other Vulnerable Adults London Clinical Network

The common purpose of the London Health in Justice and Other Vulnerable Adults London Clinical Network (HIJOVA LCN) is to contribute clinical and other relevant knowledge and expertise including research based evidence, to inform the strategic direction and work programme of NHS (England) London in order to enhance the wellbeing of London’s vulnerable people in contact with the criminal justice system.

At the start of this report it is important to record our thanks to everyone who took the time to arrange visits, meet and show us round their services, or talk on the phone. We are very grateful for the open way that people discussed their practice, including their achievements and the challenges they face in supporting people who may have learning disabilities. Thank you.

Alison Giraud-Saunders
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Executive summary and recommendations

1. Background and context

People with learning disabilities are over-represented in the youth and criminal justice systems. The London Clinical Network sponsored an audit to explore how health and justice services commissioned by NHS England are working for people with learning disabilities. We visited eight London prisons and the immigration removal centre (IRC); we met staff from the Havens (the sexual assault referral centres) and from liaison and diversion services in three areas. We also met representatives from partner agencies and interviewed a number of people on the phone. We used a set of questions to guide the conversations (see box), based on the agreed focus for the audit and on available good practice guidance. We sought out examples of good practice. We also gathered and reviewed service specifications and other documentation offered by interviewees.

Themes used to guide interviews and discussions

| Being prepared: training, accessible information, access to learning disability expertise, working together |
| Identification and screening |
| Pathways: for full assessment, reasonable adjustments and onward referral |
| Information sharing |
| Data collection and use |
| Involvement of people with learning disabilities and families. |

Each type of service operates in a different context; in some cases the context and environment place significant constraints on healthcare staff. Liaison and diversion services are still developing, with a national implementation programme under way. Prison healthcare services are operating in a context of substantial prison and probation reform. Some of the service specifications are set nationally. NHS England (London) has amended some specifications to include extra attention to and support for people with learning disabilities, which is very good practice.

2. Summary of findings

2.1 Being prepared

There is great variation across the services visited. The expertise of learning disability practitioners and co-ordinators, where available, is highly valued by colleagues and partner agencies. Most services that do not have such a post were keen to do so, or at least to have a formal route for obtaining equivalent advice and support. We think that evaluation would be useful to show whether the different models in place are equally effective or whether one is better. We hope that the London-wide community of practice will give people in these roles a place for peer support, sharing of ideas and learning; we
will share with them the good practice examples we noted. Various easy read and training resources are already available, but not all services knew about these. It would be useful to collect and share such information (and to identify gaps to be filled). Training, accessible information, access to expertise and joint working were more systematic where there was a learning disability practitioner in post. In most services joint working with partners depended heavily on relationship-building and good will.

We assess this theme as ‘partly met’.

2.2 Identification and screening

Most interviewees thought that staff in both their services and partner agencies were quite good at noticing a person who might be vulnerable and raising an alert, though there were persistent concerns about people who might be missed. The Havens do not use a screening tool at present. A national group led by NHS England is considering the question of an appropriate screening tool for IRCs. Liaison and diversion services are not yet operating to the national specification across the whole city and do not provide 24 hour cover; it is not yet possible to be sure that they see, and therefore screen, everyone who may be vulnerable. Services are currently using different screening tools. Prison healthcare systems vary; those that do not yet have effective screening in place should be brought up to the standard set out in the most recent service specification and use appropriate Read coding to flag people with learning disabilities in SystmOne. We would like to see detailed case reviews to understand how people assessed with very low IQ came to be imprisoned and what could have made a difference.

We assess this theme as ‘partly met’.

2.3 Pathways

As for identification, pathways for full assessment, reasonable adjustments and onward referral were most robust where there was a learning disability practitioner in post. All services were able to give examples of reasonable adjustments they had made (some compensating for deficits in other services). Where this is problematic there may be a need for NHS England to discuss with partner agencies whether they are fulfilling their Equality Act duties. Some services are not yet making the reasonable adjustments set out in the most recent prison healthcare specification. The single biggest issue of concern raised by all was the paucity of community support for people who very often fall between the eligibility criteria and competencies of the services available. Two kinds of gap were described:

- basic support to understand and comply with requirements and to cope with housing, money, benefits and relationships
- adapted programmes and other interventions to help the person understand and change their behaviour.

In order to inform discussion with partner agencies about gaps and how to fill them it would be helpful to have data on how often people with learning disabilities have been unable to get the types of support needed. This could include more thorough identification of problems in joint working between different NHS services.
We assess this theme as ‘partly met’.

2.4 Information sharing

While all services had arrangements in place for sharing information, there was a good deal of frustration at the difficulties of getting the right information to the right people in a timely way (even within the NHS) and the information then being used reliably. It does not appear that, as currently used, the Summary Care Record provides sufficient information about conditions such as learning disabilities or the reasonable adjustments that individuals may require. There may be a case for all health practitioners working within the justice pathway to have access to the same electronic information system.

We assess this theme as ‘partly met’.

2.5 Data collection and use

Good data is collected in ‘wave 1 and 2’ liaison and diversion services and used in service and workforce planning; this is starting in prisons with learning disability posts. Elsewhere data was not collected systematically. It will be important to ensure that there is consistency in definitions and that numbers of people with learning disabilities are related to throughput.

We assess this theme as ‘partly met’.

2.6 Involvement of people with learning disabilities and families

It can be challenging for these types of services to find ways of obtaining feedback and of involving people in service development; nevertheless it was disappointing to hear only a small number of examples. As with accessible information, there are resources available (some free) and this may be something the community of practice could investigate.

We assess this theme as ‘not met’.

2.7 Autism

Although not the primary focus, we did ask whether there were any different points to raise about people with autism. Growing awareness and demand was reported, with consequent needs for training, practice development and more options for support. These comments suggest that data should be collected to inform future workforce and service development. We heard about a small number of examples of people with autism giving feedback or training.
3. Recommendations

Recommendation to healthcare providers

1. Healthcare providers should ensure that:
   • systems are in place to identify people with learning disabilities, using validated screening tools, at an early stage in the justice pathways
   • results are recorded in the healthcare information systems, using appropriate clinical coding
   • funding allocated for co-ordinator posts is applied as intended and there is an agreed pathway for people with learning disabilities that includes access to appropriate clinical expertise
   • information about needs is shared along the pathway in accordance with safe information governance.

Recommendations to NHS England

2. NHS England should reinforce the expectations of the learning disability co-ordinator role and:
   • seek assurance that healthcare providers are using additional funds as intended to appoint individuals or teams with the full range of clinical, managerial and service development skills required
   • match funding to indicators of workload (for example, prison population and turnover)
   • consider formal evaluation of the role and models of implementation to enhance understanding of the options and to support future development.

3. NHS England should draw partner agencies’ attention to their obligations under the Equality Act, the Care Act and the Human Rights Act in respect of gaps in provision, especially:
   • community support for people who have been victims of sexual violence
   • personal care and equipment for detainees in or discharged from the IRC
   • support and adapted interventions for people with offending behaviour.

Recommendation to the Health and Justice and Other Vulnerable Adults London Clinical Network

4. The Network should consider commissioning a detailed case review to understand how people assessed as most vulnerable (for example, those with IQ <60) came to be imprisoned, what these examples demonstrate about how the systems are working and what alternatives might have been possible.

5. The Network should support dissemination of the project findings and the examples of good practice offered by interviewees and support the planned community of practice.
1. Introduction

1.1 Background

People with learning disabilities are over-represented in the youth and criminal justice systems. National data\(^1\) show that 5-10% of adults and a higher proportion of young people detained by the police or in prison/youth custody have learning disabilities, compared to about 2% in the general population. Early findings from liaison and diversion services nationally suggested that data is not yet being collected consistently. National research\(^2\) under way with ex-prisoners with learning disabilities has already shown that around one in three are back in prison or detained in hospital within 10 weeks of release.

Two small screening studies in immigration removal centres (personal communication) showed very different proportions of people who might have learning disabilities (one showed 1% and the other 10%).

We are not aware of comparable data from sexual assault referral centres (although an unpublished case review from 2008 suggested that a third of children and young people seen in one centre had learning disabilities). Prevalence of rape and sexual violence against people with learning disabilities is difficult to assess from published studies\(^3\); some reports suggest rates much higher than in the general population. Research from the University of Kent\(^4\) highlighted the experiences of women with learning disabilities who had experienced domestic violence.

People with learning disabilities experience worse health and worse access to healthcare than the general population\(^5\).

The Equality Act 2010 requires public services to make reasonable adjustments to promote equal access for disabled people (amongst other groups with ‘protected characteristics’). NHS England has:

- issued specific guidance for prison healthcare staff on treating patients with learning disabilities\(^6\)

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\(^1\) Evidence from the Prison Reform Trust’s ‘No One Knows’ project: http://www.prisonreformtrust.org.uk/Projects/Research/Learningdisabilitiesanddifficulties and the 2013 national literature review on offenders with learning disabilities and difficulties: http://www.3sc.org/news/3sc-improving-services-offenders-learning-disabilities-and-difficulties

\(^2\) Research led by Prof Glynis Murphy and the Tizard Centre, University of Kent; early findings reported at the 15th International Conference on the Care and Treatment of Offenders with an Intellectual and/or Developmental Disability, April 2016

\(^3\) Olsen, A. and Carter, C. (2016) Responding to the needs of people with learning disabilities who have been raped: co-production in action. Tizard Learning Disability Review, 21, 2, pp30-38

\(^4\) https://www.kent.ac.uk/tizard/research/research_projects/domviolence.html?tab=findings


\(^6\) ‘Equal Access, Equal Care’: https://www.england.nhs.uk/commissioning/health-just/hj-resources/
• included specific provision for people with learning disabilities in the national specification for liaison and diversion services and supplemented this with a resource paper\textsuperscript{7}
• included learning disability requirements in London service specifications for prison healthcare and immigration removal centre (IRC) healthcare and drafted national guidance to accompany the pilot of a screening tool.

1.2 What we planned

As part of the London Clinical Network’s workstream on vulnerabilities it was agreed that an audit should be undertaken of commissioning and delivery in relation to people with learning disabilities across all services commissioned in London by the Health and Justice team. The findings would inform future commissioning and serve as a baseline for development.

The services to be covered were:
• liaison and diversion (all age) across London
• healthcare in London prisons/youth offender institution (YOI)
• healthcare in London immigration removal centres
• healthcare in London sexual assault referral centres (the Havens).

Note: there are no secure children’s homes or training centres in London.

The agreed focus included:
• systems for identifying people who may have learning disabilities
• systems for recording and, where appropriate, sharing this information (both across health services and with other services, such as the prison regime) in accordance with good information governance
• pathways for acting on such information, including reasonable adjustments within healthcare, onward referrals and links with community-based learning disability services
• staff understanding about the issues experienced by people who may have learning disabilities and the rationale for reasonable adjustments.

We agreed to ask, if time allowed, whether the service wished to raise additional or different points in relation to people with autism.

We based our approach on the principles of realistic evaluation\textsuperscript{8} (covering context, mechanisms for implementation and outcomes). We planned:
• review of documents (such as specifications, monitoring reports, operational protocols)
• interviews with commissioners
• interviews with a sample of service managers, practitioners and front line support staff
• call for evidence of outcomes, such as reasonable adjustments offered, detection of and action taken on previously undiagnosed health problems


supporting a ‘community of practice’ of staff who have particular responsibilities in relation to people with learning disabilities (to include the new prison healthcare learning disability co-ordinators and the liaison and diversion learning disability practitioner). The idea of a community of practice is to bring together people doing similar jobs, for peer support and to facilitate practice development.

We agreed to make links with both the London Transforming Care Board and the London group of senior learning disability nurses that meets quarterly, as well as the national Offenders with Learning Disabilities Steering Group and the national group steering work on people with learning disabilities in immigration removal centres. We checked that we would not be duplicating work planned by the Centre for Mental Health.

The project team consisted of Alison Giraud-Saunders and Dr Mohammed Rashed, with oversight from a steering group:
- Prof Annie Bartlett
- Dr Andrew Forrester
- a commissioner from the London Health and Justice team
- Chrissy Reeves
- Anthony Fletcher (an expert by experience from the Working for Justice Group - a national group of people with learning disabilities who have all been in contact with the criminal justice system), supported by Neisha Betts.

We submitted the audit proposal via the Central and North West London NHS Foundation Trust (CNWL) quality governance process and it was agreed.

1.3 What we did

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<td>Eight prisons/YOI: Belmarsh, Brixton, Feltham, Isis, Pentonville, Thameside, Wandsworth, Wormwood Scrubs</td>
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<td>Three liaison and diversion services: north east London; north, central and west London; south London</td>
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<td>Havens: one meeting with staff</td>
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<td>Combined immigration removal centres at Heathrow</td>
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In addition to health staff we met people from a range of partner services during the visits and talked to some on the phone if they were unable to meet. (Some visits were arranged at short notice.) On some visits we met a very small number of people (and only from healthcare) and on others we met both larger numbers of healthcare staff and a wider range of people from other agencies. See Appendix 1 for a note of the range of people interviewed. In total we talked to 77 people. We recognised that in some services we met a limited sample of people and that they tended to be people who already had some interest in the experiences of people with learning disabilities. We also recognised that we were relying on self-reporting, rather than observation of practice.
We developed a set of questions to guide conversations (based on the agreed focus described above and the available specifications and good practice guidance) – see box below and Appendix 2.

Themes used to guide interviews and discussions

- Being prepared: training, accessible information, access to learning disability expertise, working together
- Identification and screening
- Pathways: for full assessment, reasonable adjustments and onward referral
- Information sharing
- Data collection and use
- Involvement of people with learning disabilities and families.

We asked all interviewees about the issues and priorities from their own perspectives and used the interview guide to prompt and fill in gaps. Where possible, we asked in addition about whether services had any different experiences in relation to people with autism. The findings in section 3 of this report are based on the notes we took during these meetings and interviews. We explained that we were not conducting an inspection; we were there in a spirit of enquiry. Staff in one meeting commented that they welcomed the approach of looking at the service ‘through the lens’ of a particular population group.

We did not receive names and contact details of learning disability co-ordinators before we started, so we collected this information during the visits. The idea of a ‘community of practice’ was well received and a date is now being sought for a first meeting. The group will be facilitated by Maureen Mansfield.

We reviewed the service specifications for the four service types and noted explicit or implicit references to people with learning disabilities.
2. Context

2.1 NHS England commissioning responsibilities

NHS England’s strategic ambition in commissioning health and justice services is “to narrow the gap between those in the criminal justice system and the rest of the population, in terms of health and care outcomes, reducing the number of people who are detained as a result of untreated health problems and ensuring continuity of care after release”\textsuperscript{9}.

Seven priority areas underpin this ambition:

- “A drive to improve the health of the most vulnerable and reduce health inequalities
- A radical upgrade in early intervention
- A decisive shift towards person-centred care that provides the right treatment and support
- Strengthening the voice and involvement of those with lived experience
- Supporting rehabilitation and the move to a pathway of recovery
- Ensuring continuity of care, on reception and post release, by bridging the divide between healthcare services provided in justice, detained and community settings
- Greater integration of services driven by better partnerships, collaboration and delivery”

Each of the services audited is commissioned by the London Health and Justice team in accordance with national partnership agreements or commissioning frameworks. These set out responsibilities for reducing health inequalities and for safeguarding vulnerable people; for detained people there is an important principle of ‘equivalence’. This means that a person detained in prison or an immigration removal centre should receive a standard of treatment and care that is equivalent to what they would receive if they were not detained.

2.2 Guidance and standards

We drew on several sources to develop the interview guide for the audit:


\textsuperscript{9} https://www.england.nhs.uk/commissioning/health-just/
We understand that NHS England is developing good practice guidance in relation to people with learning disabilities and immigration removal; this is still in draft.

We identified common themes for more detailed evaluation across the four different kinds of services. We grouped these under six headings (see box on p.11).

2.3 Context for the Havens

The national specification for sexual assault referral centres starts with a strong statement about equalities duties. Later there are references to children and young people with learning disabilities in the context of the risks they face. Access to specialist learning disability services is given as an example of a reasonable adjustment in the section on equality and diversity. Issues of consent and mental capacity are noted.

The London Havens are run by King’s College Hospital NHS Foundation Trust, in collaboration with the police. People (children, young people and adults) may self-refer or be referred by another service; people are seen by appointment only. One of the Havens is specially for children and young people; development of additional Child Houses is under way. The Havens offer forensic medical examination by a sexual offences examiner and follow-up care including counselling. Some Independent Sexual Violence Advisers (ISVAs) are based at the Havens; others are available via voluntary organisations. ISVAs for people with learning disabilities are available via the charity Respond, with which the Havens have a good working relationship.

2.4 Context for healthcare in Heathrow immigration removal centres (IRCs)

The London primary care specification for IRC healthcare makes it clear that the service is expected to identify and reach out to people with learning disabilities. Screening is to be carried out, leading to a health plan to ensure the detainee is supported in self-management as well as assisted in access to health services. A specific section on people with learning disabilities gives examples of reasonable adjustments, including support with day-to-day living skills and provision of accessible information. There is a separate section on mental capacity.

The centres are managed as one site by Mitie Care and Custody. Healthcare (both primary care and mental health care) is provided by CNWL. The Heathrow IRCs have a very large number of people passing through every year (around 13,000, we understand). Some people arrive there via other IRCs, some from communities where they have been living for some time, some from prison and some straight from ‘lorry drops’ soon after arrival in the country. People may be released or deported at very short notice (e.g. an hour) and healthcare staff may have no information about how long a person will be there, nor where they will be going; some people are detained and released several times. A substantial mental health needs analysis report on IRCs across England was published recently by the Centre for Mental Health10; this describes both the very high levels of need and distress in the population and the impact on healthcare staff of working in the IRC environment.

10 https://www.centreformentalhealth.org.uk/immigration-removal-centres
There are established mechanisms for staff to raise concerns with the Home Office about detainees who appear at risk of harm and may not be fit to detain (with an updated policy issued in 2017). The Home Office’s ‘Detention Services Order 08/2016: Management of Adults at Risk in Immigration Detention’ does not mention learning disability specifically, but refers to people with “a mental health condition or impairment”. The Centre for Mental Health report notes that there is little screening for ‘hidden’ disabilities such as learning disability or autism.

Unlike prisons, the Care Act 2014 does not give local authorities responsibilities for social care in immigration removal centres. If detainees are released and remain subject to immigration control, they have “no recourse to public funds” and are not regarded as “ordinarily resident” for social care. Local authorities may, however, have duties to them under safeguarding or the Human Rights Act.

In 2015 NHS England initiated work to consider how people with learning disabilities may be identified in IRCs and what action healthcare staff can and do take. A variety of existing screening tools were reviewed; it proved difficult to find one that would be suitable for use with this population. For example, many detained people speak little or no English, come from cultures in which learning disability is not recognised or discussed, have had little or no formal education and may not be familiar with the kinds of everyday activities that screening tools cite. A pilot to test one possible tool, accompanied by practice guidance, is planned in an IRC outside London.

2.5 Context for liaison and diversion services

The national liaison and diversion programme has a specific focus on people with learning disabilities alongside people with mental health problems or other vulnerabilities. The national specification sets out expectations including:

• use of validated screening tools
• availability of easy read explanations of the service
• advice from the service to justice agencies about reasonable adjustments
• inclusion of a learning disability practitioner (minimum Band 6) in the core team.

There is one reference in the operating model to reasonable adjustments in relation to “mental health capacity”, which appears to be a conflation of mental health and mental capacity issues.

Liaison and diversion services have developed differently in different parts of London. In advance of the national programme (following the Government’s acceptance of the Bradley Report) there were already well established liaison and diversion services operating in a number of police stations and courts across London; there was also a learning disability court liaison practitioner in post in one area. North-east and east London formed part of the ‘wave 1’ sites for the national roll-out, which sought to enhance current provision in line with the newly developed national specification and was delivered as a collaboration between Together for Mental Wellbeing (Together), Barnet, Enfield and Haringey Mental Health NHS Trust, East London NHS Foundation Trust and North East London NHS Foundation Trust. Central, north-west and west London was a ‘wave 2’ site.
for the national roll-out, delivered as a collaboration between Together, CNWL and the West London NHS Mental Health Trust.

All three mental health trusts in south London also provide liaison and diversion services to all the police stations and magistrates' courts in their respective boroughs. They do not currently operate in line with the enhanced operating model, although this expected to be in place by April 2018.

Liaison and diversion services are also provided to both British Transport Police and City of London Police custody suites.

The national roll-out continues, with full coverage expected by 2020.

While early developments of liaison and diversion services often started with a focus on adults with mental health needs, the national specification requires services to cover all ages and a wide range of vulnerabilities, to extend the operating hours and to provide a community support work function that can, for example, assist a person to make and attend agreed appointments. Liaison and diversion services work closely with the police, youth offending services, court staff and judiciary, the organisations managing security in court cells and prisoner escorts from prison, probation and third sector organisations providing a variety of services. Practitioners work in settings managed by the police and courts.

Development of the liaison and diversion services from their different local origins is taking place against a backdrop of significant change in the youth and criminal justice systems, including:

- the Government’s response to Charlie Taylor’s review of the youth justice system
- substantial restructuring of probation, with new community rehabilitation companies taking over supervision of all but the highest risk offenders; recent inspection reports show that these new arrangements are not yet delivering to a consistently good standard
- review and restructuring of courts and tribunals
- reorganisation of prisons.

Current Government policy emphasises ‘swift justice’, with pressure on courts to process cases quickly, and rehabilitation of offenders with the aim of reducing reoffending. In London policing is led by the Mayor’s Office for Policing and Crime; the new Mayor is proposing changes to enhance neighbourhood policing. Availability of appropriate adults is patchy across London and we were told that it can be difficult for the police to find one with the right knowledge and skills to support an individual with learning disabilities.

Another significant part of the context for liaison and diversion services is the set of changes taking place in health care, public health and social care. Responsibility for funding some relevant programmes, such as substance misuse, transferred to public health. Significant reductions in local authority budgets are now reducing availability of and access to such programmes, as well as reducing the availability of social care. In many areas ‘Supporting People’ programmes and specialist social work teams have been
converted into generic locality teams, with consequent loss of expertise as well as capacity. Grant funding for third sector organisations has been reduced in many areas, resulting in reduction or loss of services and supports. Reducing the risk of offending or re-offending does not necessarily fit tight interpretation of Care Act duties. Meanwhile some NHS community learning disability services have also been reduced and have set tighter eligibility criteria. We were told that some youth offending services are carrying vacancies for relevant posts, such as child and adolescent mental health workers and speech and language therapists.

Some people are identified by the police as potentially benefiting from liaison and diversion involvement, but are released before a practitioner is available and may then be difficult to trace. Some people refuse involvement for a variety of reasons (possibly for fear of stigma if the service is referred to as ‘mental health liaison’).

2.6 Context for prison healthcare

Most prison healthcare is commissioned by NHS England – both primary care and mental health services (not necessarily from the same provider). Healthcare is provided within a setting and regime that is managed by the prison service. The most recent London specification for prison healthcare (2015) includes a number of references to prisoners with learning disabilities throughout the text. The service is expected to identify and reach out to people with learning disabilities. Screening is to be carried out (using a validated tool), leading to a health plan and (where the person is in prison for long enough) an annual health check. Reasonable adjustments are to be made as appropriate to support access to health and social care, including screening programmes and interventions for mental ill health. The service provider is expected to make appropriate referrals prior to release and to work with probation (NPS or CRC) on the offender resettlement plan and to ensure that they have the knowledge and links needed to support the person on release (for example, with substance misuse). A specific section on people with learning disabilities, learning difficulties or autism reinforces these points and gives examples of reasonable adjustments, including support with day-to-day living skills and provision of accessible information. This level of attention to people with learning disabilities reflects NHS England’s good practice guidance and is very welcome.

To support implementation of these requirements the prison healthcare provider is expected to employ a learning disability nurse. This post is to:
• support improved identification of need
• build resources to improve access to services
• facilitate more detailed assessments to determine whether the person has learning disabilities
• case manage vulnerable patients in prison
• act as a resource to healthcare and to the prison in the management and care of people with autism
• work in partnership with the education provider to co-ordinate support.

NHSE put additional funding into contracts in 2016/17.

There is a separate section on mental capacity.
The Care Act 2014 gives local authorities responsibilities to assess prisoners who appear to be in need of social care, and to provide care to meet eligible needs. Implementation of these provisions is still under way, so delivery is variable.

The prison service is undergoing significant change following the release of the Government’s White Paper on safety and reform and the formation of the new Her Majesty’s Prison and Probation Service (HMPPS). HMPPS will take on the operational responsibility for prisons in England and Wales with a clear focus on rehabilitation and resettlement.

This means that over the course of the next three years some prisons will close, new prisons will be built and the remaining prisons may have changes made to their functions or the type of prisoner they house and their sentence status. The only women’s prison in London closed recently.

The new HMPPS will offer a greater degree of empowerment to governors and directors; this should offer opportunities for greater joint working to produce improved outcomes for the individual prisoner in accessing health and social care services.

Interviewees told us that prison leadership and staffing levels have a significant effect on the delivery of healthcare (for example, whether prisoners are able to attend appointments) and on the degree and nature of joint working between the regime and healthcare (for example, on whether and how knowledge about a person’s condition and the reasonable adjustments they may need is shared and acted on).
3. Findings

3.1 Being prepared

3.1.1 Havens
All Havens staff have mandatory Level 4 safeguarding training and there is bespoke training on mental capacity and consent. Clinical psychologists have a module on learning disability during their training. Those interviewed thought that other staff could benefit from training about learning disability, especially about how to question people with cognitive impairments. Communication and capacity were identified as key issues.

The Havens do not have any easy read information (though a good example was cited of using a body map to help someone explain what had happened). We understand that NHS England is pursuing development of a national suite of materials and we think this would be very helpful.

The Havens have a good working relationship with the charity Respond, which offers independent sexual violence advisers (ISVAs) who specialise in working with people with learning disabilities. Havens staff can involve a Respond ISVA and can also consult the Trust’s adult safeguarding lead if they require additional support. Those interviewed were not aware of the learning disabilities co-ordinator (acute liaison nurse) employed by the Trust.

Health staff work closely with the police to ensure that evidence is gathered as appropriate; sometimes there can be difficulties in relation to people who lack capacity to consent to examination if the police involved do not have a good understanding of best interests processes. Havens staff work hard to understand what has happened and to give the person confidence that they are believed; it can be very difficult for the person if the Crown Prosecution Service then decides not to pursue charges.

Although the Havens do not have a specific focus on people with learning disabilities, their person-centred approach and attention to capacity mean that they are very responsive.

3.1.2 IRC
No specific awareness training was mentioned. Healthcare staff are very well aware of the very high levels of distress and vulnerability in the detained population.

Easy read information about specific health problems is available if required via the Trust website. However, healthcare staff do not know of any easy read information about detention and the immigration removal processes – yet they may be expected to explain these. An example was given of a person with Down syndrome who was detained but could not understand why, despite efforts by healthcare staff to explain. One nurse said: “I cried for days over that one”. We understand that NHS England is looking at the development of easy read information in connection with the pilot of a screening tool (see section 2.4 above).
NHS England added funding to the contract with CNWL for a learning disability coordinator for the IRC, but no appointment had been made at the time of the visit and those interviewed did not know what was happening about this. Access to learning disability expertise was reported to be difficult, with no service level agreement in place to secure support from within the Trust or from the local community learning disability team.

Healthcare staff described joint work with the IRC operator’s staff on the basis of good will. There appears to be a gap in formal responsibility for personal care (although the service specification does refer to “support with day-to-day living skills”), and another gap in relation to access to equipment such as wheelchairs.

3.1.3 Liaison and diversion

(a) Learning disability awareness training
Availability of learning disability awareness training for liaison and diversion staff (including in youth justice) was closely linked to the availability of a learning disability practitioner. In the area that has such a post the whole team has training. Some relevant training is planned in other areas. No examples were given of a formal training offer to partner agencies, though some happens informally and there was some interest in organising joint training and/or training for specific groups (e.g. the Crown Prosecution Service, judiciary). Training for partner agencies is not specified in the national specification and operating model, but is recommended as good practice. No examples were given of specific Equality Act training; Mental Capacity Act training was said to be mandatory but of variable quality.

(b) Accessible information
There is some easy read information available nationally (see examples at [http://www.keyring.org/cjs/easy-read](http://www.keyring.org/cjs/easy-read)), but not everyone was aware of it. Some practical difficulties were mentioned (such as carrying large quantities of printed materials). Together is planning to review the paperwork given to all users of the service to make it all easier to read, given the data on widespread literacy problems.

**Good practice: easy read**
Stoke Newington police custody suite has an easy read pack of information on site. This includes explanations of police processes, such as searches.

One court was described as displaying rights explained in easy read form, in the cells area. This was not ideal, as people were not able to stop in the corridor to read them, but the good intention could be built upon.

(c) Access to learning disability expertise
The availability of a learning disability practitioner in one area was very much appreciated by her colleagues (and a second post had recently been created). She had established screening and pathways, delivered training and acted as an expert resource to colleagues, and created contacts with other relevant services, in addition to working directly with service users. Before her appointment, and in the other areas, access to learning disability expertise was described as extremely difficult; many people with mild or borderline learning disabilities may never have been in touch with community learning...
disability teams and may well not meet current eligibility criteria. Practitioners and partners in other areas commented on the gap that they perceived.

(d) How justice and healthcare staff work together
Justice partners commented very positively on the overall impact of liaison and diversion services in terms of joint working. “It changed our lives”, said one person, commenting on the availability of immediate advice to the court (reasonable adjustments to processes, pre-sentence reports) and help to access the right services. On the other hand, many of those interviewed described some difficulties. For example, the pressure for swift justice processes could make it difficult for liaison and diversion services to assert needs for more time for assessments and engagement with the individual, particularly if it was not possible to say definitely that the person had a specific diagnostic label; sometimes there were debates over which agency should pay for a specialist assessment. A few examples were given of liaison and diversion submitting advice to a court about an individual’s cognitive difficulties, but the court drawing different inferences from the person’s behaviour.

We were told that the all age model of liaison and diversion services has proved challenging to implement across London, in part due to the localised ownership of youth justice services. NHSE has therefore worked with CCGs in the development of the youth pathway by building capacity and expertise within youth offending services. This means that a local pathway will be in place for young people as they come into contact with the youth justice system rather than a pan London response as there is for adults. This also means that there will be local variation in the delivery of liaison and diversion services for young people. Some of those interviewed from a court perspective commented on the differences they saw between the youth and adult liaison and diversion approaches and hoped that the courts would benefit from greater consistency in future.

Good practice: working together
The police were often called on Sundays to incidents relating to one young man’s behaviour. When the liaison and diversion service got involved the practitioner discovered that the police thought he had learning difficulties of some sort, felt sorry for him and would take him to the station and heat up a microwave meal for him. They had not realised that this was reinforcing his behaviour. Tackling this required collaboration to work out what was happening and agree on different responses, alongside referrals to try to get his needs for company and activity met in other ways.

An important learning point emerged from discussions about the nature of the liaison and diversion role: the ‘boundary spanning’ skills required and the need for practitioners to be able to establish themselves in justice settings as professionally credible and reliable colleagues. We understand that Health Education England and NHS England are doing national work on the competencies required by liaison and diversion practitioners.

3.1.4 Prison healthcare
As noted above, the London Health in the Justice System team gave additional funding in 2016/17 for a dedicated learning disability post in each of the secure environments, with the Greenwich cluster of prisons offered two posts for the three prisons.
(a) Learning disability awareness training

There is limited awareness training offered to prison officers across the eight prisons included in this audit. Only one of eight services offers training to the general prison officer group. In that service it is part of the monthly Safer Custody mental health training and the learning disability session is delivered by the learning disability co-ordinator. In half of the services training is offered to primary care staff and select prison officers who work on healthcare.

Despite this, all services noted the importance of, and the need for, awareness training. In one service, the Mental Health Manager and the Equality and Diversity Manager noted that staff have limited understanding of learning disability, which has an impact on their ability to manage behavioural problems on the wings. Training can help prison officers understand the causes of behavioural problems, and manage this appropriately. On a related point, a governor in another service noted that increased awareness of learning disability is crucial in order for prison officers to know how to react to prisoners who break rules. For example, instead of seclusion, withdrawal of privileges, or other forms of punishment, staff would understand why the prisoner broke a certain rule, and deal with this in a more appropriate manner. The key here, according to the governor, is to tailor the response to the prisoner's mental and intellectual needs. A prison officer at a different service agreed with this assessment, noting that officers on the house blocks have limited knowledge of learning disability and might not be able to identify prisoners who need special management and perhaps a referral to healthcare or to the learning disability practitioner. In addition, the concept of 'reasonable adjustments' is not one with which prison officers, in general, are familiar. A prison officer noted that, if there are more trained officers on the wings, this could help vulnerable prisoners. According to him, there are hundreds of vulnerable prisoners on the wing, and if they cannot cope they are moved repeatedly between the wing and healthcare. This cycle can be broken if there are prison officers who can manage their needs.

A number of services have future plans for holding training. In general, there is agreement that this needs to be part of shutdown training in order for all prison staff to be able to attend. However, there are a number of obstacles to this that have been noted across all services. A key challenge is that the prison service, at the present moment, is facing huge staffing difficulties. There is no time for staff to be released for training, and shutdown training is difficult to implement. A related challenge, noted by a number of prison officers, is that even if training is offered, staff may not have the time to give prisoners with learning disabilities the required attention.
There was general consensus on the kinds of difficulties prisoners with learning disabilities can face in prison:

- difficulties adapting to and understanding prison life: inability to keep up with the rigid regime of the prison, including difficulties filling in application forms, and writing letters. An issue noted in several services is that prisoners with learning disabilities can find it difficult to read analogue clocks - the kind of clocks routinely available on the wings - and hence can miss appointments
- to have their behaviour interpreted as a discipline issue, rather than arising from limited understanding of certain information. This can result in a 'revolving door' situation, in which a prisoner repeatedly moves between segregation, healthcare, and prison wing
- prisoners who do not cause problems tend to be "lost in the system" and drop out of education and work
- prisoners with learning disabilities are bullied and taken advantage of by other prisoners. In one case a prisoner was used as a 'drug tester' to test the safety of a batch of illegal substances that had come into the prison.

In the majority of services vulnerable prisoners (including certain prisoners with learning disabilities) would be housed in a single cell to minimise risk of bullying. This is subject to risk assessment and is facilitated by Safer Custody.

(c) Accessible information
In all the services easy read information is made available by the learning disability practitioner or co-ordinator, or by other health staff, on the basis of the prisoner's needs. One person noted that it could be a good idea to display easy read information to encourage take-up. Accessible information is not routinely available on the prison wings, with one exception (see box).

Good practice: training
In HMP Belmarsh there is a proposal for a Mencap module (5 sessions) on learning disability to cover issues of identification, management, safeguarding and communication. This will be funded by the prison and by healthcare. Training will be offered to designated learning disabilities and learning difficulties (LDD) champions, who are prison officers identified by the safer custody officer to take a lead on LDD in the prison. Twelve champions have been identified in HMP Belmarsh. These are identified on the basis of their passion to work with this prisoner population, their commitment and dedication, and, in some cases, having had personal experience of LDD among family.

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provision of clear, visual timetables (the latter two in HMP Belmarsh); provision of dyslexic rulers to aid reading (HMP Pentonville). Aside from these adjustments, staff members individually assist prisoners with certain tasks such as: explaining licensing conditions in a simple language; help with arranging appointments. However, these extremely helpful interventions are not an outcome of a system of reasonable adjustments, and depend on the effort of individual practitioners.

(d) Access to learning disability expertise
At the time of our visits, six of the services had a learning disability practitioner: in four of these the practitioner is from a senior nursing background and in two the practitioner is an assistant psychologist. (Note: three prisons are covered by one practitioner; he is taking a pragmatic approach and establishing systems in one prison before moving on to consider the other two. We had questions about capacity to manage the possible caseload and fulfil the rest of the brief in all three; we note that NHSE expected that there would be two posts.)

The remaining two services are, in one case, awaiting the arrival of a learning disability practitioner and, in the second case, have advertised for the position. Aside from these appointments, some of the services have access to further specialist expertise. In two services a consultant psychiatrist with specialisation in learning disability holds a fortnightly clinic; in another a consultant specialising in neurodevelopmental disability holds a weekly clinic and there is a mental health nurse who has a particular interest in people with learning disabilities. In one service a newly appointed speech and language therapist holds a weekly clinic. All the prison health services have access to mental health expertise, but this is not learning disability specific.

(e) How justice and healthcare staff work together
There is variability in the interaction between justice and healthcare staff in the eight services. Staff need to work together in order to facilitate referral of cases and implementation of care plans and reasonable adjustments. The quality and extent of communication between justice and healthcare staff is a key issue. Among the services where this works well is HMP Pentonville. Two factors were noted as contributing to good communication in that particular service:

• regular meetings in which different professional groups discuss complex prisoners (including those with learning disabilities) such as: Safer Custody meeting (monthly), segregation reviews (weekly), Violence Reduction Board, and ACCT (assessment, care in custody and teamwork) reviews
• setting up a ‘functional email system’. This is a system in which there is a joint email for each team – for example, one email for Safer Custody, and one email for the mental health team. All members of a particular team have access to this email. In this way, if information pertaining to a particular prisoner is sent by the mental health team to Safer Custody, it is less likely this information will be missed.

A key challenge is for healthcare staff to ensure that staff on the wings are always aware of the needs of a particular prisoner (without identifying them in ways that are visible to other prisoners). In practice this means that the involved member of the healthcare team, or the learning disability practitioner, has to routinely and repeatedly reinforce the
message to prison officers on the wings. In prisons where there is high turnover of prison officers the message has to be reinforced more frequently, while in services where officers are allocated to a wing and can stay there for up to two years better continuity of care is in place.

In one service the lack of a systemic response to prisoners with learning disabilities was evident. The learning disability practitioner in that service routinely discusses the needs of a prisoner with prison officers on the wing, such as the need for information to be explained in a simple way, and that the prisoner requires more time to attend appointments. However, partly due to time pressures on prison officers, and partly due to lack of interest, such needs are not taken into account and the learning disability practitioner spends significant periods of time taking a prisoner to an appointment or filling in his canteen sheets and other forms for him.

In another service, a front-line prison officer noted difficulties with communication between staff, resulting in officers on the wings not knowing about any specific adjustments put in place for a prisoner. He said: “an email would be sent but most officers would not see it, or if they do would not act on it”.

Good working relationships and personal interest in learning disability has been found to greatly improve communication between healthcare and justice staff. In one service the learning disability co-ordinator developed good relationships with Safer Custody and other senior prison officers with an interest in learning disability. On the other hand, in cases where there are no good working relationships, or where prison officers are over-stretched, it becomes difficult to sustain the interest of justice staff in prisoners with learning disabilities. Leadership from governors may make a difference.

The view of all staff interviewed is that in prison the priorities of the regime take precedence and healthcare staff need to work around that. Nevertheless, exceptions and adjustments are made in so far as that is possible; where there is better communication and co-operation between healthcare and justice staff, prisoners with learning disabilities are offered better, more personalised care.

In summary, a key aspect of the relationship between healthcare and justice staff is communication. It is crucial that healthcare staff engage front-line prison officers and reinforce the care plan for a particular prisoner. But this needs to be supported by a more systemic response that involves senior officers who can bridge the gap between healthcare and front-line justice staff (a related proposal is to have learning disability champions – see below).
3.1.5 Being prepared: observations and suggestions

Clearly there is great variation across the services visited. The expertise of learning disability practitioners and co-ordinators is highly valued by colleagues and partner agencies as a resource to enhance their own practice and service delivery, in addition to direct involvement with individuals. Most services that do not have such a post were keen to do so, or at least to have a formal route for obtaining equivalent advice and support. Some of the expertise resides in health professionals with neurodevelopmental specialisation and one of the prison learning disability co-ordinator posts has set out to cover the wider population of people with learning difficulties. We do not know of any comparison of the effectiveness of learning disability vs neurodevelopmental specialisation in justice settings and this may be a question to suggest for future research.

We also note that NHS England specified that prisons should use the additional funding allocated to employ a learning disability nurse. Some have chosen to employ one senior nurse across a prison cluster, or one per prison; some have chosen to employ an assistant psychologist. We think that evaluation would be useful to show whether these different models are equally effective or whether one is better. Given the range of responsibilities (from the more strategic system development and influencing to the more clinical caseload work), it may be worth considering a team approach.

The specialist practitioner or co-ordinator role can feel isolated (and this is similar to reports from acute liaison nurses in hospitals). We hope that the London-wide community of practice will give people in these roles a place for peer support, sharing of ideas and learning.

The personal characteristics and skills required in specialist practitioner or co-ordinator roles share some similarities with other ‘boundary spanning’ roles (e.g. joint
commissioning). Such ‘soft’ skills are not always reflected in job descriptions and person specifications. Sharing learning about success factors may be something the community of practice could do, while NHS England could encourage employers to make such requirements more explicit.

There are various easy read and training resources already available, but not all services knew about these. It would be useful to collect and share such information (and to identify gaps to be filled); this may be something the community of practice could do.

3.2 Identification and screening

3.2.1 Havens
90% of all people who attend are referred and brought by the police; others self-refer or may come with a friend, family member, health or social care staff. Haven staff ask whoever makes the appointment whether the person has any specific needs and also ask about capacity to consent to examination. If the referrer mentions learning disabilities, staff ask more questions: what makes the referrer think that; what degree of disability the person may have; whether a supporter will accompany the person. The Havens do not use any learning disability screening tool; the Manchester Haven is considering use of the Learning Disability Screening Questionnaire (LDSQ), so there may be learning to share.

3.2.2 IRC
Healthcare staff commented on the challenge of identifying possible learning disabilities in the detained population. They and the IRC operator do notice and discuss people who appear vulnerable to exploitation or who show very impulsive behaviour, but there is concern that they may be missing other people who need extra consideration or support. Healthcare staff described two people (in the past year) who they thought had learning disabilities. The issue of identification is complicated by the fact that some people claim a disability or health problem in the hope of being discharged from detention and this can engender a culture of disbelief in Home Office and centre operator staff.

Healthcare reception does include some screening questions about learning disability, but these were not thought helpful or appropriate to the population. For example, some people have never used a watch, nor had formal education. Healthcare staff were very keen to have a screening tool that would be more reliable and were eager to know more about NHS England’s planned pilot in another IRC. Some people are detained and released more than once and staff commented that repeating screening every time an individual is detained seemed unnecessary.

3.2.3 Liaison and diversion
Many of those interviewed commented on the number of ‘alert’ opportunities in the system: people in different roles who may notice that an individual appears vulnerable and ask liaison and diversion to get involved. Police (especially detention officers) and court staff were those mentioned most frequently. Interviewees generally felt that someone who was really struggling with understanding would be noticed, but that a person who presented as more ‘street smart’ might not be referred. There was concern in one area that people might be missed, particularly when cells are very busy and liaison and
diversion have to prioritise people who appear most at risk. Some parties may hold back from raising questions about vulnerability if this could cause delay. Further, some young people may refuse involvement with liaison and diversion if they perceive this as stigmatising.

People drawn to the attention of liaison and diversion are screened. Different areas use different tools for adults: the LDSQ, a short form of the LDSQ, or rapid assessment of potential intellectual disability (RAPID). The latter is undergoing validation. Some practitioners noted practical difficulties with tools that require the person to use a pen and paper if such materials are prohibited in the custodial environment. Youth justice workers use AssetPlus. The screening tools are seen as underpinning professional judgement and can help to reinforce the case for further detailed assessment. Previous involvement with learning disability services can be checked via electronic NHS records (depending on the level of access the practitioner has). One group commented that most people identified as clearly having learning disabilities were already known to learning disability services, but noted that people with mild learning disabilities (and especially young people) were not.

### 3.2.4 Prison healthcare

Three prisons screen using the LDSQ (7 questions) during secondary screening. This occurs within 48 hours of admission to prison, is carried out by primary healthcare staff, and the result is recorded on SystmOne. Any prisoner who scores 1 or more is referred to the learning disability co-ordinator for further assessment using a longer version of the LDSQ (the co-ordinator covers all three services). (Note: SystmOne is the electronic healthcare record, only accessible to healthcare staff.)

One service screens by asking a set of questions such as: Can you read and write? Did you go to a special school? Can you cook? Can you clean your room? If there are concerns, the prisoner is referred to the mental health team through SystmOne, upon which the learning disability practitioner would pick up this referral and conduct a more detailed assessment.

Another service screens twice: at the first night centre, and again within 48 hours, using the same set of five questions. Questions inquire directly about learning disability (asking, for example, if the prisoner has been to a special school). If the prisoner answers positively to any of the questions, this is recorded on SystmOne and a referral to the mental health team is made.

A resettlement prison told us that they do not screen newly transferred prisoners, as they assume that all prisoners would have been screened at the local prison from which they have been transferred. The mental health team and the learning disability practitioner therefore have to search all SystmOne records in order to identify prisoners who may have a neurodevelopmental disability (so far, 26 people have been identified). They did not know of any learning disability or neurodevelopmental ‘flag’ in the system, although we understand that on the front sheet Read codes can be used to identify conditions such as learning disability or autism. Lack of flagging increases the risk of missing prisoners with learning disabilities and increases the amount of work healthcare staff have to do, trawling the prisoner's record for evidence. Primary care staff could ask prisoners on admission
whether or not they have had contact with learning disability staff in the previous prison, but this relies on a number of assumptions about the services in other prisons; further, the prisoner might not know or might not disclose previous contact.

The Head of Healthcare in one prison suggested a clinical reference group to look at the possibility of adding appropriate ‘flags’ to SystmOne. As noted above, we understand that Read coding can already be used to flag people with learning disabilities, so the question may rather be one of ensuring that systems are in place to identify learning disability and to apply and use the correct Read codes.

The youth justice Comprehensive Health Assessments (CHAT) are carried out on each person admitted to the young offenders institution. CHAT1 and CHAT2 are done within the first day. They are more focused on physical health, but do inquire if there is a history of learning disabilities or difficulties. CHAT3 is focused on the history of drugs and alcohol use. CHAT4 is done within three days and is a mental health screening tool for depression, anxiety, psychotic conditions, personality and eating disorders. CHAT5 is done within ten days and is a neurodevelopmental screening tool that includes learning disability. This assessment is carried out by the learning disability practitioner (assistant psychologist). The results are recorded on SystmOne.

Finally, in another service primary care nurses ask questions on first night screening that include: "have you ever been diagnosed with a disability?" and a question about "impressions of behaviour and mental state". No specific learning disability screening tool is used.

Aside from intentional screening on admission, there are many sources from which learning disability can be provisionally identified and prisoners referred to the mental health team. For example, a prison officer on the wing, a practitioner at education, or a prisoner’s personal officer may note a prisoner who is struggling to keep up with the prison regime or understand information. Indicative behaviour can include: missing their appointments regularly, not coming out of their cells, self-neglect, regularly forgetting their identity card, aggressive behaviour, repeated bullying. Prisoners can also be referred by the equality and diversity team or the social care team. Some referrals, however, are inappropriate, owing to ongoing confusion of learning disability with learning difficulty. We did not hear of examples of healthcare staff proactively seeking information from the basic custody assessment or education assessments to aid identification of prisoners who might have learning disabilities.

Learning disability can also be identified on admission if a prisoner has been in contact with learning disability services in the community. However, this depends on the information being shared from services that do not use SystmOne. The local learning disability service will not necessarily know that a person has been sent to prison, nor to which establishment. Communication between liaison and diversion services and prison healthcare varies; in one prison we were told that this was easier when all staff were employed by the same NHS Trust. (See matching comments from the liaison and diversion perspective in section 3.4.3 below; liaison and diversion services also reported difficulties on occasion in getting through to prison healthcare teams.)
We were very concerned to hear that one prisoner had been assessed with IQ less than 60; prison healthcare staff queried how this could have happened and expressed more general concern about people with learning disabilities in prison. Vulnerable prisoners may have to stay in the prison inpatient unit for months. As noted above, although there is pan London provision of liaison and diversion services, they do not operate 24 hours a day and they rely on notification that an individual may be vulnerable. It is therefore possible that some people may get missed at the point of arrest. Furthermore, courts do not always follow recommendations from liaison and diversion services. A detailed study would be required to track how these individuals had passed through the criminal justice system and ended up in prison, and what alternatives might have been possible.

3.2.5 Identification and screening: observations and suggestions

The Havens may have the opportunity to learn from their Manchester colleagues about use of the LDSQ.

A national group led by NHS England is considering the question of an appropriate screening tool for IRCs.

Liaison and diversion services are not yet operating to the national specification across the whole city and do not provide 24 hour cover; it is not yet possible to be sure that they see, and therefore screen, everyone who may be vulnerable. Some interviewees described practical difficulties with using the LDSQ in some circumstances; it may be useful for services across London to adopt a common approach to screening when time is very short or pencil and paper are not allowed. We are keen to hear whether the RAPID tool is validated in due course.

Prison systems vary; those that do not yet have effective screening in place should be brought up to the standard set out in the most recent service specification. NHS England could encourage the use of appropriate Read coding to flag the identification of a person with learning disabilities (or neurodevelopmental disability) in SystmOne.

We think there is a need for a detailed case review to understand how people assessed with very low IQ came to be imprisoned and what could have made a difference.

3.3 Pathways

3.3.1 Havens
Exploring capacity and consent is a very important part of the pathway and a rigorous approach was described to assessing capacity to consent to examination and to onward referral, and capacity to consent to the sexual acts alleged. Where capacity is uncertain or a best interests process is required, Havens staff try to involve the person as much as possible and try to involve others who know the person (e.g. family, friend, social worker).

Those interviewed described a variety of reasonable adjustments that they had made, based either on information passed on by the referrer or on their own assessment of the
person’s needs. The sense conveyed was of a strongly person-centred ‘business as usual’ – the way the service tries to make people attending feel as welcome and comfortable as possible. Examples included support with mobility, taking extra time (“not rushing the person out of the door”), establishing rapport, offering breaks and adapting communication.

Good practice: reasonable adjustment
One person would only speak if a ball was thrown from one person to another in the room. Haven staff adopted that technique and were able to engage with her successfully.

While the Havens offer some follow-on group therapy, there are no adapted programmes for people with learning disabilities. There is concern that the Havens see repeat attendances from people who have been exploited and abused over long periods but who get no community support (for example, they do not meet the eligibility criteria of local community learning disability teams). There is often a background of little education or support about sexual health.

Following examination the immediate concern for Havens staff is to try to help the person with immediate medical issues (via their GP) and to liaise with the police and social services over the person’s safety. This should be short term involvement, but Havens staff will sometimes continue to follow up if they have particular concerns about the person’s circumstances. There was a view that community services do not in general understand or do enough about risks of sexual violence.

3.3.2 IRC
Those interviewed saw it as difficult to obtain access to additional expertise for more detailed assessments, and difficult to observe a person for long enough. Lack of a robust screening tool or full assessment can result in healthcare staff finding it difficult to make a case to the Home Office about safeguarding or vulnerability concerns. Once healthcare staff have filled in the relevant documentation the Home Office ask for evidence, which can be difficult to obtain. Healthcare staff gave examples of involving an independent mental capacity advocate, other advocacy and the Independent Monitoring Board. They also described raising concerns about the vulnerability of a person who was about to be released (asking for time to plan or make onward referrals), but being told that this could result in a claim for unlawful detention.

Good practice: joint working
Examples were given of drawing up joint plans with operator staff for support of certain individuals to manage hygiene or behaviour or safety. For instance, one person seen by healthcare staff as vulnerable was neglecting himself. Healthcare worked with an officer who built rapport with the man and was able to support him to have a shower. One person was seen as so vulnerable that a healthcare assistant was allocated to be with him all day, every day. They tried to find activities to occupy him.
As noted earlier, healthcare staff can be put in the situation of trying to explain detention. Planning healthcare interventions such as psychological programmes is challenging because of the uncertainty about how long a person will remain at the centre.

Onward referral can be extremely difficult or impossible, partly because of the short notice at which someone may be released or deported and partly because of the rule that unlawful immigrants have ‘no recourse to public funds’ in the UK. People are often released to ‘no fixed abode’. Healthcare staff raised concerns that some people are told they must comply with certain requirements (e.g. to report to a certain place at set intervals), but may get no support to understand or comply.

3.3.3 Liaison and diversion

(a) Pathways for further assessment
Securing a full assessment following screening can be difficult, especially for young people. There are long waiting lists for child and adolescent mental health services (CAMHS); one area has a neurodisability team and this was seen as helpful. The learning disability practitioner can offer advice about young people (though she would not carry out a cognitive assessment herself on a young person); she can carry out a fuller assessment on adults and secure access to additional professional expertise. In other areas a referral might need to be made via the person’s GP to secure community learning disability team involvement. There is a tension, as noted above, between the courts’ time pressures on the one hand and expectations of more definitive diagnostic labelling on the other.

(b) Pathways for reasonable adjustments
Reasonable adjustments described fell into several groups:
• assessing the individual’s cognitive difficulties and suggesting reasonable adjustments to processes. For instance, the court could be asked to apply ‘youth rules’ (e.g. easy language) even if there were no diagnosis; an example was cited of offering speech and language therapy support to the court with this. As noted above, the court does not always accept such recommendations, but can be extremely flexible (for example, allowing the defendant to walk in and out, limiting numbers of people in court, managing questioning). Occasionally the court will agree to use of an intermediary, but it can be difficult to find the right person or agree funding
• compensating for deficits in the processes, e.g. explaining bail conditions in a way the person could understand. For example, a person might be told “do not touch this person” and fail to understand that they should generalise this to not touching other people. Some of those interviewed were concerned about the capacity of probation to understand support needs and to make reasonable adjustments
• alerting the court to the need for a pre-sentence report and advising on this; for example, commenting on the person’s ability to comply with orders or participate in programmes. The learning disability practitioner’s expertise was described as “invaluable” by colleagues; input from community teams was seen as “almost impossible”
• offering brief interventions (mentioned by youth offending services) or time-limited support from a community link worker (for adults). Community link workers can help
with making and attending appointments, and finding local voluntary services. One area did not have link workers and commented on this as a gap.

Promising practice: pre-sentence report template
The youth justice liaison and diversion service in Hounslow plan to amend the pre-sentence report template to draw specific attention to difficulties with behaviour and understanding. They are willing to share this.

(c) Pathways for onward referral or transfer
The single biggest issue raised by all those interviewed was concern about the paucity of community support and interventions for offenders with learning disabilities, which limits the options that can be recommended to justice partners and the options for onward referral from liaison and diversion. Two main types were mentioned:

- lack of support to comply with conditions or orders (e.g. understanding what was required, telling the time, finding the way to the right place). Lack of support to understand and comply with bail conditions was mentioned several times. Another example was a person sent from remand prison to court and released, without money, keys or any idea how to get home to another city. Advice and support if crises occurred ‘out of hours’ could be particularly difficult in relation to people living with no or very limited support. One man who lived with and had support from his mother and was charged with assaulting her was remanded in custody because it proved impossible to arrange alternative accommodation with support
- lack of adapted programmes or other interventions to reduce offending behaviour, via either probation or the NHS and social care. For young people there could be extremely long waiting times for support from CAMHS; for adults people were described as falling between all the different eligibility criteria (community learning disability teams, mental health services, substance misuse services, social care) and unable to participate in programmes designed for people with assessed IQ of 80+. One team commented in particular on the lack of programmes for young men displaying sexually harmful behaviour. (As a result of the audit visit the service is now in touch with Respond and is aware of the specialist services available.)

One result of these deficits was described as increased risk of custody: one example was given of a person who was “in and out of prison a dozen times over a year or so”; a court might decide not to suspend a custodial sentence if community support could not be arranged (or a person might be sent to a medium secure hospital). This has implications for NHS England’s Transforming Care programme.

Some community services for offenders can be “scary” for a person with learning disabilities and some charitable organisations that did provide some appropriate support have closed for lack of funding. On the other hand, an example was given of the learning disability practitioner succeeding in securing support from the local commissioner to prevent one person re-offending. One positive suggestion was that liaison and diversion services (perhaps using the community link workers) should map the resources available in each area.
Gaps were described in joint working between services. For example, liaison and diversion practitioners employed in one NHS Trust found it very difficult to get colleagues in other services involved because of strongly delineated silos within the organisation. Examples were given of NHS services not working together: for example, between mental health and learning disability services, or a learning disability team saying that the person’s substance misuse must be addressed before they would accept a referral. Some of those interviewed were not aware of the Public Health England guidance on the role of school nurses in working with youth offending services. One youth offending service suggested that young people in contact with liaison and diversion services should have the same priority with CAMHS as looked after young people.

3.3.4 Prison healthcare

<table>
<thead>
<tr>
<th>Good practice example: pathways</th>
</tr>
</thead>
<tbody>
<tr>
<td>For the Greenwich cluster of prisons the learning disability practice development nurse devised a pathway for prisoners with learning disabilities or learning difficulties (LDD), supported by a project plan that includes joint working with prison staff and education. Links are also being made with services to support release. The initial focus is on embedding this way of working at HMP Belmarsh. Some examples of specific aspects are cited in good practice boxed examples in earlier sections of this report.</td>
</tr>
</tbody>
</table>

(a) Pathways for further assessment
Following initial screening, all prisoners who might have learning disabilities or difficulties are provided with more detailed assessments. The pathway for further assessment varies from one service to another. In a number of services, the learning disability co-ordinator/practitioner conducts an assessment based on the long version of the LDSQ. In another service, prisoners who score positively on initial screening are discussed at the mental health referral meeting, where a decision is made as to whether further assessment by a consultant psychiatrist or clinical psychologist is required. In three services a more encompassing neurodevelopmental pathway is initiated that screens for learning disability, ADHD, traumatic brain injury and autism. Further input from a learning disability consultant psychiatrist is sought if required. In all cases collateral information is obtained from relevant sources, including family, mental health services, solicitors, probation and supported accommodation. Further IQ and functional assessment may be required, but not all services have easy access to psychological services. At this point, and depending on the prisoner's needs, a care plan is initiated.

(b) Pathways for reasonable adjustments
Once a care plan is put in place, the next step is to communicate it to justice staff, including prison officers on the wing where the prisoner resides, safer custody officers, the equality and diversity team and, where available, to learning disability champions. Communication occurs through a number of means: directly, by making an entry in the observation book, by making an entry on PNOMIS (the prison information system), and/or by discussing the prisoner's case in one of the meetings that bring justice and healthcare staff together. Care plans include guidelines for prison officers on how to manage the specific needs of the prisoner. In one service these guidelines include explicit advice on how to communicate with the prisoner and understand his behaviour; for example, being
more visual, breaking down information, keeping the prisoner aware of what is happening, and giving structure.

If a prisoner is particularly vulnerable to bullying or requires more attention than can be provided on an ordinary wing, he would be transferred to a different location in the prison. This will depend on the facility itself: in some services there are quieter wings; in others there are wings that house trusted prisoners and where the prisoner with learning disabilities would be less likely to be bullied. In certain cases, prisoners with learning disabilities may present with behavioural problems and/or vulnerability to the extent that he can only be safely housed on the inpatient unit. This can be a temporary measure, but in some cases referral to an external learning disability service is initiated.

Accommodation of the prisoner's needs are attempted where possible, though this varies with the flexibility of the prison and the quality of the communication between healthcare and justice staff. For example, in one service, the quantity and timing of meals is changed to take account of medication times. Yet in another service there are difficulties with facilitating reasonable adjustments on the wings, for reasons specified earlier. One of the barriers is that reasonable adjustments by prison officers need to be discreet in order to avoid drawing attention to the individual's vulnerability.

One consultant psychiatrist noted that an important benefit of identifying someone with learning disabilities was the opportunity to check for common co-morbidities. According to the principle of 'equivalence' of care between community and custody, identification of learning disability should prompt a full health check (repeated at least annually), unless there is evidence that this has been done by a GP within the last 12 months. This is not routine in all prisons (despite the service specification).

Aside from this, prisoners are connected with services in the prison as required. These include education, speech and language therapy, work, day centre and various groups.

(c) Pathways for onward referral, transfer or discharge
The standard action is to refer a prisoner with learning disabilities who is due for release to the relevant community learning disability team so that he can access external learning disability services. Such referrals, it was reported at several prisons, are not always successful; community learning disability services have a much higher eligibility threshold than prison healthcare services, in addition to having long waiting lists. Services for ex-prisoners do not necessarily offer enough support for someone with learning disabilities. This makes discharge planning and continuity of care very difficult. One prisoner with learning disabilities who was too vulnerable to be on an open location in the prison had to remain at healthcare for several months until an external place was available.

This is complicated by the fact that many prisoners have no fixed abode, and hence no specific services to which they can be referred. Prisoners can be released with a letter that they can take to a GP or other health services once they settle. One interviewee agreed that giving this to the person in an accessible format might increase the chances of it being used. If possible, staff refer to outside agencies as required, and this can involve the relevant council to arrange housing. If a prisoner already has supported accommodation,
attempts are made to keep this in place until discharge. In one service the learning
disability co-ordinator is looking into liaising with Mencap for the possibility of linking
prisoners with day services and volunteering possibilities. In another, a healthcare worker
tries to support people ‘through the gate’, but has difficulty finding appropriate community
services. In theory continuity of healthcare and support with other aspects of resettlement
should be improved through collaboration between healthcare and the Community
Rehabilitation Company, but this did not seem to be making a difference to people with
learning disabilities yet and there was still reliance on the initiative of committed
individuals in the prison.

We heard from another source that a care and treatment review\textsuperscript{11} had been used for one
young person in custody and this had proved useful.

Given that prisoners move around the country, having SystmOne across prison healthcare
helps to provide better continuity of care. (One interviewee was unsure whether this
system was in fact in use in all English prisons.) We understand that prison healthcare
staff have access to Summary Care Records, but the usefulness of these depends on the
amount and quality of information included. (See section 3.4.5 below for further comment.)

3.3.5 Pathways: observations and suggestions

As with access to advice, services that do not have a learning disability practitioner or co-
ordinator would value having a formal route to secure thorough assessments.

All services were able to give examples of reasonable adjustments and more ideas were
shared in discussions; there may be a role for the community of practice in collecting and
sharing examples (as happens with learning disability acute liaison nurses, for instance).
Some of the examples show how NHS-funded services are compensating for deficits
elsewhere in the system (for example, explaining bail conditions to a person in a way they
can understand). Where this is problematic there may be a need for NHS England to
discuss with partner agencies whether they are fulfilling their Equality Act duties.

Some services are not yet making the reasonable adjustments set out in the most recent
prison healthcare specification (for example, offering a full health check to people
identified as having a learning disability).

A significant concern for all services was the paucity of community services and supports
for people with learning disabilities, especially those who do not meet the eligibility criteria
for social care or for community learning disability services. One suggestion was that
liaison and diversion community link workers (where these exist) might be able to map
local services; if this could be done in areas not covered by link workers as well, and the
whole lot shared with colleagues in prisons, that would be a useful resource.

In order to inform discussion with partner agencies about gaps and how to fill them it
would be helpful to have data on how often people with learning disabilities have been

\textsuperscript{11} \url{https://www.england.nhs.uk/learning-disabilities/ctr/}
unable to get the types of support needed. This could include more thorough identification of problems in joint working between different NHS services.

3.4 Information sharing

3.4.1 Havens
There is an information sharing protocol with the police that governs information about the circumstances surrounding an alleged offence. This might include sharing information relevant to the safety of others, or information about the person’s capacity to consent to sex. Staff can call on the Trust’s safeguarding and legal teams and the Caldicott Guardian for help if needed with ethical questions. If a person refuses consent to onward contacts, staff can also seek support as above; it may not be possible to maintain confidentiality if, for example, the safety of a child is involved.

3.4.2 IRC
Healthcare staff can put an ‘alert’ on the centre operator’s system if they are concerned about a person’s vulnerability.

3.4.3 Liaison and diversion
Good communication was noted between liaison and diversion practitioners working in police custody to those working in court. Onward communication was sometimes more difficult; practitioners described trying to pass information on to prison healthcare and being unable to contact the right person. Likewise information was not always passed to court liaison and diversion from prison. Information sharing between NHS staff is easier when people work for the same NHS trust; otherwise there is access to summary records that may not contain any information about disability. Youth offending services have access to the new education health and care plans, but again these may not give clear information about a young person’s disability. There is a formal information sharing agreement between the liaison and diversion services and the Metropolitan Police, but we were told that it is sometimes difficult for liaison and diversion staff to get information from the police or court about where a person has gone. Conversely one police representative said that it was often difficult to get relevant information from NHS colleagues; the formal agreement felt one-sided.

3.4.4 Prison healthcare
All services seek informed consent prior to sharing information pertaining to learning disability and collecting collateral history. In cases where the capacity to offer consent is lacking, decisions are made with that person’s best interests in mind. In meetings that involve several professional groups, only clinical information relevant to the problem at hand is shared. Practitioners follow the professional codes of information sharing relating to their own profession. For example, assistant psychologists follow the British Psychological Society guidance in addition to NHS protocols.

As noted earlier, information sharing with prison officers may be verbal and may have to be repeated frequently, as it does not seem to be communicated reliably between changing shifts or when new officers arrive.
3.4.5 Information sharing: observations and suggestions

One of the common challenges identified was in difficulties of sharing information between NHS services along the justice pathway (including from prison to liaison and diversion, as well as vice versa). Communication was easiest technically between staff working within the same organisation (although organisational silos could still cause difficulties in joint working, but less so than inter-organisational boundaries), and those with access to SystmOne. As noted above, even within SystmOne better use of Read coding to identify active problems would aid rapid identification.

Access to Summary Care Records via the NHS ‘spine’ is supposed to ensure that all authorised health staff have access to the most important health information about an individual. However, this relies on information being entered from primary care. Many people with mild learning disabilities are not recorded as such in GP registers, and the problems of ensuring that ex-prisoners are registered with a GP at all are well known. It does not appear that, as currently used, the Summary Care Record provides sufficient information about conditions such as learning disabilities or the reasonable adjustments that individuals may require. There may be a case for all health practitioners working within the justice pathway to have access to the same electronic information system.

3.5 Data collection and use

3.5.1 Havens
Those interviewed thought that people with learning disabilities were under-represented in the population of people who use the service. It is not clear why, but this does provoke questions about what assumptions guide those in contact with people with learning disabilities who experience sexual violence.

3.5.2 IRC
There did not appear to be robust data available; as noted above, healthcare staff were concerned that vulnerable people might not be identified.

3.5.3 Liaison and diversion
In the six months ending September 2016 the London ‘wave 1 and 2’ sites had 5,149 people identified to them; nearly 80% of those engaged with the service. Of that population, 196 (nearly 5%) were identified as having learning disabilities (and 63 as having autism). This is reasonably consistent with screening studies undertaken in London police custody suites\(^{12}\). The majority were recorded as having had contact with learning disability services, though it is not clear from the data what the nature or extent of this may have been, nor whether the contacts were current.

3.5.4 Prison healthcare
Most services keep a tally of the number of prisoners with LDD and those under their care.

### Data given to us on prisoners with learning disabilities or learning difficulties

<table>
<thead>
<tr>
<th>Prison</th>
<th>Prisoner Numbers</th>
<th>Learning Disability Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>HMP Belmarsh</td>
<td>40</td>
<td>12 for learning disability assessment (5 taken on caseload), 8 for learning difficulty</td>
</tr>
<tr>
<td>HMP Thameside</td>
<td>80</td>
<td>15 for learning disability assessment (1 on caseload), 20 for learning difficulty</td>
</tr>
<tr>
<td>HMP Isis</td>
<td>27</td>
<td>5 for learning disability assessment, 10 for learning difficulty</td>
</tr>
<tr>
<td>HMP/YOI Feltham</td>
<td>since January 2016, 24 referred to the mental health team with suspected learning disability. 17 prisoners have been seen by a specialist consultant psychiatrist, and of these 2 prisoners have been taken onto the caseload of the learning disability practitioner for further support</td>
<td></td>
</tr>
<tr>
<td>HMP Brixton</td>
<td>between September 2016 and January 2017 the neurodevelopmental pathway identified the following cases: 6 prisoners with LDD, 7 with traumatic brain injury, 14 with ADHD, and 6 on the autistic spectrum disorder. Six prisoners with learning disabilities are on the caseload of the learning disability practitioner and the occupational therapist</td>
<td></td>
</tr>
<tr>
<td>HMP Wormwood Scrubs</td>
<td>all data is coded on SystmOne and can be accessed if required</td>
<td></td>
</tr>
<tr>
<td>HMP Pentonville</td>
<td>65</td>
<td>12 prisoners on Enhanced Support Service (but this is not limited to learning disability).</td>
</tr>
<tr>
<td>HMP Wandsworth</td>
<td>around 40 people with learning disabilities per year.</td>
<td></td>
</tr>
</tbody>
</table>

No specific analysis of this data was conducted at the reviewed services. It is difficult to compare the numbers cited with published research, as they have not been collected on a consistent basis and each prison is different in terms of annual throughput.

### 3.5.5 Data collection and use: observations and suggestions

Robust data is needed to inform workforce and service development. It is very helpful that many of the services visited are now collecting better data on numbers; it will be important to ensure that there is consistency in definitions and that numbers of people with learning disabilities are related to throughput. Commissioners will then be able to have greater confidence in the systems for screening and for recording the results. Information on needs and gaps in supports should follow.

### 3.6 Involvement of people with learning disabilities and families

#### 3.6.1 Havens

Staff do collect feedback, but would like to do more to involve people who have used the service. There were no examples they could recall in relation to people with learning disabilities. One person with autism was willing to return to offer suggestions for improvements.
3.6.2 IRC
No examples of involvement were described.

3.6.3 Liaison and diversion
One example was given of a person with autism delivering autism awareness training. One person remembered some learning disability awareness training being delivered by a co-trainer with learning disabilities and commented positively on this.

3.6.4 Prison healthcare
There is no user involvement for prisoners with learning disabilities in any of the services. In one prison the learning disability practice development nurse sits on the patient council where feedback pertaining to patient care in general is provided. In the majority of services, feedback forms are available on healthcare for prisoners to offer their views, but these are not specific to those with learning disabilities. Similarly, healthcare satisfaction surveys are occasionally carried out.

Families of people with learning disabilities are sources of important collateral history. They are also involved in the care of certain prisoners, for example by facilitating family visits to the prison. None of the services had learning disability awareness training carried out by trainers with learning disabilities. All thought that would be a good idea.

3.6.5 Involvement: observations and suggestions

It can be challenging for these types of services to find ways of obtaining feedback and of involving people in service development; nevertheless it was disappointing to hear such a small number of examples. As with accessible information, there are resources available (some free) – see for example [http://www.keyring.org/cjs/equal-and-fair-project](http://www.keyring.org/cjs/equal-and-fair-project). This may be something the community of practice could investigate.

3.7 Autism

3.7.1 Havens
Those interviewed were able to think of a few people with autism who had been seen; staff did their best to accommodate each individual's needs and took time to establish communication and rapport.

3.7.2 IRC
No additional points were raised.

3.7.3 Liaison and diversion
The learning disability practitioner provided some advice to enable probation to make reasonable adjustments. Some of those interviewed noted growing awareness of autism – or increasing numbers of people presenting – and saw a need for increased training and practice development. One person suggested this should be similar to the personality disorder training, which involves experts by experience.
Autism services are not available in every area and in any case often focus on diagnosis rather than ongoing support. People often fall between eligibility criteria for support and may not able to join existing offending behaviour programmes (e.g. if the person is unable to work in a group). Those interviewed saw a need for more support and reasonably adjusted interventions to be available.

3.7.4 Prison healthcare
In prisons that use a neurodevelopmental pathway assessment autism is one of the conditions that can be picked up. One neurodevelopmental consultant noted that the majority of referrals he received were for autism or ADHD. His priority for additional screening would be for ADHD, as there is often an immediate prescription issue. HMP/YOI Feltham has received autism accreditation from the National Autistic Society. It has trained staff and prison spaces designed to meet the needs of prisoners with autism. The learning disability co-ordinator for HMPs Belmarsh, Thameside and Isis is planning to seek autism accreditation for the Greenwich cluster of prisons.

3.7.5 Autism: observations and suggestions
Comments about growing demand (either because of growing awareness or actual increases in numbers of people) suggest that data should be collected to inform future workforce and service development.

Good practice: autism-friendly environment
Woolwich police custody suite was described as having been made more autism-friendly. Liaison and diversion practitioners said this had made a big positive difference.

Good practice: liaison with support workers
One team described linking up with the support team of a person with autism who was sent to prison. Support workers made sure the person was visited every week in prison; the liaison and diversion team thought this had helped keep the person safe and reduce their anxiety.
Roles of people we met or interviewed

Interviews were undertaken on a non-attributable basis. Here we list the roles of the people we met or interviewed on the phone.

The Havens
Management and clinical staff

IRC
Primary and mental healthcare staff

Liaison and diversion services
Liaison and diversion practitioners (police custody and court)
Community link workers
Service managers
Police
Probation
Magistrate
Judge
Youth offending services
Court staff
Voluntary organisation

Prisons
Learning disability practitioners
Learning disability co-ordinators
Head of health care
Mental health managers
Primary care nurses
Safer custody governors/representatives
Equality and diversity governors/representatives
Prison custody officers
Senior prison officers
Psychiatrist
Speech and language therapists
Clinical psychologists
Assistant clinical psychologists
Appendix 2

Interview guide: what we will be asking about

1. ‘Anticipatory’ reasonable adjustments
   • provision of awareness training for all staff in the NHS-commissioned service:
     learning disabilities; Equality Act; reasonable adjustments
   • availability of key information in easy read formats
   • arrangements in place for access to learning disability expertise as required:
     o to support the NHS-commissioned service
     o to support the relevant partner agency(ies)

2. Identification and screening
   • locally agreed system (internal and with local partner agencies) for noticing that a
     person might have learning disabilities and acting on this
   • arrangements in place for screening, using a validated tool

3. Pathways
   • existence and awareness of pathway for more detailed assessment based on
     positive screening result
   • existence and awareness of pathway for reasonable adjustments to be offered by
     NHS-commissioned services to remove or reduce inequalities (e.g. assertive
     contact, learning disability health check and health action plan, support for decision
     making, adapted programmes)
   • existence and awareness of pathway for onward referral, transfer or discharge to
     ensure continuity of care

4. Information sharing
   • protocol in place to govern information sharing about an individual’s disability and
     its implications (subject to consent or best interests decisions) with other parties as
     required to support safe and effective care (e.g. other health services, social care,
     the person’s family and partner agencies such as the prison regime)

5. Data collection and use
   • data is collected on numbers of people with learning disabilities coming into contact
     with the service, their needs, actions taken and any gaps in service
   • data is analysed and used to inform service and workforce planning

6. Involvement
   • people with learning disabilities are included in arrangements for user involvement
   • families of people with learning disabilities are included in arrangements for
     involvement of families
   • learning disability awareness training includes trainers with learning disabilities

If there is time: ask whether there are similar or different issues for people on the autistic
spectrum – they are not the focus for this audit, but we can report back
Is there any information or support that services need in order to provide a good service to people with learning disabilities?

Finally: is there something the service is proud of, or good practice they know about? We would like to collect good practice examples to share with other people, in London and beyond

For learning disability co-ordinators in prison and IRC healthcare
Tell me about your role.

Prompts: What is your background?
How long have you been in this role?
What are your aims in this role?
What do you think you’ve been able to achieve so far?
What have you found difficult so far?

Would you be interested in the planned community of practice for learning disability co-ordinators?