



**NHS Greater Glasgow and Clyde**

**Prison Healthcare Project**

**for**

**People with Learning Disability**

**Executive Summary**

**December 2014**

**[REDACTED]**

## **Introduction**

*‘.....health is an important part of a prison's work, and good quality health care is integral to successful health and justice outcomes.....reflecting the fact that offenders move often between prison and community, health inequalities are profound amongst offenders and the potential for health improvement and long-term quality improvement in health care of prisoners is achievable through the stewardship of the NHS, in close partnership with prisons’*

Chief Medical Officer (2010) ‘Assets for Health’ Chapter 4

*‘Health inequalities are the ‘systematic differences in the health of people occupying unequal positions in society.....’*

Graham, H. (2009) Understanding Health Inequalities

Socio-economic factors and discrimination are most commonly associated with Health Inequalities; therefore, those with protected characteristics such as learning disabilities (LD) or autistic spectrum disorders (ASD) are more at risk of experiencing them, even more so if they find themselves serving a custodial sentence.

The Scottish Government has a clear priority towards reducing health inequalities across Scotland and NHS services, including prison healthcare, have much to contribute. Thus, the prevention of poor health for those most at risk and promoting equality of access to service provision is crucial.

The transfer of prison healthcare to NHS Scotland in November 2011 provided an opportunity to explore the issues relating to health inequalities for prisoners who have a learning disability or autistic spectrum disorders and in 2012 a successful bid was submitted to the Scottish Government by NHS Greater Glasgow and Clyde, which secured health inequalities funding to create a Learning Disability Prison Healthcare Project.

## **Background**

Recent national reports have highlighted a limited understanding of the prevalence and needs of people with learning disability and ASD in prisons, and that these individuals are more likely to experience greater difficulty coping and be more vulnerable to bullying or exploitation whilst in custody.

They also suggest that people with learning disabilities or ASD present a distinctive set of needs to prison services, which includes personal experience of multiple deprivation alongside co-morbid mental health problems or needs relating to substance misuse. The borderline nature of many prisoners who experience learning disabilities can result in many individuals experiencing additional vulnerabilities in the prison environment.

## **Project Objective**

The learning disability prison healthcare project was created to ‘explore and scope out the programme of work required to increase awareness of, and facilitate access to, an appropriate level of evidenced based healthcare for adults and young offenders with learning disabilities or ASD within the prison system’ which would be achieved through:

- Scoping and auditing the current practice of support for individuals with Learning Disabilities within Scottish Prisons.
- Identifying a common understanding of learning disabilities and identifying population characteristics.
- Proposing a standardised model of health care support across all Scottish Prisons
- Scoping the role of the community learning disability nurse (CLDN) in supporting individuals with learning disability or ASD who are experiencing custodial sentences, including the development of a care pathway on release from prison.

The results of this have been used to advise and develop a ‘framework’ for service delivery which can be applied to other Board areas across Scotland and includes recommendations that will be relevant to all who are responsible for the design, development and delivery of healthcare services within the prison environments.

## **Design and Methods**

A programme of work was developed which related to the 3 prisons across NHS Greater Glasgow and Clyde. Proposals and initiatives were developed collaboratively with colleagues in NHS, Social Work, Local Authorities, Voluntary sector and Scottish Prison Service in ways that ensured they were sustainable once the project came to an end. This programme endeavoured to influence any member of prison staff who would have a responsibility for the support and care of a prisoner who may have a learning disability, alongside key stakeholders who are responsible for the design, development and delivery of prison healthcare services.

Scoping methods included reviewing documentary research, focus groups, case studies, observation and visits, questionnaires and interviews. These were conducted across the prison estates mentioned above.

It is worth noting that early in the life of the project NHS Forth Valley secured Health Inequalities funding from the Scottish Government to develop a prison healthcare project in their board area, therefore input by this project in that area was limited to preliminary information gathering only.

A pilot study to screen for prisoners who may have learning disability was developed and completed over a 16 week period and a care pathway relating to this was developed for use across each of the prisons. For the purpose of the screening pilot, information was collected from every new prisoner during their admission using 5 pre screening questions and analysed to include those prisoners identified as possibly having a learning disability. Information was reviewed for prevalence, number of referrals generated to the learning disability clinic on a weekly basis for each establishment and those who scored at a level that would indicate a trigger for further referral for diagnostic assessment.

## **Policy Context**

### **Scottish Government Learning Disability Strategy ‘Keys to life’**

There are 5 Criminal Justice recommendations in the Scottish Governments recently launched ‘Keys to life’ learning disability strategy document. The Prison Healthcare Project has in some ways developed in line with these and this was reflected within the project plan. The recommendations are around the following areas:

- Rec 45: Easy read and other accessible information resources to be developed across the criminal justice system.
- Rec 46: A national criminal justice action group to be established in 2013.
- Rec 47: ‘That by the end of 2014 all relevant organisations will review and implement recommendations of ‘No-one Knows –Prisoners with Learning Difficulties and Learning Disabilities, Scotland’ where they have not already’
- Rec 48: All professionals in the criminal justice system should have access to the 2011 guide ‘people with learning disabilities and the criminal justice system’.
- Rec 49: Research is undertaken across the criminal justice system by the Scottish Consortium for Learning Disability and NHS GG&C to analyse the nature and extent of the health needs of people with learning disability within the criminal justice system.

It may be necessary to have further discussions within prison operation management groups as to how these recommendations will be implemented.

The project also aligned to other policy areas such as

- Strengthening the Commitment (The role and contribution of Learning Disability Nurses)
- NHS GG&C Learning Disability Strategy Change Programme

- Various Legislation in terms of addressing Inequalities in Health and local policy drivers
- NHS Scotland Healthcare Quality Strategy (2010) Triple Aims and Quality Ambitions

### **Collaboration with others**

There are a number of groups and organisations with a vested interest in ensuring that the healthcare needs of people with learning disability (PWLD) within the criminal justice system are identified and that they are appropriately supported. In reality, this presents a complex picture with varying priorities, differing objectives, possible duplication of work and an uncoordinated approach. Any potential impact of this situation could be lessened following the creation of the criminal justice action group (CJAG) and also by the creation of a Scotland wide national action plan.

The project lead engaged and participated in the following groups and contributed to work carried out by them, was active within the CJAG and Supporting Offenders with Learning Disabilities (SOLD) networks and supported their aim of ‘reducing offending and improving support for offenders with learning disabilities’

- **The Same As You (SAY) Criminal Justice Sub Group**

This group was facilitated by people first Scotland <http://www.peoplefirstscotland.org/> who supported one of their members to chair the meetings. Following the launch of the Scottish Governments strategy document the ‘Keys to Life’ and the forming of the criminal justice action group (CJAG) this group no longer exists in its original form. However, People First still support the involvement of people with learning disabilities in the SOLD Network

- **Supporting Offenders with Learning Disabilities (SOLD) Network**

The Association for Real Change (ARC) Scotland <http://arcuk.org.uk/scotland/> facilitates the SOLD Network which has over 300 members from a broad range of sectors including: voluntary sector providers, Police Scotland, NHS, social work, academic institutions, Scottish Courts, Scottish Government and the procurator fiscals office.

The SOLD network was established in 2012 and to date its members have been supported to meet on four occasions. A report from the first SOLD network meeting ‘Supporting Offenders with Learning Disabilities in Scotland: Feedback from Professionals’ was produced and used to advise the networks action plan and subsequent proposals to the Scottish Government to form the Criminal Justice Action group (CJAG).

- **Criminal Justice Action Group (CJAG)**

Recommendation 46 of the 'Keys to Life' strategy document suggests that 'A national criminal justice action group be established in 2013' A proposal to create this group was developed by members of the above two groups, led by the ARC and agreed with the Scottish Government's criminal justice dept, this work will be carried out in a partnership between ARC Scotland and People First Scotland. ARC Scotland have been awarded funding to host this and have appointed a Policy and Development officer who will oversee the work of this group

### **Findings**

Findings of the project are presented as main headlines in the main report and are reflective of the objectives contained within the project plan. In doing this the Prison Healthcare project aims to offer clear information on all areas of work undertaken and any issues that were highlighted, subsequent work streams or pilot studies, followed by recommendations that could be implemented to alleviate any issues. Some of these findings are listed below.

- Between 0.3% and 0.8% of prisoners screened during admission triggered a referral for follow up
- Between 3.08% and 8.3% of prisoners followed up screened as being appropriate for further assessment
- 14.8% of prisoners in HMP Barlinnie Day Care Services screened as being appropriate for further assessment
- Further assessment had a positive outcome for those identified
- There is a real desire amongst Scottish Prison Service (SPS) and NHS staff to address health inequalities for all prisoners including those with learning disability
- The prison environment presents challenges which are unique in terms of structure and regime
- There is a major role for specialist community learning disability services to play in relation to prison healthcare for people with a learning disability.

## **Impact of the project on People with Learning Disability**

The project has impacted positively on the lives of people with learning disability by offering specific advice, support and training to Prison Healthcare staff for prisoners who are identified as potentially having a learning disability. It has also facilitated access to an appropriate level of evidenced based healthcare by way of advising on and developing needs led assessments and a care planning processes for adults with learning disabilities or autism within the prisons and the development of a robust care pathway to maintain consistency of approach.

## **Sharing knowledge and developments**

The project has shared knowledge and developments with other NHS board areas by working collaboratively with them towards a common goal, i.e. to develop and facilitate a revised proposed model of healthcare and support within Scottish prisons. Links were made with NHS Forth Valley, NHS Lothian and NHS Ayrshire and Arran in an attempt to minimise or avoid duplication, and add value to, work carried out across these areas through sharing of experiences, information, findings and examples of good practice. This was specifically in relation to ideas around screening in prisons and police custody suites and the development of health action plans.

## **Assessing Impact on Equality**

There is a statutory obligation through the Equality Act 2010 (Specific Duties, Scotland Regulations 2012) on organisations to ensure that they ‘eliminate discrimination, and advance equality of opportunity and foster good relations between people who share a relevant characteristic and those who do not’

An equality impact assessment has been undertaken, in conjunction with the equality and diversity health improvement lead for learning disabilities in Greater Glasgow & Clyde, to ensure that all areas of the care pathway developed within this report meet the required standards. Any new pathways developed from information within this report should be evaluated for their impact on equality and diversity and once implemented should be re-evaluated annually.

## **Other NHS board areas**

The clinical nurse specialist worked collaboratively with senior colleagues in NHS Forth Valley, NHS Ayrshire and Arran and NHS Lothian to propose further developments that will review and enhance services for people with learning disability who are in prison within these board areas. NHS Forth Valley has now embarked on a joint venture with SPS to trial the ‘Do-it profiler’ (Smith and Kirby 2006), which is a tool that screens and assesses for specific learning difficulties, and have committed learning disability resources to this pilot. The results of this will be of interest to all board areas and will undoubtedly impact on the services that are offered within Scottish Prisons once it is completed.

NHS Ayrshire and Arran have subsequently appointed a learning disability Forensic community nurse to take forward initiatives within their local prison.

NHS Lothian has appointed their existing learning disability liaison nurse to scope and develop a liaison role within the prisons in their board area.

The project has linked into a variety of Scottish Prisons to identify good practice examples across the prison estates and encourage sharing of these through networking, with the aim of replicating examples of practice that work well and building on existing practice where appropriate.

The clinical nurse specialist liaised with NHS Grampian and advised on raising staff awareness on a range of issues around developing or adopting screening processes that would help identify prisoners who may have a learning disability within HMP Grampian.

### **Conclusions**

The number of new admissions to the prisons who triggered a referral for learning disability input during the 16 week screening pilot may seem small. However, the number of existing prisoners who triggered a referral for learning disability input during the screening in HMP Barlinnie Day Care Services was significant. This latter group represents prisoners who were already in the prison and who most likely would have also been identified during the admissions process had they been part of this pilot study.

The outcomes for both groups of prisoners was positive given that they had access to a learning disability nurse specialist who advised them on their options and in certain cases, referred to services or organisations that could offer additional supports on release. This screening process highlighted individuals who may have a protected characteristic and therefore require reasonable adjustments to be made in respect of their journey through the prison system.

The Prison Healthcare Project has strived to highlight the opportunities, benefits and challenges associated with the development of a learning disability service within the prison environment and are mindful that whilst recommendations are desirable, local or national funding may preclude the development of a dedicated or standalone specialist learning disability service.

It may be helpful in these situations that there is a review of the skills set required and a pro-active approach taken towards future appointments of practitioner nursing staff, to include experience of supporting people with a learning disability or ASD and an awareness of the additional health and support needs of that client group.

The following report should be used in conjunction with other resources to inform cross policy working within the Scottish Government and may link indirectly to several policy areas. The themes



in these areas may not necessarily be specific to the work carried out in the learning disability project e.g. Foetal Alcohol Syndrome, ADHD, however, the information and recommendations contained within should be considered in relation to them, as they may inadvertently influence change or have some effect on the impact of these conditions on those who experience them.



**NHS Greater Glasgow and Clyde**

**Prison Healthcare Project**

**for**

**People with Learning Disability**

**Final Report**

**December 2014**

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## **Introduction**

In 2012 NHS Greater Glasgow & Clyde embarked on a review of all Adult Specialist Learning Disability services. The scope of this review was wide and aimed to develop a ‘strategy for the future’ for all people with learning disabilities who may require specialist intervention, including those who have come into contact with the criminal justice system. Consequently, the learning disability change programme was created and incorporated the Prison Healthcare Project for people with learning disabilities, which was taken forward as part of that programme.

### **NHSGGC Learning Disability Strategy - Criminal Justice Work Stream**

The Prison Healthcare Project commenced in January 2013 and was immediately involved in the criminal justice work stream group, which was part of the bigger NHS GG&C learning disability strategy development that was under way. This criminal justice work stream group was tasked with developing a ‘case for change’ document that would influence the Specialist Community Learning Disability Teams contribution to Prison Healthcare for people with learning disability and/or autistic spectrum disorder. This was achieved by reviewing national and local strategy, exploring case studies and identifying emerging issues and cross cutting themes.

The work of this group was completed and a case for change document produced which includes the 7 recommendations listed below that will be taken forward as part of the NHS GG&C learning disability change programme. This work was completed alongside other project developments and whilst establishing links to a wider group of Criminal Justice fora across the Scottish central belt, which assisted the project to establish main areas of focus for further developments and scoping. It was envisaged that the core membership of this work stream group would naturally develop into the steering group for the Prison Healthcare Project.

Below are the 7 recommendations from the criminal justice ‘case for change’ document.

1. Ensure that there is a systematic and routine approach to screening and identification of people with learning disability (PWLD) within the criminal justice system and subsequent recording of need.
2. Establish a clinical performance framework for prison healthcare that includes minimum standards, outcome measures and a service user feedback system
3. Develop clear pathways of care that describe a person with learning disability’s journey through the criminal justice system, detail the interfaces with other services and agencies and describes their roles and responsibilities.
4. Work collaboratively with other services delivering care to PWLD to ensure that throughcare arrangements are as effective as possible in supporting liberated prisoners on release.

5. Develop and deliver a workforce plan that aims to ensure staff are equipped with the skills and knowledge to meet the needs of PWLD in the criminal justice system.
6. Review current systems and processes for accessing healthcare in the criminal justice setting to ensure that, for example, written information does not create a barrier for PWLD.
7. Establish a steering group to guide the work of the prison healthcare project for people with learning disabilities in the criminal justice setting over the next 2 years.

### **Prison Healthcare Project steering group**

An integral part of the prison healthcare project was the project steering group. This group was formed from the main body of the criminal justice work stream group with the inclusion of additional stakeholders and chaired by the Service Manager for prison healthcare in NHS GG&C.

The purpose of the Prison healthcare project steering group was to

- Steer the Learning Disability Prison Healthcare Project and gain necessary agreements from key stakeholders to develop existing or implement new ways of supporting people with a learning disability whilst in the criminal justice system.
- Develop, consult on and agree the Prison Healthcare Project aims, objectives and delivery action plan.
- Monitor and review the implementation of the actions from the project delivery action plan.
- Provide directional guidance, information and support to the project.
- Raise and discuss matters of concern.

The first meeting of this group was held in November 2013 and 6 weekly thereafter. The group was well represented and had input from the following NHS and (SPS) stakeholders.

- Prison health centre manager
- Forensic services manager
- Learning disability change programme manager
- Learning disability consultant psychiatrist
- Head of learning disability psychology
- Learning disability speech and language therapist
- Head of Learning and creating opportunities unit at SPS HQ

- Two SPS offender outcome managers
- HMP Barlinnie day care services manager
- HMP Barlinnie day care services officer
- Two prison based practitioner nurses who have learning disability nurse training

### **Opportunities and Challenges**

The Prison Healthcare Project was conducted at a time of significant organisational change within the prisons across Scotland when responsibility for commissioning prison healthcare had recently transferred from SPS to NHS. This has been one of the most significant changes to prison healthcare services in recent years. This, alongside the ongoing NHS GG&C learning disability strategy development, afforded prison health services in Greater Glasgow and Clyde the opportunity to improve liaison with their local Community Learning Disability Teams (CLDT) and subsequently reduce the health inequalities experienced by people with learning disability in the prison system.

Common challenges encountered were mainly in relation to the three prisons all having unique operational characteristics and well embedded systems or processes, which the clinical nurse specialist found difficult at times to navigate around. Attempting to amend existing regimes could be complicated as they may have been devised with custody or security in mind or to align with other established processes. Operational challenges were commonly encountered in relation to officers' workload, potential additional costs and NHS versus SPS role responsibilities. Initially these led to previously arranged initiatives being delayed or cancelled and to a level of 'red tape' not previously experienced by the nurse specialist in other roles.

As a singular clinical nurse specialist working within a vast organisational landscape the project lead found it sometimes challenging to introduce new or change established processes or practices.

It therefore became clear that meeting the projects objectives involved a certain reliance on other key stakeholders which had the potential to delay decision making and development of initiatives, thus impacting on project timescales. With such a range of stakeholders there were interdependences in terms of implementation of initiatives, including a sustainable screening process and care pathway.

## **Scoping exercise**

Scoping was carried out across the three prisons in NHS GG&C using various methods, including documentary research, questionnaires, case studies, site visits, interviews, observations, focus groups for community learning disability nurses and one pilot study. The clinical nurse specialist spent approx 75% of his time during this phase of the project talking to NHS and SPS staff, observing processes and talking to prisoners.

This exercise highlighted that there were challenges with identifying people who may have a learning disability or ASD who arrive into the prison environment and a lack of awareness around learning disability and ASD generally across the prison estates. It also identified a lack of services and availability of therapeutic interventions aimed at improving health outcomes for anyone who has a learning disability or ASD in prison.

## **Existing service delivery**

Primary healthcare and specialist mental health and addiction services have long been established within the prison system, however, there is no dedicated service for prisoners who may have a learning disability and very few prisons visited had any form of in-reach services offering specialist support for learning disabled prisoners. There is some learning disability work being carried out in HMP Greenock by a practitioner nurse who is learning disability trained, but this tends to be sporadic and on an ad hoc basis, typically following a referral to the health centre for other issues.

A series of 'checklists for action' relating to police, courts, prison, probation and NHS learning disability partnerships was developed by Jenny Talbot in her report 'No one Knows, prisoners voices' (2008) The project utilised the prison related checklist (Appendix 9) during the scoping exercise to gauge awareness of both NHS and SPS staff of learning disability services within their establishment and external learning disability teams or services available in the community.

Jenny Talbot 'No one Knows, prisoners voices' (2008 P 93) advises 'these checklists for action will help to ensure that people with learning disabilities or difficulties are identified and their needs met as they enter and travel through the criminal justice system; they are not exhaustive and professionals and practitioners will no doubt identify more that can be done'.

Therefore, in line with this and in keeping with recommendation 47 from the 'Keys to Life' strategy document, the project would encourage services to utilise these checklists to their benefit when scoping or auditing their service for people who have a learning disability.

## **HMP Greenock**

Learning disability screening was available in HMP Greenock on a referral basis and was reliant on Health Centre staff or other prison based staff identifying that an individual was experiencing difficulties and subsequently making an appropriate referral. This was carried out by a practitioner nurse, who is a registered learning disability nurse but is not employed as such, who had an interest in offering a learning disabilities service. This created limitations on the efficiency of the service offered depending on the practitioners' workload and availability and was not sustainable as there was no agreed systematic approach to the process.

The project has taken account of the work already completed by this practitioner and will build on and develop the service already offered within HMP Greenock in line with the project plan and anticipated project outcomes. These are based on recommendations from several literature sources and the criminal justice case for change document which advocates for 'a systematic and routine approach to screening' for learning disability and 'identification and recording of need'.

It does not appear that any other practitioner nurse in HMP Greenock has had their skills developed in this area to address that deficit and the nursing staff we spoke with in HMP Greenock had not undertaken learning disability or ASD awareness as part of their induction and had no knowledge of what learning disability screening tools were available.

There is currently no screening available for ASD in HMP Greenock.

## **HMP Barlinnie and HMP Low Moss**

There is currently no screening for learning disability or ASD being carried out in HMP Barlinnie or HMP Low Moss. Referrals received at the health centre in both prisons are typically for prisoners that may be struggling to cope with prison life, and would be directed towards the mental health team to determine the cause. If this was due to having a learning disability or ASD there is no specialist practitioner or care pathway available to identify or screen for these conditions and interventions would be based on the practitioners own knowledge and experience. The nursing staff we spoke with in both prisons had not undertaken learning disability or ASD awareness as part of their induction and had no knowledge of what learning disability screening tools were available.

## **Models of service delivery and challenges to providing service**

The Glasgow Prison Health Needs Assessment (HNA) (p65) states that 'a review of the literature on models of delivering health care in prisons did not identify a preferred model of care but highlighted a number of key features of contemporary health care in the prison setting'



This was in the context of the general prison population and was taken into account when deciding on some key features that would be desirable in any model of service delivery for learning disabled prisoners. The list below mirrors the aspirations of the HNA's provision of healthcare and includes the following aspects:

- Routine screening for LD on admission and at any point in the persons journey through the prison system
- Health Action Plans and Annual Health Checks offered to anyone identified through screening
- Joint working between prison healthcare and CLDT's, day care services, education, residential staff and 3rd sector organisations, focussing on the needs of people with learning disabilities
- Health promotion related to learning disabilities
- Education of prison staff about the health care needs of prisoners with LD
- The development of models of care that move beyond the prison setting into the community

The HNA goes on to say that 'Whilst there is broad agreement that these core features should be present in a prison health care system, the evidence base in this area is limited.

One project aim was to gauge the interest of relevant staff in becoming link practitioners for people with learning disability and ASD within the prison system, with a view to building this into the care pathways and service delivery framework. A network of ASD link practitioners had previously been developed from clinical staff within the community learning disability teams and facilitated by the Autism Resource Centre ARC. Discussions took place with the ARC to consider revisiting this model of service delivery, as it was envisaged that we could collaborate with this network and develop strong in-reach links to prison healthcare. This would have been done in conjunction with training these staff via a Continuing Professional Development (CPD) arrangement with the Adult Autism Team to increase their clinical skills and thus become competent to screen prisoners for ASD.

The project reviewed this proposal in relation to its feasibility and concluded that there were too many variables and potential for lack of sustainability in the future. This should not however exclude any proposals through the learning disability change programme to establish key contacts within each of the community learning disability teams to be called upon to advise and liaise with prison healthcare staff on any issues regarding learning disability. There is an enthusiasm within learning disability

services to develop a model which enables the best service to support people wherever their care needs may take them.

### **Examples of service delivery in England and Wales**

There are several different models of service delivery across England and Wales. These range from dedicated specialist learning disability nurses being employed as LD nurse practitioners, to liaison schemes that involve two or more prisons, some of which also have a police custody liaison role. One local NHS secure forensic unit operates an in reach service to their local prison and another local CLDT have nurses within a prison with strong links back into their team.

The project undertook visits to, or made contact with, learning disability practitioners in the following establishments to observe, discuss and collect information on different models of learning disability service delivery.

#### **HMP Risley**

HMP Risley ran a 6 month pilot scheme where they had a learning disability nurse on site and working as part of the health care team. Screening was carried out on a referral basis and therapeutic input from the learning disability nurse covered several areas of adaptive functioning and behavioural strategy. This nurse also held responsibility for liaison with internal and external agencies and facilitating the learning and development of both NHS and Prison staff within the establishment. There is a proposal to continue this pilot for an additional 3 months due to its success.

#### **Calderstones**

Calderstones medium secure unit has learning disability nurses on site who screen their admissions routinely for learning disability using a self developed 'probability questionnaire'. This unit also links into their local prison, HMP Styal, as necessary and recently completed a pilot study where they screened a large number of prisoners for learning disability and raised awareness of learning disabilities with all prison staff.

#### **HMP/YOI Hindley**

At HMP Hindley there have been 2 learning disability nurses on site since 2009 following a study that showed there were a significant number of prisoners with learning disability in the local prisons. They maintain good links back to the CLDT for AHP input and screen all prisoners routinely for learning disability, as part of their admissions health check assessment, within 10-14 days using the LD section of the Comprehensive Health Assessment Tool (CHAT) which was developed jointly by the Department of Health (DoH) and the Youth Justice Board. They then carry out a Vineland adaptive behaviour assessment with family members and carers for all prisoners identified as 'probable' for

learning disability. They work closely with all prison staff and offer advice on managing, interpreting and responding to problematic behaviour in a person centred way, they provide learning disability support to the onsite behavioural units and deliver ongoing training and development to all staff on learning disability. They have a pro-active approach and have developed a health screening booklet alongside health action planning initiatives that have been helpful with communication and reducing health inequalities for prisoners in HMP Hindley. They also support prisoners with learning disabilities to adapt to their new environment.

Of the above 3 models of service delivery observed this model offers the most robust and comprehensive service to prisoners with learning disability, it offers the best links to the local learning disability team and benefits prisoners who may have learning disability in all aspects of diagnosis, prognosis, behavioural management, risk management and appropriate and coordinated through care.

### **HMP Parc**

Having recently won a Butler Trust award for their work in transforming provision for prisoners with learning disabilities, HMP Parc is considered a progressive and innovative flagship for G4S who operate the prison. Their prison healthcare team was determined to change the culture of the establishment and create a whole prison, multi-disciplinary approach that extended to support for prisoners on release, the result of which was their Learning Disabilities Pathway.

The first step on their pathway is the initial assessment of all new prisoners to establish if any require a supported living plan, this is completed using the 'Do-it profiler' (Smith and Kirby 2006) and the Activities of Daily Living (ADL) nursing assessment. This leads to an individual case management process managed by the officers in the halls and that can extend as far as full-time mentor support from appropriately trained fellow prisoners. All staff are made aware of the individual activity plans and the importance of treating prisoners with learning disabilities with decency and care.

The Supported Living Plans (SLP) used in HMP Parc provide additional support for vulnerable individuals, improves their transition into prison life and may prevent mental health problems escalating. The implementation of the Learning Disability Pathway has reportedly led to reduced levels of violence, confrontation with staff, self-harm, segregation or removal to specialist units.

Skills development programmes are available for all prisoners and include support around practical issues such as employment, being able to support themselves, and returning to the community and not re-offending by utilising support to make links with external and throughcare services.

It is of interest to note that the skills mix of Prison Healthcare nursing staff in HMP Parc is largely made up from learning disability nurses. These have been recruited over time to replace other

disciplines of nursing staff and develop a designated learning disability service within the prison, which operates alongside the primary care and mental health services. They offer support to prisoners with learning disability and learning difficulties and support prison custody staff to manage the supported living plans and episodes of challenging behaviour.

Overall this is an excellent model of service delivery; however, it would require a longer term commitment and investment by the SPS in terms of staff training and development and financially to operate the 'Do it profiler' for all admissions nationally.

### **HMP High Down**

The project made contact with the learning disability nurse employed within the 4 prisons across Surrey who has a liaison role within the county.

This learning disability nurse works closely with prison staff and other healthcare professionals both inside the prison and in the prisoners' local area to ensure that people who are identified for additional support can access services whilst they are in prison and continue to receive support once they are released.

This includes developing training for prison staff, developing resources such as 'easy read' leaflets for offenders alongside offering support to take part in activities and therapies designed to rehabilitate prisoners and make them less likely to reoffend once they have been released.

This is another example of a successful model of service delivery that makes a significant difference to the lives of learning disabled prisoners.

### **Identification of LD in prison environment**

Fiona Myers '**On the borderline**' (2004) identified three main triggers to identifying an individual with learning disability in the prison system as follows:

- From background information provided prior to or at admission
- From information collected at admission or routine assessment following admission
- From information collected at an assessment because a problem has arisen and a referral was made to health services.

A review of current approaches to identifying and working with prisoners who have additional support needs across the 3 prison estates shows little variance to the above, as the most common route to potential identification is usually following referral to the health centre for other issues.

It also highlighted that information that someone may have a learning disability was not always readily available at admission, and unless the prisoner disclosed this, it may not be picked up at that

point. These situations in effect lead to a missed opportunity in terms of anticipating the needs of people with additional support needs in the prison, and a reliance on reactive rather than proactive approaches.

### **Where best to screen**

Whilst exploring suitable environments in which screening could be established, it quickly became apparent that the reception area and admissions process was far too high pressured to be conducive to reliable screening for learning disability, this was due to operational practicalities such as a population shift of approx 250 prisoners per week across the three prison estates. We have considered including pre screen questions in the 'Vision' admission assessment software and explored the suitability and training requirements of this once we scoped the rest of the existing frameworks. It was felt that pre screening at a later stage would be more beneficial than including only one or two questions within this system.

The first night centre staff in HMP Barlinnie were consulted regarding the suitability of their area for screening prisoners for learning disability. They advised that this area was part of a process and prisoners were only there for one night, were still settling in, could still be suffering from the effects of an illicit substance, experiencing alcohol withdrawal symptoms or be extremely stressed by their imprisonment. Therefore it was agreed that there would be little opportunity to assess someone reliably at this point.

The next stage of the prisoner's journey through the prison system is the SPS induction and core screen. This is offered to every prisoner within 72 hours of arrival in prison and occurs in the links centre of HMP Barlinnie and HMP Low Moss and in two of the halls in HMP Greenock. The purpose of this is to highlight areas of support need for a prisoner and triggers referrals to SPS partner agencies for support with issues such as housing, benefits, addictions and mental health. We scoped this area significantly and shadowed officers in HMP Barlinnie and HMP Low Moss to observe the process.

This area appeared to be one of the most suitable for screening as it was part of an existing framework and gave a reasonable amount of time from admission to allow most prisoners to settle down. Eventually, agreements were reached via the project steering group as to the feasibility of using the above area, and the SPS staff therein, and a 12 week screening pilot was proposed.

At that time, due to governance issues, limited approaches were made to health staff regarding screening and identification of learning disability. It was anticipated that we would, at a later date, develop a questionnaire to determine their capacity to deliver an additional service at current resource levels to the learning disabled population within their establishment.

## **Screening for Learning Disability**

Much has been written over the last few years about screening for learning disability and ASD in prisons and the criminal justice system. It is generally agreed that there are a number of accused who have a learning disability or autistic spectrum disorder who enter the criminal justice system inappropriately. However, there is no denying that some people who have learning disability or ASD, due to the nature of their offence, will have to take that journey through what can be a very daunting and confusing process. These individuals have an equitable right to be supported appropriately at all stages of this journey based on need rather than diagnosis, however, tend to be overlooked due to lack of awareness of their condition. It is therefore essential that they are identified as early as possible in the Criminal Justice system and it would be desirable to screen these individuals whilst in police custody. Therefore, staff working in police custody suites would benefit from being able to recognise whether someone may have a learning disability or ASD and know who to contact in order to make sure the person is screened and subsequently receives the appropriate supports.

As mentioned previously, there is currently no routine screening for learning disability or ASD being carried out in any of the 3 prisons in NHS GG&C and whilst there are several screening tools available to screen for learning disability, few have been validated for use within the criminal justice systems or prison environments. There is currently no validated ASD screening tool for use within the prison population and there have been at least two studies carried out that recommend against the use of existing screening tools that were developed for the general population, namely the Autism Spectrum Quotient (AQ) and the ASD Screening Instrument which are mentioned later in this section.

### **Other considerations**

There is a limited understanding of the prevalence and needs of individuals with learning disability or ASD in Scottish prisons and any screening studies would be at best a snapshot in time of the cohort of prisoners being screened. The operational practicalities in relation to the prison population in NHS GG&C area change considerably on a weekly basis and there can be as many as 200-250 prisoner movements due to admissions, transfers and liberations across the 3 estates each week.

The Department of Health (DoH), England publication 'Positive Practice Positive Outcomes' (2011 edition, Page 13) highlights an example of good practice in relation to screening for learning disability in prisons, which includes the use of a screening tool to identify prisoners who may have a learning disability, and recommend the use of the Learning Disability Screening Questionnaire (LDSQ) (McKenzie, Paxton 2005) in England and Wales.

The prison healthcare project considered piloting the use of the LDSQ in HMP Low Moss working collaboratively with external clinicians to screen all new admissions for learning disability. However, following scoping of the processes and pathways within all 3 prisons, it was agreed that the project

would utilise the link centres and SPS officers to screen for learning disability, which would be done at the same time as the 'core screen' was being carried out, thus utilising the existing framework.

Initial proposal included links centre officers carrying out the screening using a validated learning disability screening tool with training and support from the clinical nurse specialist, however, operational concerns around the amount of time that could be devoted to this, alongside other admission procedures and assessments, meant it was deemed more practical to develop a series of pre screen questions to trigger a referral to health staff for further screening.

### **Agreed screening methods**

5 pre screening questions were developed (see appendix 2), the purpose of which was to offer a quick and easy way of filtering all admissions. This would help to determine if the person might have a learning disability, and therefore require some additional support during their time in prison. It also offered the right amount of information to allow the clinical nurse specialist to make an informed decision as to what, if any, follow ups were required. The scoring of the questions was relatively straight forward and, once scored, could trigger an onward referral for a more specific screen for learning disability.

These 5 questions were extracted from the 25 point Renfrewshire Learning Disabilities Service (RLDS) referral screening tool. This is a screening tool developed by two Consultant Clinical Psychologists from RLDS and can be used by health staff to determine if someone may have a learning disability prior to referral for diagnosis. All questions are evidence based and include comprehensive guidance to assist completion of the tool. The 5 questions selected for the prison pre-screening process were chosen following discussion with the authors and through personal clinical judgement around the information they would collectively produce.

During discussion at the project sub-group, which was formed to discuss project action plans and proposals in more depth, concerns were raised regarding clarity in relation to the role of SPS staff in the screening process, which was perceived as being medically based, and the appropriateness of the officers in asking the questions. This was discussed and reassurance given that none of the questions were of a clinical or medical nature and would only require a yes or no response, beyond that no additional information would be sought. The outcome of this was that an agreement was reached which would see the questions being split into two sections. The first would consist of 2 questions (appendix 3) and be asked by the links centre officers during their core screen, with the remaining 3 questions (appendix 4) being asked at a later date by the clinical nurse specialist or mental health nurses in the prisons.

The clinical nurse specialist, via the project steering group, also proposed a short training session with the officers who would be asking the pre screen questions, this would have been a 45 minute session

explaining the rationale behind asking these questions, how the responses would be used and interpreted and what the onward process would be to diagnose someone thought to have a learning disability. This however was deemed to be unnecessary by the SPS representative on the group.

If indicated, more specific screening would then be carried out by the clinical nurse specialist, using the Hayes Ability Screening index (HASI) which is a well known learning disability screening tool, well validated within prison settings and widely used across the globe. The HASI is designed to be administered by non clinical staff as it does not diagnose learning disability, what it does is help identify individuals who need to be referred to clinical psychology services for further diagnostic assessment, or if in police custody, need to have procedures, such as the appropriate adult procedure, implemented on their behalf.

In recent years the HASI has been utilised at times within some of the Scottish prisons and has proven to be useful. However, more significantly for the project in deciding to use this tool, was that the learning disability homelessness service had previously used the HASI to screen new referrals to their service in HMP Barlinnie and found it to be robust and reliable.

### **Cautionary note**

It is appreciated that screening tools such as the HASI, LDSQ and others can be over inclusive and have the potential to identify people who do not have a learning disability. It is therefore essential, and part of our care pathway, that screening tools are not used in isolation or as the sole source of identifying that someone may have a learning disability. The pathway shows that additional assessments such as an Activities of Daily Living assessment (ADL) and Adaptive Behavioural Assessment (ABA) must be carried out to inform any onward referral for diagnosis or further assessments.

This process must be followed up by experienced learning disability practitioners from clinical psychology and occupational therapy departments, as part of a multi disciplinary process, either through referral to the specialist community learning disability teams or through an in reach approach to the prisons.

### **Diagnosis**

It was felt that it would have been beneficial to secure clinical psychology input to the screening pilot to offer diagnostic assessments to those who met the scoring thresholds. However, in the current climate the project was unable to achieve this due to existing demands across learning disability clinical psychology services in Greater Glasgow and Clyde.



Preliminary discussions have taken place with psychological services around the diagnostic referral pathway for prisoners to the community learning disability teams and how this might develop. It was agreed that the prison healthcare agenda has to be included within the learning disability strategy and a clear pathway linking the prison learning disabled population to specialist learning disability healthcare services established. Within this strategy clinical psychology services have proposed a tiered approach to the assessment of eligibility for specialist learning disability health services which takes a more multi-disciplinary approach, including a screening interview developed from the RLDS screening tool, and should ensure that psychological assessments are only required in the most complex cases. Referrals from prisons would also go through this process and, given the data reported within the learning disability screening pilot section below, the number of cases requiring a specialist psychological assessment may be small. Discussions regarding this, and any other disciplines input to prison healthcare, will take place within the learning disability strategy local implementation groups.

There are three levels of assessment within the proposed prison screening care pathway which need to be carried out by an experienced learning disability practitioner. These are the HASI, ADL and ABA and occur prior to any referral for diagnosis being completed, thus reducing the chance of inappropriate referrals being made. It is useful to note that not all prisoners who score in the range to trigger a diagnostic referral would be referred to the community teams as there are 3<sup>rd</sup> sector organisations that accept referrals based on a Hayes Ability Screening Index score and the prisoners needs, rather than a diagnosis.

In the absence of a standardised approach to accessing learning disability services by prison healthcare professionals, referrals for diagnosis of learning disability should be made directly to psychology services within the local Community Learning Disability Teams. This should be in keeping with any existing diagnostic pathways or future developments agreed through the learning disability strategy service specification.

### **Screening Results**

One mental health nurse was involved in the screening pilot in HMP Barlinnie and tasked with following up referrals and administering the remaining 3 pre screening questions. Smaller numbers of admissions in HMP Greenock meant that the clinical nurse specialist followed up the very small number of referrals directly, and in HMP Low Moss, the link centre officers asked all 5 questions together, thus referrals generated came straight to the nurse specialist for the learning disability screening clinic.

The results of the 16 week screening pilot are outlined in the tables below. These results show prevalence only and are for new admissions to the prisons over this period, they do not include prisoners who may have learning disability that were identified by the project through other referral routes, those who were already in the prison system, or those who were referred to the learning

disability clinic and were liberated before they were followed up. With additional resources, these areas of data could have been analysed further to include the prevalence of those who;

- Were ruled out due to having a full UK driving licence
- Possess formal qualifications
- Attended mainstream or special needs schools or were resident in secure accommodation
- Have experienced a significant head injury and at what age
- Have evidence of adaptive behavioural impairment
- Were referred but liberated prior to being seen at the learning disability clinic

**(Table 1) HMP Barlinnie**

Forms reviewed	2042
Referrals generated	227 = 11.11%
PWLD Identified	7 = 0.34% of all forms reviewed 3.08% of referrals screened

**(Table 2) HMP Low Moss**

Forms reviewed	426
Referrals generated	69 = 16.19%
PWLD Identified	2 = 0.46% of all forms reviewed 2.89% of referrals screened

**(Table 3) HMP Greenock**

Forms reviewed	116
Referrals generated	12 = 10.34%
PWLD Identified	1 = 0.86% of all forms reviewed 8.30% of referrals screened

It is worth noting that in the latter stages of the 12 week screening pilot question 2 was reviewed and altered to create 4 multiple choice options (appendix 5). This was necessary due to the extremely high number of inappropriate referrals that were generated whilst this question was limited to a yes or no response.

The pilot was subsequently extended for 4 weeks to gauge the effect of the change to question 2, the outcome of which showed a significant and immediate effect on the number of referrals being generated. In HMP Barlinnie alone this led to a reduction in referrals from 24 to 6 in the first week due to the disambiguation of the question. If the question had been changed at an earlier stage in the pilot this would have had a significant effect on the above data and would have increased the percentage of prisoners identified from the referrals received and subsequently reduced the percentage of referrals received from the pre screen forms.

### **Day Care Centre**

The Day Care service in HMP Barlinnie is exclusive to that establishment and offers a service to the most vulnerable prisoners in the prison. These vulnerabilities may be due to mental health issues, learning disability, autistic spectrum disorders or prisoners who need additional support for any other reason. There are many groups that are facilitated in the day care centre and the prisoners attend one or more sessions per week.

Day care services vision is that of 'making a positive difference to people's mental health and well being' by providing 'support and opportunities to help improve self-confidence, self esteem and promote good mental health'. This area has been particularly responsive to the needs of both learning disabled prisoners and prisoners with ASD during the time this project has been running.

The day care service mainly receives prisoners who are resident within D Hall South Lower (DSL) which is a smaller and more sheltered environment which houses prisoners who may be more vulnerable to bullying, exploitation or who require closer observation.

### **Screening in Day Care Services**

The NHSGG&C Prison Health Needs Assessment (2012) states that whilst it was acknowledged that there were risks in recommending routine screening for learning disability in prison, the use of simple tools that could be applied by non-specialists to identify individuals requiring further assessment was suggested.

With this in mind, the officers in Day Care Services undertook learning disability awareness training and were trained to use the Hayes Ability Screening Index (HASI) learning disability screening tool. With the support of the clinical nurse specialist, and one other learning disability nurse, they were involved in a programme of screening of 47 prisoners within their service. This programme had planned to screen all attendees within this area, approx 200 prisoners; unfortunately this had to be terminated early due to operational concerns. During the programme all 47 prisoners were asked 5 pre screening questions, which the project had developed as part of a screening proposal, and then had the Hayes Ability Screening Index (HASI) carried out. Subsequent scoring of the HASI was checked

against the answers given to the 5 pre screening questions. The results correlated closely in respect of prisoners that would have been referred for a HASI from their answers to the 5 pre screening questions had they been asked them during the admissions process.

For HASI scoring, a score of 70 or below, or a score of 70-75 but with evidence of adaptive behavioural impairment would trigger an ADL assessment (see appendix 6) and an ABA assessment (see appendix 7) The results of these along with the individuals' wishes or preference would be used to advise a referral to the CLDT for diagnosis or to one of the 3<sup>rd</sup> sector organisations for ongoing advice or support.

It is recommended that the screening pilot within this area be re-instated and that all prisoners, other than those already screened, are included. This would be done by utilising the 5 questions to filter and the HASI to screen prisoners and identify any prisoners who may have a learning disability that are already in prison.

**(Table 4) Screening Results (Day Services)**

Prisoners Screened using HASI	47
Score 70 or below	7 = 14.8%
Score 71-75 and Yes to Q5 on pre screen	3 = 6.3% (Total = 21.1%)
Score 76-80	4 = 8.5% (Total = 29.6%)

We can see that 7 prisoners scored below the threshold score of 70 and would therefore be further assessed and referred for diagnosis if they wished.

Another 3 prisoners scored between 71 and 75 and answered yes to Q5 which was, 'Before you came into prison did you rely on support from family, friends or paid carers, with everyday activities e.g. budgeting, meal preparation, letter reading or independent travel?' thus indicating adaptive behavioural impairment and could therefore be referred for diagnostic assessment or to Cornerstones Positive Tracks project, the Wise Group or any other relevant agency

Another 4 prisoners scored between 76 and 80 which is well above the expected learning disability threshold of 70 but still below the SPS Psychology services cut off score of 80 for consideration for re-offending programmes.

This means that 21% of those screened either had a score that would automatically consider them for further assessment and referral or had evidence of a significant degree of support need due to a lack of self help skills.

Following the development and piloting of the screening process we would recommend that a validated screening tool is used at an appropriate stage in the admission process to identify prisoners who may benefit from further assessment for learning disability, additional support whilst serving their sentence or referral on to an appropriate service for diagnosis or support.

### **Case study**

William is a 52 year old man who was seen by the learning disability nurse specialist after being identified through the learning disability screening pilot.

William had attended special needs school in the East end of Glasgow but had never been given a formal diagnosis of learning disability, he has no formal qualifications, he relies heavily on others for support with every day activities and has never had contact with learning disability services.

William disclosed that due to his difficulties he has always found it very challenging to cope with the demands of life. As a young adult he discovered that offending behaviour would typically lead to him being sent to prison, which was a place that he found much easier to exist within, he also shared that he *'feels safer in Jail out of the way'* and has therefore spent most of his adult life in and out of prison.

During his appointment with the nurse specialist, William agreed to undertake further screening for learning disability using the Hayes Ability Screening Index (HASI) and subsequently scored at a level that would make it likely that he was in the range of mild learning disability.

His options were discussed in detail with him around further assessment of his health, daily living skills, self help skills and a referral for diagnosis. Other options were also explored, which included avoiding all of the above assessments and a direct referral being made to a 3<sup>rd</sup> sector organisation for more practical and daily living support.

William preferred the latter option as he thought it to be *'too late in life to be bothered with all that'* [assessments] and reflected that;

*'in all the years that I have been in and out of Jail, you are the first person who has ever told me that there is something else out there for me'*

A referral was subsequently made to an organisation that were running a project called 'positive tracks' who have been successfully supporting offenders with learning disabilities to avoid reoffending by offering accommodation and support to embark on a new lifestyle.

## **Screening for ASD**

As mentioned previously, there have been at least two studies that reviewed the use of a screening tool for ASD in prisons in Scotland, Gallagher and Rooke (2007) and Robinson, Spencer et al (2012)

The first study evaluated the use of the ASD screening instrument (Robinson, Spencer et al: 2012) and concluded that ‘rather than routinely screen for ASD in prison, staff should be encouraged to raise concerns about individuals struggling to cope in prison’, and ‘that mental health staff should be trained to recognise ASD and that there should be access to specialist ASD services where clinically appropriate’.

Gallagher and Rooke (2007) reviewed the use of the Autism Quotient (AQ) as a screening tool in HMP Barlinnie and concluded that, ‘there are inherent difficulties in using the AQ within the prison population and it is therefore not a useful tool to use in isolation for the screening of prisoners. The AQ can be useful to form the start of screening assessment but this would be required to be carried out by an experienced clinician who has in-depth knowledge of working with those with autism spectrum disorders. Early social and developmental histories also require to be taken as part of the screening process’.

The prison healthcare project has used the AQ in its full version to screen during the life of the project; however the project lead is an experienced ASD Practitioner with extensive ASD diagnostic experience

In accordance with the 2007 study, the project has discussed with the adult autism team, the possibility of having prison healthcare staff with an interest in ASD spend time with them to develop their knowledge and skills. This has been agreed and will develop with a view to creating an experienced ASD resource within the prison that could be called upon to carry out screening as required but would also form a key part of any prison healthcare learning disability nurses role.

## **Care Pathways**

The development of a care pathway allows for improved monitoring and streamlining of service delivery and is of particular significance where there are a range of professionals or agencies involved in the support or management of a prisoner.

The purpose of the prison learning disability care pathway is to ensure that prisoners with learning disabilities are identified, receive appropriate assessment and support planning and a quality service that is accessible, consistent and appropriate to their needs. The pathway is intended as a guide and undoubtedly variation will be necessary to suit local needs, establishments and services.

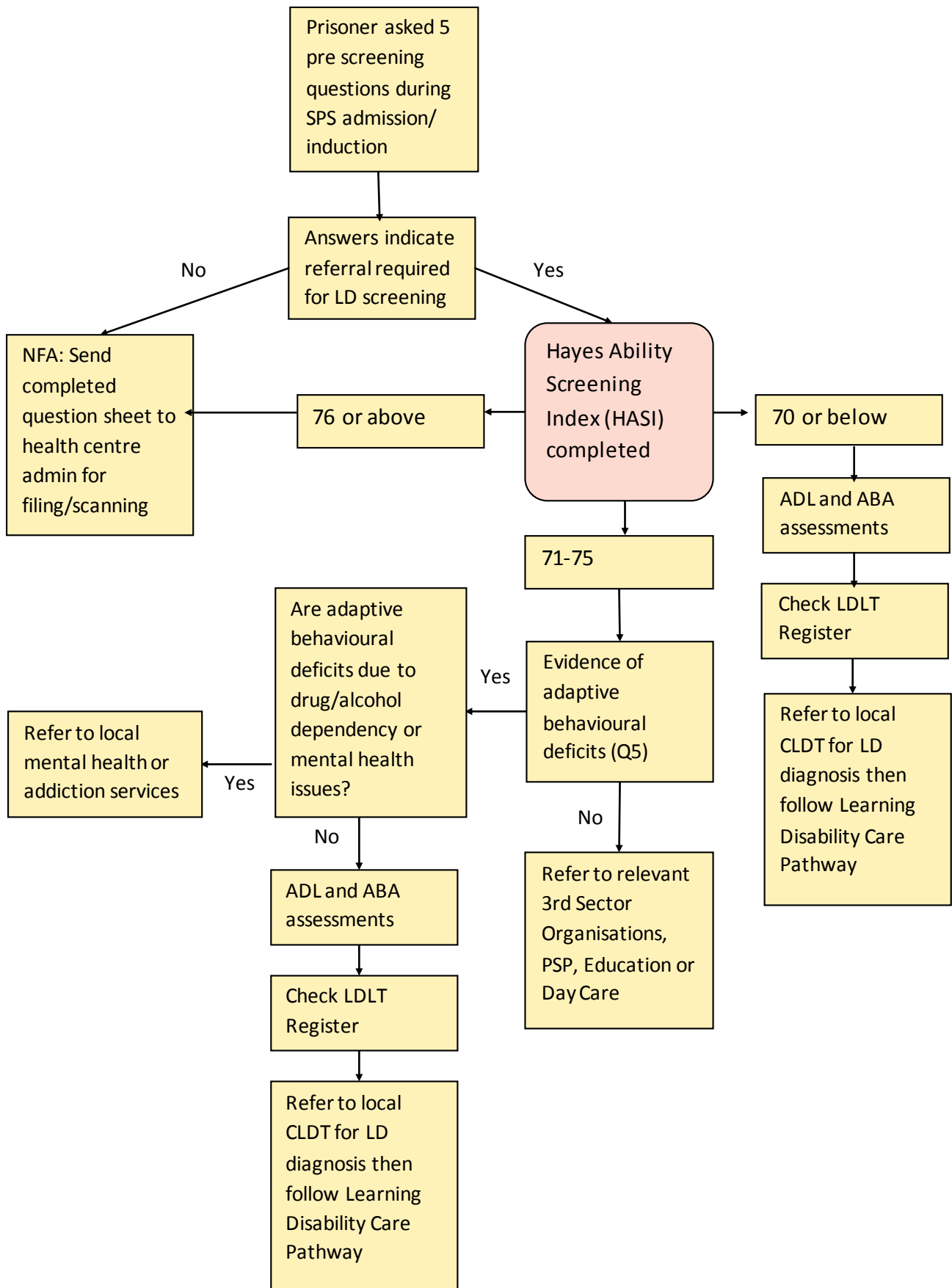
Referral pathways for diagnosis or support need to be agreed and clearly defined in agreement with the local Community Learning Disability Teams, the underlying principle of which is to ensure that

everyone receives the right care at the right time by the right service. There should also be agreements regarding who is referred, based on factors such as;

- The prisoners HASI score
- The activities of daily living assessment
- The adaptive behaviour assessment outcomes

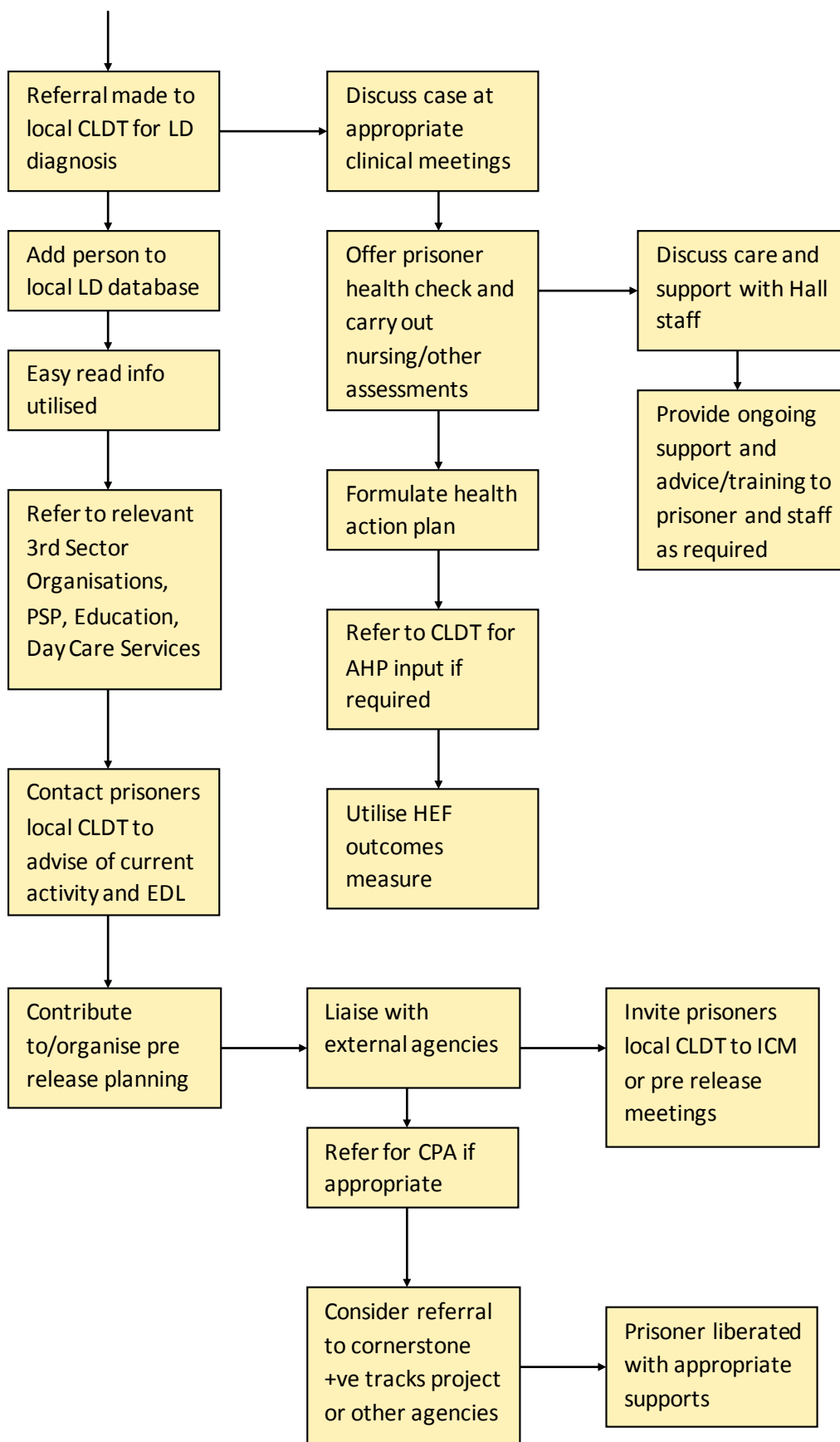
Agreeing when the prisoner is referred will be advised once decisions are reached as to whether the referral is accepted for an individual still in prison or during pre release planning, bearing in mind that most prisoners could be assessed and supported within the prison system. It is also important that the choices of the prisoner are taken into account and whether their preference is for a referral to a team who will diagnose them or to be referred straight to a suitable 3<sup>rd</sup> sector organisation for practical help and support. It is also important to agree what response could reasonably be expected when referring a prisoner to the local learning disability team. In Greater Glasgow & Clyde this will be taken forward in line with the change programme 'Strategy for the Future', any care pathways developed within this process should be evaluated for their impact on equality and diversity and re-evaluated annually.

**(Diagram 1) Process Map of Screening Care Pathway**

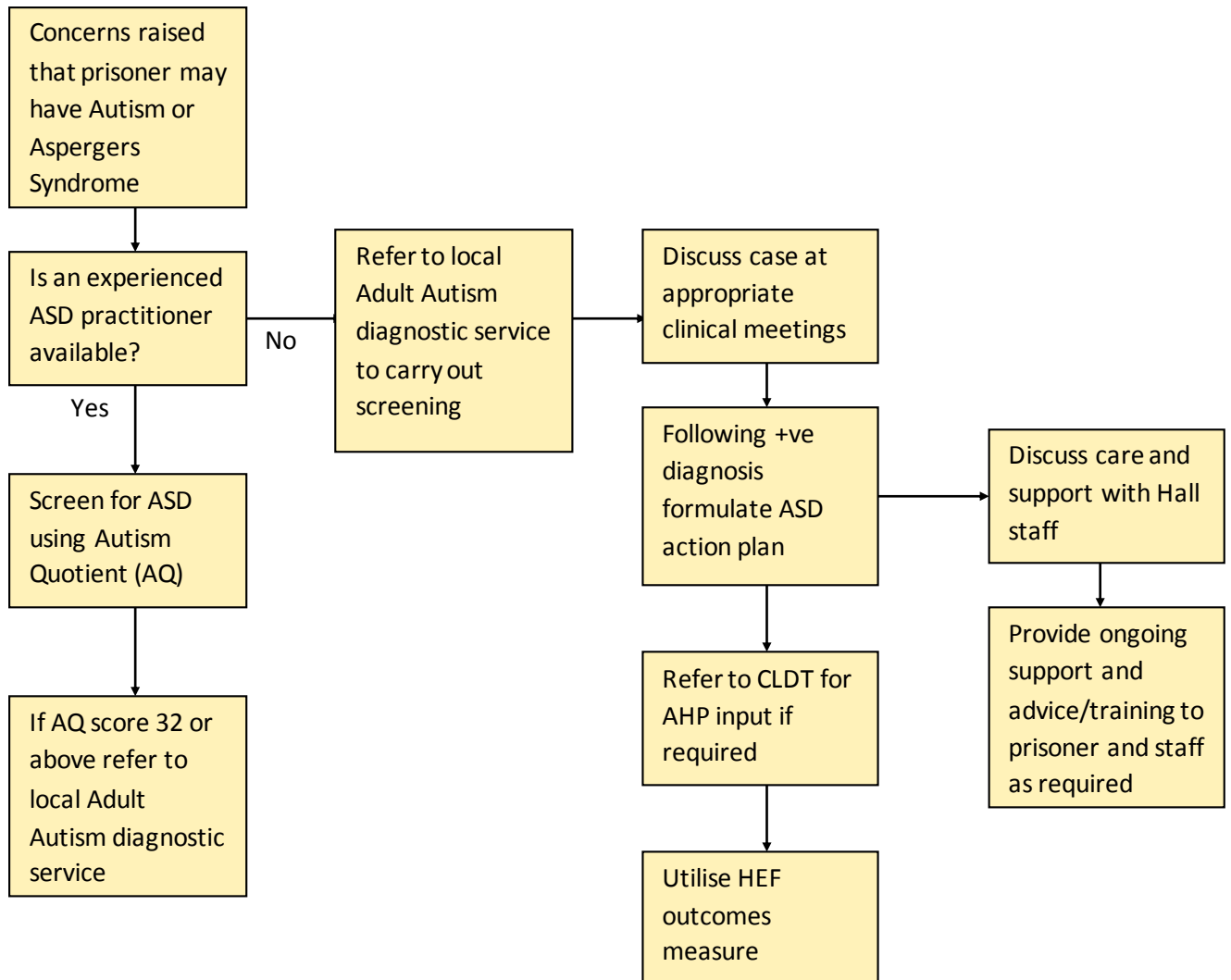




**(Diagram 2) Process Map of Learning Disability Care Pathway**



**(Diagram 3) Process Map of ASD Care Pathway**



## **Health Inequalities**

It is well documented that people with learning disabilities have shorter life expectancies than the general population and are more likely to experience poorer health outcomes. In her review of evidence relating to this, Dr Lesley-Ann Black in 'Health inequalities and people with a learning disability' (2013 Pg3) states:

*'Health inequalities are described as preventable and unjust differences in the health status between groups, populations or individuals. They exist because of unequal distributions of social, environmental and economic conditions within societies. These conditions determine the risk of people getting ill, their ability to prevent sickness, and opportunities to access the right treatments'.*

Imprisonment can only serve to compound this situation, especially where there is a lack of a systematic approach or procedures to identify prisoners who may have a learning disability. This in turn leads to a missed opportunity for establishments to offer appropriate care and support or make reasonable adjustments for those individuals.

In 'No One Knows' (Loucks and Talbot. 2007) it is highlighted that many prisoners who experience learning disabilities also experience health inequality and are at risk of re-offending because of unidentified needs and consequent lack of support and services.

These risks can be overcome by offering prisoners with learning disability improved support whilst in prison, when planning for release and subsequently in the community. Post release support is one of the most important elements that will determine whether a person re-offends and inevitably ends up back in the criminal justice system, or worse, back in prison. It is therefore crucial that supports are developed collaboratively with teams within the locality to which the prisoner will return and includes all relevant agencies from health, social care and prison staff. Health screening for prisoners identified and the development of health action plans (see appendix 8) and annual health checks will further improve outcomes for those individuals, as will regular audit of service through quality indicators and outcome measures.

## **Quality Indicators and Outcome Measures**

In 2012 a set of Prison Health Performance and Quality Indicators (PHPI) was developed and published by the Department of Health (DoH, England and Wales) (see appendix 9) which are specific to Learning disability on pages 63&64, and can be used as a guide for prisons in judging their own performance in delivering healthcare services to prisoners. The indicators are based on a red, amber, green (RAG) system of measure and incorporate evidence to validate each indicator. As stated in the guidance notes of the document, the overall indicator should reflect the area of least good

performance; therefore, if one of the three areas is red, the overall indicator is red and deficits causing this should be addressed.

The PHPI can be sourced here:

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/215080/dh\\_133382.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215080/dh_133382.pdf)

The Health Equalities Framework (HEF), published in march 2013 by the UK learning disability consultant nurse network, is described as ‘an outcomes framework based on the determinants of health inequalities’ which ‘provides a way for all specialist learning disability services to agree and measure outcomes with people with learning disabilities’

This is an outcomes measure that can be used by all services to measure the effectiveness of their service and its delivery, in reducing health inequalities experienced by people with learning disabilities, and has the potential to be used with other vulnerable groups.

The HEF can be found here:

[http://www.ndti.org.uk/uploads/files/The\\_Health\\_Equality\\_Framework.pdf](http://www.ndti.org.uk/uploads/files/The_Health_Equality_Framework.pdf)

Both of the above measures would be easily implemented and reviewed and should be introduced into the measure and audit of service delivery, prior to and following release from prison. Therefore they have been included in the projects recommendations.

It would be helpful for these to be developed in alignment with the principles published by NHS Quality Improvement Scotland Learning Disability 2004 Quality indicators at

[http://www.healthcareimprovementscotland.org/previous\\_resources/indicators/ld\\_quality\\_indicators.aspx](http://www.healthcareimprovementscotland.org/previous_resources/indicators/ld_quality_indicators.aspx)

### **Role of the Learning Disability Nurse in Reducing Health Inequalities in the prison population**

Strengthening the commitment (Scottish Government 2012) summarises the central roles of learning disability nurses as;

- Effectively identifying and meeting health needs
- Reducing health inequalities through the promotion and implementation of reasonable adjustments
- Promoting improved health outcomes and increasing access to (and understanding of) general health services, consequently enabling social inclusion

Learning disability nurses have an important role to play in prison healthcare, whether that is within a specially commissioned learning disability service inside the prison or by way of an in-reach arrangement with local CLDT's, key functions of this should include;

- Working closely with prison staff, healthcare and social work professionals, both in the prison and in the prisoners' local area, to ensure that people who have additional support needs due to learning disability or ASD are identified and can access services while they are in prison and continue to receive support after their release.
- Developing, facilitating and delivering a rolling programme of awareness training for learning disability and ASD for all healthcare, prison and social work staff
- Developing and maintaining accessible resources such as 'easy-read' leaflets and health passports for offenders
- Facilitating support for individuals with learning disability to take part in activities and therapies designed to rehabilitate prisoners and make them less likely to re-offend once they have been released.
- Developing the learning disability service and influence change within the prison environment
- Auditing and measuring effectiveness, quality and outcomes of the prison learning disability service
- Development and delivery of reoffending programmes tailored to the needs of prisoners who may have learning disability
- Supporting the prison healthcare service and SPS to undertake health screening for prisoners with learning disability
- Receiving referrals for screening via the admissions process developed by NHS GG&C learning disability prison healthcare project and undertake assessments and refer for diagnostic and other assessments as per prison and local team care pathways.
- Liaising and developing links with all external agencies and relevant departments within the criminal justice system to offer specialist advice on all matters relating to learning disability and ASD.

All disciplines within prison healthcare would benefit from having an understanding of the needs of people with learning disabilities and there is an essential contribution to be made by all health professionals in addressing the inequalities that people with learning disabilities face whilst in the criminal justice system or prison.

## **Learning and Development**

There is a clear need for training and workforce development across the prison service focused on awareness of learning disabilities, autistic spectrum disorder and, particularly, issues around communication. The project reviewed the current NHS GG&C Prison Healthcare learning and development plan and noted that Learning Disability and ASD are not included. We canvassed a cohort of staff working in the 3 prisons who have all stated they would require, at the very least, awareness training on learning disability and autistic spectrum disorders, some staff also showed an additional interest in developing their knowledge and skills around advanced levels of training in ASD. We reviewed recent literature on studies conducted by the Prison Reform Trust that supports the development of initiatives to increase awareness of learning disability and ASD in Scotland's prisons. The project plans to develop a rolling programme of training for prison officers, health centre staff and other SPS staff such as Social Work and day service, education and workgroup staff. To achieve this we negotiated with NHS colleagues and other agencies and contributed to this as necessary.

As part of the project Learning Disability and ASD awareness training was offered to members of staff in every prison in Glasgow and Clyde area. The training was delivered to groups of approximately 10-15 staff at their local prison training suites and delivered by the project clinical nurse specialist and a nurse specialist from the NHS GG&C Complex Needs Team.

The development of local and national resources is important and we have encouraged the use of e-Learning resources. The use of systems such as Learn Pro for NHS staff and e-Learning for SPS staff will encourage self learning and be a catalyst for the development of online learning modules for learning disability and ASD. The project anticipates that further work to develop this can be done through practice development departments.

Following discussion with unit managers at HMP Low Moss, the clinical nurse specialist developed a local proposal for learning disability awareness training (see appendix 11) which should be replicated across the remaining 2 prisons in the GG&C Board area. It transpired that these initial proposals were possibly very optimistic and even though there is a need for this more advanced training for all staff, at this stage in the project basic learning disability and autism awareness was deemed a more suitable approach. The development of more advanced levels of training could be an important role of a specialist learning disability prison nurse.

Approaches to the Autism Resource Centre to discuss training and development in ASD for Prison Officers and other SPS staff was based on working collaboratively to ensure that developments were sustainable once the prison healthcare project finishes. The ARC were unable to offer a rolling

programme of ASD awareness training at the moment, but have agreed to commit to this in the autumn of 2015 on the basis of the costs being accepted by the SPS.

The ARC have developed an e-learning resource which is available to all staff at the following location: [http://www.westlearningnetwork.org.uk/asd/en\\_index\\_offline.htm](http://www.westlearningnetwork.org.uk/asd/en_index_offline.htm)

The clinical nurse specialist, alongside colleagues from the complex needs team, has been involved in delivering learning disability and ASD awareness to police custody nursing staff during their induction and, following discussions with the service manager for police custody services, would envisage local learning disability services would be involved in any rolling programme of further training for this staff group in the future.

### **Throughcare**

Integrated Case Management (ICM) in Scottish prisons is only offered to prisoners serving sentences of 6 months or longer. This has the potential to exclude a high proportion of people who may have a mild learning disability characteristic as they tend to be imprisoned for repeat offences and typically serve very short sentences ranging from a few weeks to a couple of months. It is widely recognised that prisoners leaving custody have a wide range of support and reintegration needs, as these tend to be difficult to provide to prisoners who do not have a learning disability, they would also be extremely difficult to provide, without robust and creative pathways in place, for those who do.

HMP Greenock has embarked on a trial of offering ICM to all prisoners and during the last 24 months has been running a prisoner throughcare project which has been very successful in supporting all prisoners who receive it to reintegrate into their local community. This service is currently restricted by resources and can only be offered to prisoners from the local area, however, this will undoubtedly improve the outcomes for people who are supported by that scheme, including anyone who may have an unidentified learning disability.

Issues such as accommodation, benefit applications, finances and employment are key areas that need to be addressed to support successful outcomes and the voluntary sector currently play an ever increasing role in this area. There are 3<sup>rd</sup> sector projects that offer support to all prisoners, including those who may have a learning disability, such as the very successful Cornerstone Positive Tracks Project [www.cornerstone.org](http://www.cornerstone.org), the HMP Low Moss Public and Social Partnership (PSP) project, and the Wise Group 'new routes' public social partnership [www.thewisegroup.co.uk](http://www.thewisegroup.co.uk). All of the above have a presence within the prisons but there are many other community based 3<sup>rd</sup> sector organisations who have a remit to support people with learning disabilities who have offended.

Liaison with these, and other relevant 3<sup>rd</sup> sector providers could be undertaken by any of the staff in the health centre, but more consistently by a dedicated learning disability nurse practitioner in a liaison role.

### **Scoping the role of the Community Learning Disability Nurse (CLDN)**

Scoping the role of the CLDN took place over a 3 month period and the project created a sub group to develop and agree a questionnaire that would collect the information required. The sub group consisted of the project nurse specialist, experienced community learning disability and forensic nurses and a learning disability trained nurse practitioner from HMP Greenock.

The 18 point questionnaire that was developed (see appendix 12) scoped personal experiences of the CLDN's in relation to the following.

- Their experience of the criminal justice system or clients who have served a custodial sentence.
- What their expectations would be as a CLDN should they have a client who ended up in prison
- What they would have to offer from a nursing perspective to prison healthcare
- What they would expect from the prison in relation to pre release planning
- What training and development needs they had in relation to contributing to the care and support of someone with a learning disability who was in prison.
- Their interest in becoming involved in a group to develop a care pathway for people with learning disability on release from prison

Following a presentation made by the clinical nurse specialist to the NHS GG&C learning disability senior nurse group, questionnaires were sent out for all trained nursing staff across all community learning disability teams to complete. The responses have been reviewed from the 10 respondents and outlined as follows.

Of the 10 respondents 7 had experienced someone on their caseload who had been involved in the criminal justice system and 5 had experienced someone on their caseload serving a custodial sentence, some of their experiences are described below.



*'I had quite a poor experience within the criminal justice system as I tried to liaise with the police and court staff but was relatively unsuccessful due to their lack of commitment to the young man. I was also told the man would have an appropriate adult representing him throughout the process but then found out from the court clerk that there was never anyone put in place'*

*'Having only recently taken up post in the community I have had one patient experience within the Criminal Justice System (CJS). Having previously worked in Forensics for 7 years I was able to support the patient and offer advice on how the CJS works. Other than this I was not really involved in the process. The patient is now serving a custodial sentence and I have had no involvement in the process or had the opportunity to offer the patient support whilst in prison. I feel that the CLDN could offer more support for the patient and could be better informed of what is actually happening to their patient'*

*'I was not involved in the criminal justice process and the only way I could find out about the patient was to speak with his support workers. Unfortunately the information available was limited and could have had more detail'*

*'I was in favour of his short sentence as this individual was not taking any responsibility for his repeated behaviours. He was put in a more secluded unit and not with majority of other mainstream prisoners so to my knowledge was supported to a greater extent there'*

*'The criminal justice process and prison systems are far too complex for individuals with learning disability to navigate through without support.  
In my experience, a lack of awareness in prison of people with learning disability and autism leads to vulnerable people not being identified or having their needs assessed. As a result, individuals do not receive the appropriate support within prison or on release. This results in a revolving door between offending and prison'*

The next two tables outline what the CLDN's saw as being their responsibility to fulfil if one of their clients was sent to prison. Respondents were given multiple answers to select and to aid clarity the results have been grouped to reflect numbers of responses to individual answers rather than overall percentages.

<b>Table 5</b>	
If someone on your caseload went into prison, which of the following would you consider your responsibility to fulfil?	
Discharge or transfer from caseload	4
Continue to coordinate persons care	3
Maintain only some input to case	4
Supply relevant information around the persons ongoing care and support to Prison Healthcare Team	9
Continue or complete any work or assessments in progress	2
Offer LD specific advice and support to Prison Healthcare Team	8
Offer advice and support to Prison Officers regarding the persons ongoing care and support	5
Adopt a liaison role	7
Adopt an advocacy role	4

<b>Table 6</b>	
If someone on your caseload went into prison how often would you visit them?	
Following admission	4
Regularly	1
Frequently	0
Occasionally	4
Only if invited	2
Not at all	0
Before release	3

Some additional comments to table 6 were as follows:

*'I would visit initially until it was established who was responsible for the persons care. If the person remained on my caseload and they were happy for me to visit, then I would continue to do so'*

*'It would depend whether the client wanted visits from a CLDN and if this was acceptable to prison services'*

*'Have not done this in the past but see the value in doing so now (you've made me feel guilty!).'*

*'Need clarification on this and access to prisoners by non prison healthcare staff'*

When asked what expertise could CLDN's offer to prison healthcare and SPS staff if they referred a person with a learning disability to them the responses were extremely positive. 80% stated that they would expect to be involved in the care and support of learning disabled clients in prison and 90% expected to be involved in supporting and developing the individuals responsible for that care. This includes specialist support, advice and training on learning disabilities and ASD for NHS and SPS staff around the following;

- Screening and diagnosis
- Specialist LD/ASD nursing assessments
- Creating LD/ASD healthcare action plans
- Physical health issues for people with LD/ASD
- Mental health issues for people with LD/ASD
- Communication and accessible information
- Behavioural management
- Awareness training on LD/ASD

It has been previously established that identifying individuals who may have a learning disability on admission to prison is important. Notwithstanding any alternative processes recommended within this report, the community learning disability nurse would have the following to offer in relation to identifying people with learning disability and the diagnostic pathway in prison.

- Training and awareness around key elements of learning disability that have to be present in order for a diagnosis
- Liaison with relevant LD services to establish if someone has a learning disability
- Support to use screening tools e.g.
  - The Renfrewshire Learning Disability Service (RLDS) Psychology Screening Tool
  - Hayes Ability Screening Index (HASI)
- Signpost prison healthcare staff to the appropriate diagnostic services
- Advice on the value of diagnostic conclusions
- Act as a link to other CLDT professionals for diagnosis
- Further assessment and screens e.g. pragmatic profile, autism and sensory integration screens

There is also an anticipation by CLDN's that they could be involved in pre release planning meetings for prisoners with learning disability or ASD, 80% stated they would expect to be part of this and could offer specialist support and advice around the following areas;

- Liaison with other health professionals within the CLDT
- Liaison with the prisoners local CLDT
- Liaison with external NHS and 3<sup>rd</sup> sector agencies
- Contribute to a discharge support plan
- Implement strategies to reduce re-offending
- Specialist nursing assessment
- Risk assessment

Whilst responding to being asked about training and development needs and what would help the CLDN's offer added value to the care and support of someone with learning disability who was in prison, 80% of responses were in relation to a limited awareness of;

- How the prison system works and what input community learning disability nursing would be allowed to provide within the system
- What a typical admission to prison is like, what happens when you are there and what is expected of the individual
- Roles and responsibilities regarding health care whilst someone is in prison and how it is delivered
- Allowances or provisions made for people with learning disabilities in prison

Other comments regarding training needs were around the following

- Training around working with people who are in the criminal justice or prison systems
- Attend network meetings within forensic services to build up a knowledge of best practice, support and services available to this population
- Forensic awareness training
- Legislative framework training re criminal justice

It is clear from the information above that the CLDN's are keen to play a bigger part in and have much to offer towards the care and treatment of prisoners who have a learning disability. However, there were questions raised within the responses which were mainly around what the CLDN's role in prison healthcare would be and the extent of that input. Some CLDN's were unsure of the appropriateness of being involved in prison healthcare and some were unsure whether they would actually be authorised to get involved.

There is a wealth of experience and knowledge that exists within CLDT's, which would prove to be a priceless commodity for any prison healthcare team, and should be tapped into. To do this would require coordination from within the prison and needs to be considered alongside other disciplines input to prison healthcare.

This can be taken forward through the structures of the NHS GG&C learning disability strategy local implementation groups that will agree and define what the future role of specialist adult learning disability services may be in supporting people with learning disabilities who are in prison.

## **Networking**

Anecdotally, there is evidence of a lack of opportunity for Prison healthcare practitioners with an interest in learning disability to network and share good practice across Scotland. Practitioners previously employed within SPS Prison Healthcare were attending events or conferences in their own time and funding their own travel and attendance costs. This is partly owing to there being no dedicated specialist learning disability service within the prisons and that learning disability was not their primary job role, therefore any service they developed was very ad hoc and sporadic, based on their capacity once their other responsibilities had been carried out.

The prison healthcare project had a remit to encourage practitioner attendance at various learning disability related criminal justice fora. This has been met by being active within, and directing other relevant professionals towards the Supporting Offenders with Learning Disability (SOLD) Network, along with other prison, forensic and nursing related criminal justice networks, and by encouraging interested practitioners within the prison healthcare cohort to initiate and develop a prison learning disability nurse network. One way this could be developed is by utilising existing networks such as the Scottish Learning Disability Nursing Network (SLDNN) and developing a sub group within that. The clinical nurse specialist has met with this group and, being keen to widen their network to diverse areas of practice, accepted the prison healthcare projects proposal to develop this.

Due to recent opportunities, the two learning disability trained practitioner nurses who were steering group members and were interested in developing this sub group have moved on to other jobs. Two other practitioner nurses with learning disability training currently work within one of the prisons covered but have no job remit for learning disabilities and occupy other very demanding roles. This leaves the recommendation to develop a learning disability prison healthcare sub group through the SLDNN open to other board areas across Scotland.

## **Summary**

We are conscious there are people with learning disabilities in our prisons and have established that, at the time of the project screening pilot, this was a smaller number than expected in NHS GG&C. However, as mentioned previously, the number of existing prisoners who triggered a referral for learning disability input during the screening in HMP Barlinnie Day Care Services was significant.

We know there has been long term debate about the methods for screening for learning disability but quickly determined that doing nothing was not an option as there is an appetite within prison healthcare services to get it right for prisoners with learning disability. The prison healthcare project established a screening process, using a validated tool to identify the possibility of learning

disability, alongside additional assessments of need, which provided positive outcomes for those identified.

It is clear that SPS and NHS staff are keen to ensure that they have the relevant skills to support everyone effectively, including prisoners who may have a learning disability; however the variance in the way in which prisons operate can create challenges to developing this.

There is evidence that uncertainty exists around the scope of responsibility of the community learning disability nurses role in prison healthcare, but we can conclude that a full range of CLDN interventions would be available if this was acceptable to prison healthcare teams and prison authorities and clarified through NHS GG&C change programme implementation groups.

The Clinical Nurse Specialist and the Complex Needs Support Team have organised and delivered training across the prisons in NHS GG&C which became very quickly oversubscribed. These were merely taster sessions but provided evidence there is a palpable need for learning disability and autistic spectrum disorder awareness training across the prison estates. This should lead to more in depth levels of training being facilitated either through the training for trainers programme, by learning disability practitioner nurses within the prisons, or through agreements reached within the NHS GG&C change programme implementation groups, to utilise community learning disability team resources.

There is also evidence that more needs to be done within the prison system to improve access to specialist healthcare for people with learning disability. This includes support to access primary care, screening initiatives and health promotion but also in terms of reasonable adjustment to assist access to reoffending programmes and appropriate social support, alongside regular monitoring of the health of this group through annual health checks.

All agencies involved in the care and support of prisoners with learning disabilities have a role to play in influencing change and should consider the following recommendations.

## **Recommendations**

- A Scotland wide prison healthcare action plan should be developed to ensure a coordinated and focused approach to work streams ongoing in different NHS board areas. This should take into consideration all NHS projects that are ongoing across Scotland
- All prisons in Scotland should carry out routine screening for learning disability in line with the process developed by the NHS GG&C Prison Healthcare Project screening pilot.

- Data on the number of offenders with a learning disability in the prison system should continue to be collected from the information gathered during admissions screening.
- Individuals identified in the prison system who have or may have a Learning Disability should be recorded on existing databases that highlight their LD status using the appropriate read code, and checked by prison healthcare staff prior to any contact.
- An outcome measuring tool should be used to agree and measure outcomes with people with learning disabilities' and monitor the services effectiveness in tackling health inequalities for people with learning disabilities. This could be achieved by utilising the Health Equalities Framework (HEF)
- A set of performance indicators should be used in Scottish Prisons to assist them to measure their own performance in delivering healthcare services to learning disabled prisoners. This could be achieved by adopting a measure such as the DoH Prison Health Performance and Quality Indicators (PHPI) or any other suitable performance indicators
- The Care Programming Approach (CPA) should be utilised for all prisoners who have been identified as having a learning disability and who meet the criteria for CPA. This should be facilitated by a designated CPA Co-ordinator.
- All prisoners identified as likely to have or diagnosed as having learning disability should be offered pre release planning and a support package if they wish. This could be carried out by a dedicated learning disabilities Prison nurse or on an in-reach basis by the specialist Community Learning Disability Teams in collaboration with prison healthcare or throughcare staff.
- All prison based NHS, SPS and Social work staff, should undertake learning disability and autism awareness training. This could be achieved partly by utilising e-learning resources such as NHS 'LearnPro' and SPS e-learning and other accredited electronic resources, prior to attending face to face awareness sessions.
- A rolling programme of advanced LD and ASD training should be developed for staff with an interest in developing their skills and knowledge in this area, thus improving outcomes for people with LD or ASD within Scottish prisons.
- Learning disability and autism awareness training should be incorporated into the Scottish Prison Services College basic training induction programme for new officers.



- A dedicated Prison Learning Disability Nurse or Nurses should be appointed to develop specifically commissioned Learning Disability Services for prisoners who meet the criteria
- Workforce planning within all Scottish prisons should incorporate a review of the skills set required to address the health needs and inequalities experienced by prisoners with LD. A pro-active approach should be taken towards future appointments of practitioner nursing staff to include experience of supporting people with a learning disability or ASD
- Referral Pathways should be developed between specialist adult learning disability services and Prisons. This could be achieved by forming a working group jointly with community LD teams and prison healthcare managers to develop the interface between their services.
- Prison in-reach services offering specialist nursing and Allied Health Professional (AHP) support to prisoners who have or may have a learning disability need to be developed in line with existing or emerging local learning disability strategies or service developments.
- Where no learning disability nurse specialist for prison healthcare is available, there should be an experienced learning disability practitioner invited to mental health team meetings to discuss and advise on any learning disabled prisoner or referrals.
- Links should be made with existing prison learning disability and liaison services in England and Wales to share and replicate where appropriate, examples of good practice and evidence based approaches.
- Prison healthcare practitioners across Scotland with an interest in learning disabilities, should develop a learning disability nursing network. This could be facilitated via the Scottish Learning Disability Nursing Network (SLDNN) and take the form of an LD prison healthcare sub group that feeds into their national steering group.

# Appendices

Appendix 1



**NHS Greater Glasgow and Clyde  
Prison Healthcare Project  
for  
People with Learning Disability**

**Steering Group Terms of Reference**

**Date: 20<sup>th</sup> June 2013**

**[REDACTED]**

### **Purpose**

This document describes the terms of reference, membership and methods of communication for the Steering Group of the NHS Greater Glasgow and Clyde Prison Healthcare Project LD/ASD

### **Background**

In 2012 NHS Greater Glasgow & Clyde submitted a bid to the Scottish Government with the aim of exploring and scoping out a programme of work to increase awareness of, and facilitate access to an appropriate level of evidenced based healthcare for adults and young offenders with learning disabilities / autism within prisons. This work will be used to develop a framework which can be applied to other Board areas across Scotland.

This bid was created to ensure that the health needs of the population of people with Learning Disabilities are known and understood in all healthcare settings and is driven by the "Learning Disabilities Equally Well", national learning network, The Same As You? and Equally Well (Learning Disabilities) emerging policy evaluation(s) and more recently the Scottish Government's National LD strategy document 'Keys to Life'

The timing of this project has been fortunate as the NHS has only recently (in November 2011) assumed responsibility from the Scottish Prison Service for healthcare within Scotland's Prisons, and the systems, processes and care pathways for prisoners are therefore currently undergoing an overall review in line with NHS approaches.

A further positive factor has been the development of the Learning Disability Change Programme within NHS Greater Glasgow and Clyde which is developing a 'Strategy for the Future' which will define the future specialist contribution of Learning Disability services including the interfaces and pathways with partner agencies in the future.

These developments are at early enough stages to ensure the Prison Programme of Work is embedded in these discussions and has a prominent profile.

From a strategic perspective the project will be lead by the Change Programme Manager (Learning Disabilities) and clinically driven by a Nurse Specialist LD/ASD. A Steering Group will govern and monitor the project.

### **Terms of Reference**

- To steer the Learning Disability Prison Healthcare Project and gain necessary agreements from key stakeholders to develop existing or implement new ways of supporting PWLD whilst in the criminal justice system.
- Develop, consult on and agree the Prison Healthcare projects aims, objectives and Delivery Action Plan.
- Monitor and review the implementation of the actions from the Project Delivery Action Plan.
- Provide directional guidance, information and support to the project.
- Raise and discuss matters of concern.

Appendix 1 continued

**Steering Group Membership**

The Prison Healthcare Steering Group will comprise major stakeholders who bring knowledge, skills and expertise to the programme.

Additional or temporary members will be co-opted as required at key phases of the project from a ranges of areas within the CJ system and who have a commitments and contribution to make to the development of the evidence based care and support of PWLD during their journey through the CJ system

**[REDACTED]**

#### **Accountability**

The Steering Group will report directly to General Operational Prison Group and the Learning Disability Change Programme Steering group.

#### **Frequency of the meetings**

It is envisaged that the Steering Group will meet on a 6 weekly basis, where the work programme and governance arrangements will be agreed. However, additional meetings may be convened according to business to be conducted.

#### **Methods of communication**

In addition to regular group meetings, as defined in the communication plan, the Steering Group Chair and Project Manager will be available for one-to-one communication with other Steering Group members and other stakeholders as and when required.

An email distribution list of all group members will be set up. The Project Manager will moderate submissions to this list. The email distribution list may be used to facilitate communication with and between Steering Group members.

#### **Timeframe of Programme**

It is anticipated that the programme of work will be completed by **December 2014** and reports to Scottish Government completed by **and March 2015**

#### **Expected Outputs**

It is anticipated that this programme of work will:

- Lead on the work required to complete the objectives of the LD Strategy Criminal Justice Work stream.
- Map out key individuals contribution across all agencies to ensure clarity of roles and responsibilities and avoid duplication of work.
- Work collaboratively with the SCLD to understand the pathway for and identify missed opportunities for identification of PWLD/ASD within the CJ system.
- Develop and pilot systems within existing frameworks to assist routine screening and identification of PWLD within the CJ system at the earliest stage possible.
- Increase awareness, knowledge and skills of all staff working with PWLD across all aspects of the CJ system
- Develop care pathways for PWLD in the CJ system ensuring that they are merged with and aligned to existing pathways.

## Appendix 1 continued

- Develop a national framework for delivery of Learning Disability specific service in Scottish prisons.
- Ensure access to evidence based care and support for PWLD during their journey through the CJ System
- Encourage and develop collaborative and inter-agency working, protocols and information sharing for ~~throughcare~~ requirements and ensure optimum onward planning for individuals before release from prison
- Identify good practice models of service delivery that help to prevent and reduce offending and re-offending.
- Establish links with relevant individuals working in all CJ sectors.
- Review approaches to identifying and working with prisoners who have additional support needs due to LD/ASD
- Contribute to and support the review of Prison Health Improvement initiatives to ensure accessibility for PWLD/ASD
- Via the LD strategy, determine what the future role of Specialist Adult LD/ASD/Forensic LD Service may be in supporting this group of people.
- Identify training and development needs of Health Centre and SPS staff in relation to LD/ASD and review the scope of the current L&D plan within the 3 prisons and develop LD/ASD specifics.
- Identify and develop a network of Link Practitioners for LD/ASD
- Identify and disseminate links to information available on LD/ASD
- Be available as an LD/ASD expert clinical resource to be called on by the Prison Healthcare teams.
- Encourage practitioner attendance at various Criminal Justice, Prison, Forensic and Nursing related networks.
- Support the workforce in improving the healthcare of PWLD/ASD in prison or within other areas of the Criminal Justice system
- Provide reports and recommendations to the Scottish Government and NHSGG&C as and when required and within the anticipated timescales for completion of the programme of work.



**Learning Disability Induction Screening Questions**

**Prison Healthcare Project**

Name: \_\_\_\_\_ Do.B: \_\_\_\_\_

Prison number: \_\_\_\_\_ Date \_\_\_\_\_

Please answer the following questions:

1. Do you currently hold or have you ever held a full UK Driving Licence?

**YES/NO (If YES: DO NOT PROCEED)**

2. What type of school did you go to? (Please tick)

- A. Local School
- B. Residential School or Secure Unit
- C. Local School with Additional Educational Support
- D. Special Needs School

3. Do you have any formal qualifications?

**YES/NO**

4. Have you ever had a severe head injury?

**YES/NO (If YES ask at what age this happened) AGE \_\_\_\_\_**

5. Before you came into prison did you rely on support from family, friends or paid carers, with everyday activities e.g. budgeting, meal preparation, letter reading or independent travel?

**YES/NO**

Please refer to separate scoring sheet for answers.

**Action: (Please tick one box)**

- No Referral - Paperwork sent to Learning Disability Nurse
- Referral made to Learning Disability Nurse

Officers Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**Learning Disability Induction Screening Questions – Answer Sheet**

Scoring for referral

Answers that score one point towards referral

Q2 - Cor D

Q3 - No

Q4 - Yes (Age 18 or below)

Q5 - Yes

Scoring 2 or more points in questions 2-5 triggers referral to LD Nurse for screening.





**Supplementary Induction Interview Questions  
Prison Healthcare Project**

Name: \_\_\_\_\_

D.o.B: \_\_\_\_\_

Prison number: \_\_\_\_\_

Please answer yes or no to the following 2 questions:

1. Do you currently hold or have you ever held a full UK Driving Licence?

YES/NO

2. Did you attend mainstream school?

YES/NO

If answer to Q2 is YES but with additional support needs then score as NO

Scoring for referral

Response to Question		Action
Q1- Yes Q2- Yes	Q1- No Q2- Yes	No referral required. Send completed paperwork to Mental Health Team.
Q1- Yes Q2- No	Q1- No Q2- No	Refer to Mental Health Team.

Action: (Please tick one box)

Paperwork sent to Mental Health Team

Referral made to Mental health Team

Officers Signature: \_\_\_\_\_

Date: \_\_\_\_\_



**Remaining questions following referral for HASI screening:**

**Prison Healthcare Project**

Name: \_\_\_\_\_

D.o.B: \_\_\_\_\_

Prison number: \_\_\_\_\_

Please answer yes or no to the following 3 questions:

3. Do you have any formal qualifications?

YES/NO

4. Have you ever had a head injury?

YES/NO (If YES ask at what age this happened) AGE \_\_\_\_\_

5. Before you came into prison did you rely on support from family, friends or paid carers, with everyday activities a.g. budgeting, meal preparation, letter reading, independent travel?

YES/NO

---

**Scoring for HASI assessment**

If person answers NO to Q1 or YES to Q2 (Age under 18) or YES to Q3 then screen using HASI assessment schedule.

**Action: (Please tick)**

HASI screen carried out..... HASI score \_\_\_\_\_

Referral made to community LD team.

HASI refused.

Assessor's Signature: \_\_\_\_\_ Date: \_\_\_\_\_



**Supplementary Induction Interview Questions (Amended)**  
**Prison Healthcare Project**

Name: \_\_\_\_\_

D.o.B: \_\_\_\_\_

Prison number: \_\_\_\_\_

Please answer the following 2 questions:

1. Do you currently hold or have you ever held a full UK Driving Licence?

YES/NO

2. What type of school did you go to? (Please tick)

- A. Local School
- B. Residential School or Secure Unit
- C. Local School with Additional Educational Support
- D. Special Needs School

Scoring for referral

Response to Question		Action
Q1- Yes Q2- A or B	Q1- No Q2- A or B	No referral required. Send completed paperwork to Mental Health Team.
Q1- Yes Q2- C or D	Q1- No Q2- C or D	Refer to Mental Health Team.

Action: (Please tick one box)

- Paperwork sent to Mental Health Team
- Referral made to Mental health Team

Officers Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Appendix 6



Activities of Daily Living Assessment (ADL)	
Personal details	
Name:	Prison ID Number:
Location:	
Date of Birth:	
Please complete the HASI and ADL assessment prior to carrying out the basic ABA	
Does the person have difficulty with the following?	
<b>Maintaining a safe environment</b>	Yes/No
Comments	
<b>Communication</b>	Yes/No
Comments	
<b>Breathing</b>	Yes/No
Comments	
<b>Eating and drinking</b>	Yes/No
Comments	
<b>Elimination</b>	Yes/No
Comments	
<b>Washing and dressing</b>	Yes/No
Comments	
<b>Controlling temperature</b>	Yes/No
Comments	
<b>Mobilisation</b>	Yes/No
Comments	
<b>Working and playing</b>	Yes/No
Comments	
<b>Expressing sexuality</b>	Yes/No
Comments	
<b>Sleeping</b>	Yes/No
Comments	
<b>Death and dying</b>	Yes/No
Comments	
<p>All assessment information from the following must be collated and used to provide as much information as possible in referrals made to the learning disability Psychological services for diagnosis and Occupational Therapy services for assessment of function and activity analysis.</p> <ul style="list-style-type: none"> <li>• 5 Pre screen questions</li> <li>• HASI score</li> <li>• ADL assessment</li> <li>• Basic ABA</li> </ul>	

Appendix 7

<b>Basic Adaptive Behavioural Assessment (ABA)</b>	
<b>Personal details</b>	
Name:	Prison ID Number:
Location:	
Date of Birth:	
Has an Activities of Daily Living (ADL) assessment been carried out? (Please complete an ADL assessment prior to the carrying out the basic ABA)	<b>Yes/No</b>
Does the person have difficulty with the following?	
<b>Communication.</b> Is the person able to understand other people and get information across verbally or written?	<b>Yes/No</b>
Comments	
<b>Self care.</b> Is the person able to manage their own personal hygiene, dressing, toileting etc independently?	<b>Yes/No</b>
Comments	
<b>Daily living skills.</b> Can the person maintain a clean and safe home, purchase and cook food without assistance?	<b>Yes/No</b>
Comments	
<b>Use of community facilities.</b> Can the person get themselves around the local area without assistance, use public transport, shops or post office etc?	<b>Yes/No</b>
Comments	
<b>Numeracy &amp; Literacy.</b> Is the person able to read or use signs & instructions, manage their money and budgeting to get by in daily life?	<b>Yes/No</b>
Comments	
<b>Self-direction.</b> Is the person able to make plans, choices and see things through, e.g. following a course of treatment or medication?	<b>Yes/No</b>
Comments	
<b>Social skills.</b> Can the person follow acceptable social cues and norms and generally get on with people in social situations?	<b>Yes/No</b>
Comments	
<b>Risk.</b> Does the person understand the concept of danger and how to keep him or herself healthy and safe?	<b>Yes/No</b>
Comments	
<b>Work and occupation.</b> Does the person make use of their time and have meaningful occupation or work?	<b>Yes/No</b>
Comments	
<p>All assessment information from the following must be collated and used to provide as much information as possible in referrals made to the learning disability Psychological services for diagnosis and Occupational Therapy services for assessment of function and activity analysis.</p> <ul style="list-style-type: none"> <li>• 5 Pre screen questions</li> <li>• HASI score</li> <li>• ADL assessment</li> <li>• Basic ABA</li> </ul>	

Appendix 8

**Learning Disability-Health Action Plan**

Issues (Mobility, Communication, Self care etc) from ADL	Action required (What support or reasonable adjustments are required)	By whom (NHS, SPS or external agency)	Status of action (Awaiting appt, ongoing etc)	Action completed	Signature and date

Appendix 8 continued

**Learning Disability-Health Action Plan-Continuation sheet**

Issues (Mobility, Communication, Self care etc) from ADL	Action required (What support or reasonable adjustments are required)	By whom (NHS, SPS or external agency)	Status of action (Awaiting appt, ongoing etc)	Action completed	Signature and date

PRISON HEALTH PERFORMANCE & QUALITY INDICATORS 2012

63 AREA: - MENTAL HEALTH

**1.27 Services for People with Learning Disability**

**Green Indicator**

**Within the prison ALL the following are evident:**

- Access to Learning Disability services specifically commissioned for prisoners
- Use of Learning Disability Screening Questionnaire (LDSQ) to identify prisoners with learning disability
- 100% of identified prisoners with a learning disability have an annual health check
- 100% of identified prisoners with a learning disability have a Health Action Plan
- Joint partnership working focussed on the needs of people with learning disabilities between healthcare department, Disability Liaison Officer, Education and Discipline staff
- Evidence that specific programmes/regimes relevant to the needs of those with a learning disability are in place, including release (discharge) planning
- Adaptive programmes developed to meet the needs of prisoners with learning disabilities

**Rationale**

Following Valuing People in 2001 and the Disability Discrimination Act 2005, both the prison service and NHS have an obligation to ensure equitable and accessible services for people with a learning disability.

At any one time, approximately 24,600 prisoners have a learning difficulty that could affect their ability to function within the prison environment. Of these around 5,700 have an IQ less than 70 and may be eligible for Learning Disability services.

People with learning disabilities have greater health needs and shorter life expectancy than the general population and have difficulty accessing health care services, which is often exacerbated by attendant communication difficulties.

**Suggested Supporting Evidence**

**Suggested supporting evidence may include:**

- Evidence of needs-led commissioning of a specialist service for prisoners with a Learning Disability
- Audit of records of identified prisoners with a learning disability to determine % with a Health Action Plan and annual health check
- Examples of joint needs assessments and the preparation and delivery of care packages, including planning for release
- Evidence that programmes/regimes appropriate to the needs of those with a learning disability are in place



PRISON HEALTH PERFORMANCE & QUALITY INDICATORS 2012

**Literature and References**

PSO 2855 – Prisoners with Disabilities

PSO 3050 – Continuity of Healthcare for Prisoners (Transfer of Prisoners with disabilities)

Disability Discrimination Act 2005

Valuing People (DH 2001)

Valuing People Now (DH 2009)

Positive Practice Positive Outcomes – CSIP 2007 updated 2011

“Prisoners Voices” No One Knows – Prison Reform Trust 2008

Health Action Planning and Health Facilitation for people with learning disabilities – good practice guidance (Sec 3.17) – Department of Health 2009

**Amber Indicator**

- The prison can access Learning Disability services but no formal commissioning or pathways exist
- Between 90% and 99.9% of identified prisoners with a learning disability have an annual health check
- Between 90% and 99.9% of identified prisoners with a learning disability have a Health Action Plan
- Evidence of joint working, but no formalised pathways
- Developing adaptive programmes for prisoners with a learning disability.

**Red Indicator**

- No access to specialist Learning Disability services
- Less than 90% of identified prisoners with a learning disability have a Health Action Plan or annual health check.
- No evidence of joint working
- No adaptive programmes in place or being developed

The overall indicator reflects the area of least good performance – i.e. if one of the three areas is red, the overall indicator is red.

## Appendix 9

## Checklists

PRISON:			
	Yes	No	Action
Is there a way of screening people to identify possible learning disabilities or difficulties on arrival into prison?			
Are information sharing protocols in place, including with healthcare and education, to ensure that appropriate information is shared for the benefit of the prisoner?			
Is prison information and are prison forms accessible, for example 'easy read'?			
Are arrangements in place to support prisoners unable to read and/or write?			
Is the prison regime accessible to all prisoners?			
Are adapted accredited cognitive skills programmes available?			
Are there good links with local adult social services and learning disability services?			
Are adult social services alerted at least 12 weeks in advance prior to a prisoner with learning disabilities leaving prison?			
Do prison staff undertake awareness training on learning disabilities/difficulties?			
Are there good links with your local Learning Disability Partnership Board?			
Prisoner learning: are staff qualified in special education needs and does provision match the population profile of prisoners? Do staff have ready access to a dyslexia specialist?			

continued

Appendix 9

Checklists

PRISON:			
	Yes	No	Action
Prisoner learning: are shared strategies in place with prison staff to help prisoners unable to read and write very well to cope better with reading prison information and filling in prison forms?			
Prisoner healthcare: are there good links with local learning disability services and a named person to contact?			
Prisoner healthcare: do healthcare staff work with prison officers to meet support needs of prisoners with learning disabilities?			
Prisoner healthcare: Do you have learning disability nurses/in reach learning disability nurses?			
Prisoner healthcare: are staff aware of the factors that might lead to a prisoner being 'diverted' into specialist healthcare and what procedures should be followed?			
Are copies of <i>Positive Practice Positive Outcomes</i> readily available?			



**NHS Greater Glasgow and Clyde**

**Prison Healthcare Project**

**for**

**People with Learning Disability**

Learning Disability Awareness Training Proposal

**Background**

In 2012 a successful bid was submitted to the Scottish Government by NHS Greater Glasgow and Clyde to secure funding to create a Prison Healthcare Project. This projects aim was to 'explore and scope out the programme of work required to increase awareness of, and facilitate access to, an appropriate level of evidenced based healthcare for adults and young offenders with learning disabilities or autism within the prison system'

**Project objectives relevant to this proposal.**

3.1 Review the scope of the current L&D plan for LD/ASD within the 3 prisons and develop LD/ASD specifics.

3.2 Identify training and development needs (TNA) of Health Centre and SPS staff in relation to LD/ASD

6.1 Support the workforce in improving the healthcare of PWLD/ASD in pris on via awareness raising and increasing knowledge on the healthcare issues experienced by PWLD

**Proposal**

It is proposed that a rolling programme of learning disability awareness training is developed in line with requirements of both NHS and SPS staff working within the 3 prisons in NHS GG&C board area. This programme will be delivered by two members of the NHS GG&C Learning Disability Complex Needs Support Team, comprising of an LD Speech and Language Therapist (SALT) and an LD Clinical Nurse Specialist (CNS)

Proposals will be discussed with the unit managers in each establishment to ensure it is offered and delivered in the best possible way for that establishment.

Maximum numbers of attendees per session will be 15 and will consist of NHS and SPS jointly as available. The length of each session will be 2.5 hours. All course materials and handouts and additional information will be supplied. Attendees must have the full support of their line managers to allow attendance at all 5 sessions.

Appendix 11 continued

It is envisaged that the programme will run until all NHS and SPS staff have attended the full course which will be offered as outlined below.

Session number	Title	Presenters
Session 1	What is a Learning Disability	CNS
Session 2	Communicating with a person who has a Learning Disability	SALT
Session 3	Challenging Behaviour	SALT, CNS
Session 4	Sensory Issues and ASD	SALT, CNS
Session 5	Health issues for people with Learning Disability	CNS, SALT

[REDACTED]



**Scoping the role of the CLDN in Prison Healthcare**

Dear Nursing Colleagues,

As part of the original bid to the Scottish government for project funding, one of the work areas of the Prison Healthcare Project was to 'Scope the role of the community learning disability nurse in supporting individuals [with LD] who are experiencing custodial sentences, including the development of a care pathway on release from prison'.

To do this there are some questions I would like to ask about your experiences and opinions of any contact you or your clients have had with both the criminal justice and prison systems, and if you would be interested in contributing to this aspect of the Prison Healthcare Project through focus groups or the care pathway development group.

Once the questionnaires are collated the focus groups will be organised to explore the role of the CLDN in supporting PWLD who are experiencing custodial sentences, this will advise the relevant sections and recommendations of the final report to the Scottish Government on Prison Healthcare for PWLD in GG&C which is due in March 2015.

Thank you in advance for taking time out to complete this questionnaire, I have set a 5 week limit and hope this is sufficient. If you have any comments or questions, please email me at the address below.

[REDACTED]

**Scoping the role of the CLDN in Prison Healthcare**

What is your current job title? \_\_\_\_\_

In what CLDT are you based? \_\_\_\_\_

Do you have a Prison in your locality? \_\_\_\_\_



1. Do you currently have, or ever had, anyone on your caseload that has experienced the criminal justice system?

Yes

No

If **yes** what were your overall experience and opinions of the process and those of your client?

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2. Do you currently have, or ever had, anyone on your caseload that has experienced a prison sentence?

Yes

No

If **yes** what were your overall experience and opinions of the process and those of the person being imprisoned?

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Appendix 12 continued

3. If someone on your caseload went into prison, please tick any of the following that you would consider your responsibility to fulfil.	
Discharge or transfer from caseload	<input type="checkbox"/>
Continue to coordinate persons care	<input type="checkbox"/>
Maintain only some input to case	<input type="checkbox"/>
Supply relevant information around the persons ongoing care and support to Prison Healthcare Team	<input type="checkbox"/>
Continue or complete any work or assessments in progress	<input type="checkbox"/>
Offer LD specific advice and support to Prison Healthcare Team	<input type="checkbox"/>
Offer advice and support to Prison Officers regarding the persons ongoing care and support	<input type="checkbox"/>
Adopt a liaison role	<input type="checkbox"/>
Adopt an advocacy role	<input type="checkbox"/>



4. If someone on your caseload went into prison would you visit them? (Please tick)	
Following admission	<input type="checkbox"/>
Regularly	<input type="checkbox"/>
Frequently	<input type="checkbox"/>
Occasionally	<input type="checkbox"/>
Only if invited	<input type="checkbox"/>
Not at all	<input type="checkbox"/>
Before release	<input type="checkbox"/>
Comments:	

5. What input would you be able to offer prison healthcare staff if they referred a PWLD who was in their prison?

6. What input would you be able to offer to prison through care (release) staff if they referred a PWLD who was being released in 6 weeks time?

Appendix 12 continued

7. Would you expect to be invited to be part of pre release planning, Integrated Case Management or CPA for a client you knew previously or had on your caseload?	
Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
Don't know	<input type="checkbox"/>

8. Would you expect to be notified of upcoming court dates or potential dates for release for a client you knew previously or had on your caseload?	
Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
Don't know	<input type="checkbox"/>



9. Would you expect to be notified of upcoming court dates or potential dates for release for a new referral?	
Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
Don't know	<input type="checkbox"/>

10. Would you expect to be invited to be part of pre release planning, Integrated Case Management or CPA for a new referral?	
Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
Don't know	<input type="checkbox"/>

11. Would you expect to be involved in learning disability/ASD awareness or other training, advice or support for NHS and SPS staff?	
Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
Don't know	<input type="checkbox"/>

12. What input could you offer to the prison healthcare staff around identifying PWLD in prison?	

Appendix 12 continued

13. What input could you offer to the prison healthcare staff around the diagnostic process of those identified?

14. What training requirements do you have as a CLDN that would help you offer added value to someone with an LD who was in prison?

15. Would you be interested in contributing to the development of a care pathway for PWLD who are being released from Prison?
Yes <input type="checkbox"/>
No <input type="checkbox"/>
If Yes e-mail

16. Would you be interested in contributing to the development of a network of link practitioners who would be involved in supporting prison healthcare staff with learning disability?
Yes <input type="checkbox"/>
No <input type="checkbox"/>
If Yes e-mail

17. Would you be interested in contributing to the focus/discussion groups to scope the role of the CLDN in prison healthcare and the development of recommendations within this aspect of the project?
Yes <input type="checkbox"/>
No <input type="checkbox"/>
If Yes e-mail

Appendix 12 continued

18. Please add any additional comments to any of the above multiple choice questions here

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